GIVING AND RECEIVING ANTICOAGULANT THERAPY AT HOME:  
A DESCRIPTION OF MOTHERS' AND INFANTS' EXPERIENCES

by

Tracey Anne Irvine

A thesis submitted in conformity with the requirements for the degree of  
Master's of Science  
Graduate Department of Nursing  
University of Toronto

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0-612-45549-1
A qualitative study was undertaken to explore the early mother-infant relationship when mothers administer anticoagulant injections to their infants for a prolonged period. A descriptive case study design was used based on Benner's (1994) interpretive phenomenological approach. Three mother-infant pairs participated in multiple home interview and observation sessions throughout the course of anticoagulant therapy. The negative consequences of the infants' conditions and care trajectories became worse over time. The findings illustrate the intensity and complex nature of care giving activities and the array of practices that mothers use to protect and comfort their babies. A theoretical interpretation of findings through Winnicott (1975) and Wynn's (1996) theorizing of the early mother-infant relationship, revealed how mothers were able to establish a deep connectedness with their infants to transform their experiences of touch, pain, and being in the world.
Dedication

To Haley, may God bless you and keep you.
Acknowledgments

I wish to thank my thesis supervisor, Dr. Patricia McKeever, for her ongoing support and guidance throughout this research endeavor. Her experience and personal insight proved invaluable to this project.

I also wish to extend my sincere gratitude to Dr. Francine Wynn whose work inspired and guided this inquiry.

To Dr. Bonnie Stevens who carefully reviewed countless drafts and continually challenged my thinking, and Dr. Patti Massicotte, who provided thoughtful contributions and encouragement, I extend my thanks and appreciation.

A special thank-you to the mothers and their babies who welcomed me into their homes and so willingly shared their time.

Finally, and most particularly, to my family and friends who have made this thesis possible through their love and commitment. Especially, to my husband Gary, for his patience, understanding, and motivation.
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CHAPTER 1: Background

A positive mother-infant relationship is essential to the healthy development of newborns (McFadyen, 1994). Ideally, the early relationship is a time of mutual discovery and engagement where the mother’s primary focus is the comfort and nurturance of her infant (Wynn, 1997). However, the transition into the maternal role following the birth of a healthy full term infant requires adjustments, which can disrupt a woman’s sense of stability, self-esteem and certainty or sense of control (Barclay, Everitt, Rogan, Schmied, & Wyllie, 1997; Mercer & Ferketich, 1994). The birth of a premature or sick infant compounds these adjustments and often leads to depression, anxiety, stress, negative perception of, and interaction with the infant (Affonso et al., 1992; Harrison & Magill-Evans, 1996; Hayes, Stainton, & McNeil, 1993; Hughes, McCollum, Sheftel, & Sanchez, 1994; May, 1997; Mercer & Ferketich, 1994; Oehler, 1990; Shandor Miles, Funk, & Kasper, 1991; Shandor Miles, Funk, & Kasper, 1992; Shields-Poe & Pinelli, 1997; Stainton, McNeil, & Harvey, 1992; Wereszczak, Shandor Miles & Holditch-Davis, 1997; Worchel & Allen, 1997).

Approximately 7% of Canadian infants are born prematurely and 5% of full term infants have a serious congenital health problem or birth injury (Hanvey et al., 1994). Although most infants in both categories now survive the acute effects of these conditions (Mupanemunda & Watkinson, 1999), many spend their first days of life in the neonatal intensive care unit (NICU). While in the NICU, most infants undergo many painful invasive procedures, often without analgesia (Anand, 1993; Barker & Rutter, 1995;
Baucher, May, & Coates, 1992; Perreault et al., 1997; Stevens & Johnston, 1994; Stevens, 1996; Stevens, Taddio, Ohlsson, & Einarson, 1997; Stevens et al., 1999). Although the reality of infant pain has been acknowledged in the research literature, practices designed to prevent or assuage pain related to therapeutic procedures are underused (Carter, 1997; Stevens, 1996).

Reflecting dramatically shorter hospital stays for people of all ages, stays in the NICU currently are as brief as possible. As a result, 10 to 15% of infants continue to require one or more invasive procedures after being discharged home (Gillette, Hansen, Robinson, Kirkpatrick, & Grywalski, 1991). In these cases, parents (most often mothers) are now taught how to perform procedures that, until recently, were the responsibility of nurses. Teaching sessions generally occur while mothers are coping with the stresses associated with giving birth, the infants’ hospitalization and their precarious health status.

Although no directly related empirical studies have been conducted about this phenomenon, requiring mothers to perform painful procedures may be in conflict with the protective care behaviours that philosopher Sara Ruddick (1989) ascribes to motherhood. Ruddick (1989) argues that mothering practices reflect preservative, protective love, and nurturance (p. 17). A few studies have reported maternal distress and ambivalence related to performing various procedures on older infants and children (Hatton, Canam, Thorne, & Hughes, 1995; Haverstock, 1992; McKeever, 1992; Spalding & McKeever, 1998). It was postulated that the responsibility of assuming care of infants who require painful/invasive procedures may have negative effects on the mothers, their babies and
their relationships. The example studied involves the administration of a subcutaneous anticoagulant that is essential to the survival of the infants. At the pediatric centre where this study was conducted an outpatient thrombophilia program was introduced to enable infants with life-threatening thromboembolic complications to be treated at home (personal communication, October 10, 1997). This program is the first of its kind in North America (Andrew et al., 1997) and involves the administration of a new subcutaneous anticoagulant (low-molecular-weight heparin, LMWH). Previously, thromboembolic complications in infants necessitated prolonged periods of hospitalization in intensive care settings. Parents are taught how to inject the LMWH through an injection port known as an "Insuflon®" (Figures 1 and 2). The new anticoagulant therapy offers clinical advantages of safety and efficacy (Massicotte, Adams, Marzinotto, Brooker, & Andrew, 1996). Prior to the infants discharge home, parents must learn: (a) the relevant anatomy and physiology, (b) specific assessment skills, (c) pain control interventions, (d) the injection of heparin, and in some cases, (e) the method of inserting the Insuflon® (personal communication, September 4, 1997).

In Canada, the prevalence of deep vein thrombosis (DVT) and pulmonary embolism (PE) in infants and children is approximately 5.3 for every 10,000 hospital admissions (Andrew et al., 1994). The frequency of thromboembolic events (TE) is highest in infants and adolescents (Andrew et al, 1994). In 1996, the participating
Figure 1: Insufion Needle

Figure 2: Inserted Insufion
hospital treated 61 children who required LMWH for (TE) and 30 of these were infants (personal communication, October 24, 1997).

Thromboembolic events in neonates are almost always attributed to serious underlying health problems, related to genetic, non-genetic and iatrogenic risk factors (Anand, Chand, Talib, Chellani, & Pande, 1996; Andrew et al., 1994; Andrew, Michelson, Bovill, Leaker, & Massicotte, 1998; Andrew et al., 1997; David & Andrew, 1993; Israels & Andrew, 1994; Sutor, Massicotte, Leaker, & Andrew, 1997; Uttenreuther-Fischer et al., 1997). A common iatrogenic risk factor is the use of central venous or arterial lines (Schmidt & Andrew, 1995; Uttenreuther-Fischer et al., 1997). These lines result in thrombus formation because they damage vessel walls, disrupt blood flow and/or are used to infuse vessel damaging substances (Andrew et al., 1994; David & Andrew, 1993; Israels & Andrew, 1994; Mehta, Connors, Danish & Grisoni, 1992).

In addition to mastering the anticoagulant treatment, most mothers learn about medication administration, physical assessments, suctioning, or gastric tube feedings. Weekly home visits are arranged for a nurse to change the Insuflon® and address related problems or other health issues. During these visits, mothers usually assist in restraining their infant while the nurse inserts the Insuflon® (personal communication, Sept. 4, 1997). The average course of therapy is three months in duration and includes monthly visits to the outpatient clinic for blood tests and follow-up. The anticoagulant injections are given twice daily.
Both insertion of the Insufion® and the injection of the anticoagulant are painful. Subcutaneous administration of heparin causes a stinging sensation at the site (Beyea & Nicoll, 1996). Although the Insufion® reduces the number of skin piercing injections required, it is much more invasive than a subcutaneous injection because a catheter sheath surrounding a needle must bore through approximately 1 inch of tissue. The most common area of placement in neonates is the anterior thigh but once the infant has gained sufficient body fat, the back of the upper arm also is used. The abdomen is generally avoided in this age group to avoid contamination from soiled diapers (personal communication, February 4, 1999).

The Research Problem

This study was conducted to gain an understanding of the early mother-infant relationship when mothers give painful anticoagulant injections to their infants at home. It was postulated that giving daily painful injections could be a stressful negative experience for mothers and their babies. The knowledge gained through this inquiry contributes to our understanding of both the mother and infant when mothers assume the responsibility of providing multifaceted care to infants at home. Ways of improving the nursing care of these dyads during this crucial period of life can be gleaned from the findings.

Review of the Literature

No research was found on the impact of the early mother-infant relationship when mothers were required to perform painful procedures over a prolonged period. However,
a review of empirical investigations in the following related areas generated a broad picture of what is known about this phenomenon:

- The Effects of Painful Procedures On Infants
- The Effects On Mothers of Performing Or Observing Painful Procedures On Children
- The Effects of Neonatal Illness On The Mother-Infant Relationship

**The Effects of Painful Procedures On Infants**

Pain in preterm and full-term neonates is a complex, multivariate phenomenon (Carter, 1997; Franck & Miaskowski, 1997; Stevens et al., 1997). As infants are unable to articulate pain, they are dependent upon their caregivers' ability to observe and accurately report physiological, behavioural and contextual indicators of pain.

Physiological responses to painful procedures most commonly are reflected in increased heart and respiratory rates, increased blood pressure, decreased oxygen saturation, vagal tone, transcutaneous carbon dioxide levels, and peripheral blood flow, variability in heart rate and intracranial pressure, and autonomic changes in skin colour, nausea, vomiting, diaphoresis, and dilated pupils (Franck & Miaskowski, 1997; Stevens, Johnston, & Gibbins, in press). Although these indicators provide important pain assessment information, their value is questionable because they also are often associated with stresses distinct from pain (Barr, 1992; Evans, Vogelphol, Bourguignon, & Morcott, 1997).

Behavioural indicators of pain, particularly facial activity, crying and body movement have been validated and appear to be more specific to pain than physiological
responses (Grunau, Johnston, & Craig, 1990; Johnston, Stevens, Craig, & Grunau, 1993; Stevens, Johnston, Petryshen, & Taddio, 1996). Facial expression is considered the most consistent and reliable indicator of pain in neonates and may include brow bulging, eyes squeezed tightly shut, deepening nasolabial furrow, open lips, mouth stretched vertically and horizontally, and a taut tongue (Craig, 1998; Hadjistavropoulos, Craig, Grunau, & Whitfield, 1997; Stevens et al., in press; Taddio et al., 1997). Infants’ cry responses to painful stimuli have been reported to have a higher pitch and are less melodic and more harsh than other cries (Franck & Miaskowski, 1997; Stevens et al., in press). However, cry response may be an inappropriate and/or inconsistent indicator of pain among unstable and/or ventilated infants who cannot cry (Stevens et al., 1997) or among preterm infants, who have been reported to cry only 50% of the time in response to painful stimuli (Stevens, Johnston, & Horton, 1994).

In full term infants, body movement in response to painful stimuli is characterized by vigorous gross motor activity and withdrawal of limbs (Fitzgerald, Millard, & McIntosh, 1989; Franck, 1986; Mills, 1989). By contrast, preterm or critically ill neonates may become limp or flaccid in response to pain (Franck, 1993). Stevens et al. (1994), found preterm infants’ responses to heel lances were consistent with pain responses described among term infants, though they were much more subtle, less sustained and more susceptible to contextual factors such as severity of illness and behavioural state.
Pain response is believed to be influenced by contextual factors both internal and external to the infant. Infants in a more alert awake state exhibit greater behavioural activity in response to noxious stimuli (Fitzgerald et al., 1989; Grunau & Craig, 1987; Stevens et al., 1994). Gestational age of the infant at birth also has been implicated in the magnitude of the pain response, with the most premature infants demonstrating the least amount of response (Craig, Whitfield, Grunau, Linton, & Hadjistavropoulos, 1993; Johnston et al., 1993; Stevens et al., 1996). In observations of premature infants’ responses to pain, Stevens et al. (1994) found severity of illness also had a significant effect on cry response. Severely ill infants exhibited higher pitched cries of shorter duration and longer latency to cry than healthy or less ill infants (Stevens et al., 1994). More recently, investigators have demonstrated the importance of contextual variables in promoting comfort and relieving procedural pain in neonates (Stang et al., 1997; Stevens, Johnston, et al., 1999; Stevens, Taddio et al., 1997). The administration of sucrose, nonnutritive sucking, and the use of a more comfortable restraint device during neonatal circumcision has resulted in reduced crying and increased comfort behaviours (Stang et al., 1997; Stevens, Johnston, et al., 1999; Stevens, Taddio et al., 1997).

Little is known about how infants respond to repeated painful stimuli and the long-term consequences of pain in infancy, researchers primarily have focused on the immediate physiological and/or behavioural effects of painful stimuli. In a study observing 30 low birth weight infants’ behavioural responses to "painful" and "non-painful" procedures neonates exposed to repeated skin punctures reacted much less or not
at all when compared to neonates who occasionally were exposed to skin punctures (Evans et al., 1997). Neonates who are exposed to multiple and repeated invasive procedures may lack the ability to respond to the painful stimulus. This finding is corroborated by the work of Johnston & Stevens (1996) and Johnston et al. (1998) who reported that infants’ behavioural pain response decreased with repeated painful stimuli among preterm infants.

The findings from the study by Evans et al (1997), also suggest that neonates have wide receptive fields causing pain like responses to touch and handling. Infants exposed to a total position change, withdrawal of fluid from umbilical catheters, and administration of intravenous medications which were identified as "non-painful", elicited behaviours associated with pain 34 to 69.3% of the time (Evans et al, 1997).

Infants are hypothesized to have memories of pain which may lead to sleep disturbances, disrupted feeding patterns and maternal-infant interaction, long after the noxious stimulus has ended (Stevens, 1996). Very early painful experiences may have long-term consequences. Taddio, Goldbach, Ipp, Stevens, & Koren (1995) found that male circumcised infants exhibited greater pain response during routine vaccination at four and six months of age when compared to uncircumcised infants. The use of a local anaesthetic prior to vaccination was more effective on uncircumcised infants who may not have been conditioned to pain (Taddio et al, 1995). These findings are further supported by a subsequent study in which the authors suggested that infant "pain memories" may account for the increased pain response among circumcised infants.
during routine vaccinations at four and six months of age (Taddio, Katz, Ilersich, & Koren, 1997). The mechanisms underlying pain memory in infants are not well understood and therefore assertions about the role of pain memories on future pain responses must be considered as speculative.

In a prospective study of 36 children who had been extremely low birth weight (ELBW)/preterm infants, researchers reported that these children (having experienced lengthy NICU admissions as infants and repeated painful procedures) had significantly more somatic complaints of unknown origin when compared with children who had been healthy term neonates (Grunau, Whitfield, & Petrie, 1994). Decreased pain response at 18 months, altered temperament at age 3 and increased somatization at age 4 ½ have all been reported among these children (Grunau, Whitfield, & Petrie, 1994; Grunau, Whitfield, Petrie, & Fryer, 1994). These findings are corroborated by more recent studies with older children and adolescents who had been ELBW, and revealed differences in pain perception, quality of life, and morbidity when compared with controls (Grunau, Whitfield, & Petrie, 1998; Saigal et al., 1996).

In summary, most of the research on pain in infants has focused on the immediate effects of pain, with little consideration of psycho-social and developmental issues or long-term consequences. Samples have been generally small and homogenous. Larger samples from a broader pool would improve the power and ability to generalize findings. Given the complexity of neonatal pain, researchers must strive to include multidimensional pain measures and document and control for potential confounding
factors that may influence pain response and study outcomes (history of previous painful procedures, infant state, co-interventions). The need for further inquiry and development of measures specific to chronic pain is necessary to expand this area of investigation.

**The Effects On Mothers Of Performing Or Observing Painful Procedures On Children**

There is very little research on the effects on mothers of observing/performing painful procedures on their children. However, it is well documented that mothers of infants admitted to the NICU are distressed by the invasive procedures their baby must endure. The experience of learning to parent a critically ill infant in the NICU has been associated with feelings of helplessness in protecting the baby from harm, uncertainty of outcome, fear that the infant might die, and distress and fear over wanting to hold the baby (Affonso et al, 1992; Hayes et al, 1993; Shandor Miles, 1989; Shandor Miles, Funk, & Kasper, 1991; Wereszczak et al, 1997). In a retrospective inquiry, some mothers reported feeling as if their baby was being "tortured", becoming especially angry when their infant was wakened for a painful procedure (Wereszczak et al, 1997). In a study on parental stress in the NICU, seeing the infant in pain, appearing to be frightened, or observing needles and tubes being put into their baby were identified by parents to be among the most disturbing aspects of their infant's appearance (Shandor Miles et al, 1991). In a prospective study, mothers perceived the painful procedures as "keeping their baby alive", or a "necessary evil" even though they found them to be intensely stressful (Affonso et al, 1992).
McKeever (1992), reported that many mothers felt they were "torturing" or "stabbing" their children during routine suctioning, insertion of tubes and/or administration of injections in her qualitative investigation of 25 mothers' experiences of caring for chronically-ill, technology dependent children at home. These women worried about the long-term effects their "cruelty" might have, concerned their children would grow to "hate" them because they were too young or too profoundly disabled to understand why the distress was necessary (McKeever, 1992). Haverstock (1992), a student of McKeever, reported similar findings in an exploratory study of five mothers learning to perform renal dialysis or tracheostomy care on their children. After their anxiety concerning skill performance abated, mothers began to worry that their children would no longer see them as mothers responsible for their nurturance, but as "technicians" who performed complex, painful procedures.

An interpretive phenomenological investigation of one mother's anticipation of assuming care for her son at home raised similar issues (Hayes et al., 1993). This mother described her apprehensions related to performing intrusive procedures regarding her son's "painful past" (frequent invasive procedures in the NICU), not wanting to do anything that would cause him discomfort (Hayes et al, 1993). She believed her newborn son would feel betrayed and struggled with the nonreciprocal nature their relationship would inevitably take (Hayes et al, 1993). Parents' perceptions of caring for infants or toddlers with diabetes revealed the significant difficulties they had in assuming the daily care regimen of insulin injection and blood glucose testing (Hatton et al, 1995). Using an
interpretive phenomenological approach, investigators conducted 14 interviews over a 5 month period with 8 mother-father couples who had been managing the child's diabetes care for a minimum of 2 months. The daily administration of the insulin injection was considered "child abuse" by one mother who felt "imprisoned" by diabetes and the "chains" of insulin and blood tests. All 16 parents voiced similar concerns related to the intrusive nature of diabetes management. Although the fathers reported a heightened sense of "bonding" with their children as a result of their increased involvement in child care, mothers reported diminished bonding and mourned the loss of the "ideal" mother-child relationship (Hatton et al, 1995).

In summary, the findings of these studies indicate that the experience of observing and/or performing painful invasive procedures on infants and children is associated with considerable maternal distress. The majority of mothers in all studies reported significant concern about the long-term consequences on their relationship with their children. Many struggled to overcome initial feelings of anxiety and awkwardness in coming to terms with the responsibility of technical care. Although the samples generally were small, they represented differing populations and procedures. Observations of parents and children during the administration of such treatments would enhance study findings and should be included in future research. Longitudinal investigations examining early and prolonged psychosocial/relational effects on parents and their infants/children are needed to build this area of study.
The Effects of Neonatal Illness On The Mother-Infant Relationship

Typically, the quality of the mother-infant relationship is addressed in terms of maternal-infant attachment behaviours. Attachment between mother and infant is understood as an interactive process where an emotional bond develops, motivating parental commitment to care for the infant (Mercer & Ferketich, 1990). Healthy full term mother-infant dyads were compared to preterm very low birth weight (VLBW) mother-infant pairs in two longitudinal studies (Belsky, Campbell, Cohn, & Moore, 1996; Mangelsdorf et al., 1996). The dyads with VLBW infants were found to be at greater risk for insecure attachment, that became more evident over time (Belsky et al., 1996; Mangelsdorf et al., 1996). Prolonged hospitalization, intrusive medical treatments, parental anxiety and infant irritability were considered major contributors to insecure attachment (Belsky et al., 1996; Mangelsdorf et al., 1996). The effects of preterm birth and perinatal infant health on mother-infant interactions were examined in a more recent study (Schermann-Eizirik, Hagekull, Bohlin, Persson, & Sedin, 1997). No significant differences were found in interactional variables among preterm mother-infant dyads and healthy full term controls (Schermann-Eizirik et al., 1997). However, interactive behaviour among full term mother-infant dyads who required NICU admission revealed less optimal interactive patterns when compared to healthy full term controls. The authors suggest that interactive behaviours among full term infants in need of neonatal intensive care are unpredictable during the first six months of life contributing to the difference between groups. The inconsistent results among studies may be attributable to
the fact that ages of the infants studied have varied considerably. Belsky et al. (1996) and Mangelsdorf et al. (1996) assessed mother-infant interaction when infants were between 12 and 20 months of age, whereas Schermann-Eizirik et al. (1997) assessed mother-infant dyads between 2 and 6 months of age. Measures of interaction and attachment varied between the two study sets.

A study comparing primiparous mothers’ perceptions of infants’ crying (full-term/low birth weight premature) indicated that mothers of low birth weight (LBW) infants were more apt to withdraw than respond to infant cries in comparison to mothers of full term infants (Worchel & Allen, 1997). The investigators agreed this finding may be due to early communication problems among LBW preterm infant-mother dyads, prolonged separation/hospitalization, decreased self-confidence in mothering ability, and acuity of illness (Worchel & Allen, 1997). Other studies examining the effects of persistent infant crying on maternal perceptions and mother-infant attachment have yielded variable results. Stifter and Bono (1998) revealed that mothers of infants with colic assessed between 5 and 18 months of age, reported feeling less maternal competence than mothers of infants who did not have colic. However, there were no differences in attachment scores between these two types of mother-infant dyads. Papousek and von Hofacker (1998) found that mother-infant relationships were more often disturbed when infants (aged one to six months) cried persistently than when infants did not have a crying problem. Persistent infant crying was associated with maternal feelings of low self-efficacy, depression, and anxiety (Papousek & von Hofacker, 1998).
Temperamentally difficult infants contribute to maternal depression and feelings of incompetence (Erickson, 1996; Papousek & von Hafacker, 1998; Zahr, 1991). Premature infants are characteristically less interactive and responsive than term infants, vocalizing less, averting their gaze more, and showing less positive affect (Miller & Holditch-Davis, 1992; Oehler, 1990). Maternal-infant interaction among these dyads primarily has been described from the mother's perspective and has been associated with diminished interactive attempts and significant stress related to maternal role alteration, negative maternal perception of the newborn, maternal depression, feelings of inadequacy and lack of control (Harrison & Magill-Evans, 1996; May, 1997; Miller & Holditch-Davis, 1992; Shandor Miles et al, 1992). Similar findings have been reported among studies addressing parental stress in the NICU. Altered maternal-infant interaction, maternal adjustment and reluctance to form an attachment to their critically ill neonate were commonly cited (Affonso et al, 1992; Hughes et al, 1994; Shandor Miles et al, 1996; Shields-Poe & Pinelli, 1997; Stainton et al, 1992; Wereszczak et al, 1997).

A longitudinal study of mother-infant dyads born at medical risk revealed that maternal interaction patterns differed based on infant morbidity (McGrath, Sullivan, & Seifer, 1998). Mothers of the most ill infants had the highest involvement scores when compared to mothers of less ill or healthy infants. Maternal involvement can be viewed as a positive compensatory behaviour in mothers of medically fragile infants (McGrath et al., 1998). As infants reached preschool age and their health status improved, mothers
adjusted and lessened the intensity of their involvement to accommodate the children’s changing developmental needs.

The necessity and value of supporting mothers to enhance their parenting experiences with ill and/or preterm infants has been well documented (Erickson, 1996; McGrath et al., 1998; Papousek & von Hafacker, 1998). Mothers with greater support and less stress, experienced higher satisfaction with life and parenting, and more positive interactions with their children throughout the infancy period (Affleck, Tennen, & Rowe, 1991; Flagler, 1990; Mercer & Ferketich, 1994; Shandor Miles, Carlson, & Funk, 1996).

In summary, studies on the effects of neonatal illness generally have demonstrated significant declines in maternal competence and compromised mother-infant interactions. The lack of consistent measures of maternal-infant attachment behaviours and control for confounding variables (e.g., maternal age, infant morbidity, maternal support) reduces the power and ability to compare and generalize findings despite relatively large sample sizes. Future inquiry is needed to explore the effect of neonatal illness on maternal health and well being.

**Summary of Literature Review**

The research reviewed indicates clearly that regardless of their gestational age at birth, infants have the capacity for pain. Most research has been oriented toward demonstrating the immediate behavioural and physiological responses of the neonate to pain, although there is beginning evidence to suggest that long-term consequences exist.
Consideration of psycho-social, developmental, and relational effects upon the infant, the mother and their relationship are needed.

There have been no studies to date that specifically address how conducting painful procedures effects the mother-infant relationship. The work by Hatton et al. (1995), Haverstock (1992) and McKeever (1992) provides some evidence that learning to perform painful procedures may be difficult for mothers and may adversely affect the mother-infant relationship. In addition, the studies reviewed clearly indicate that observing painful procedures conducted on infants in the NICU is very distressing for mothers and causes them to feel helpless in protecting their baby. Maternal-attachment difficulties, altered maternal role adjustment and early communication problems have been reported by researchers investigating the impact of illness on the mother-infant relationship. The positive effects of supporting mothers on the quality of mother-infant relationships also was noted by several investigators.

Illness and/or preterm birth may have deleterious effects on the infant, the mother and their relationship. However, most investigations have focused on either the mother or the infant with little recognition of the dynamic and reciprocal nature of the mother-infant relationship. Few researchers have incorporated both observational and interview data, relying instead on single measures at single points in time. Theoretical perspectives mostly have been drawn from stress, systems and attachment theories, overlooking the complex and interwoven worlds of mother and infant. The study reported in this thesis addressed some of these shortcomings. The early mother-infant relationship was
explored prospectively through an interpretive approach. Observations and multiple open ended interviews were conducted with mother-infant pairs engaged in giving and receiving anticoagulant injections at home.

**Conceptual Orientation**

The conceptual orientation draws upon Winnicott (1975) and Wynn's (1996) theorizing of the early mother-infant relationship. Winnicott (1975) describes the early months following the birth of a baby in terms of a mother's capacity to achieve a heightened sense of awareness and attunement to the needs of her infant. This essential temporary phase, known as "primary maternal preoccupation", begins during later pregnancy and involves a drawing back and away from other engagements, enabling the mother to "delicately adapt and respond to" her infant (Winnicott, 1975). In this way, the mother is said to provide a "setting" (Winnicott, 1975) where the infant may begin to develop. She almost loses herself in identification with her baby, so that she knows specifically what the baby needs (Winnicott, 1987). During this period of early motherhood, the mother shelters her infant from "impingements" through a "devoted caring", slowly introducing him/her to the world, sensitive to the baby's needs. Impingements may be internal or external events such as pain, hunger, loud noises, strangers or being held in an insensitive manner. According to Winnicott (1975), the mother's role is to protect her baby from such impingements. Central to this task, is the mother's "holding" of the baby which Winnicott (1987) describes as the "prototype" of all infant caring.
Drawing on the work of Winnicott that primarily centres on the mother's "holding" (physical and psychic sheltering) of the infant, Wynn (1996) reinterpreted this notion so that "holding" becomes a simultaneous "holding and being held". Hence the relationship is no longer characterized by passivity on the part of the infant and activity on the part of the mother. Instead, the mother and infant are said to engage in a reciprocated, co-constituted, "chiasmic" relationship. An essential aspect of this relationship is the chiasm that involves the drawing in of both partners toward one another, interdependently and reversibly, so that "holding" is formed as much by the infant as by the mother. Rather than the mother primarily adapting herself to the needs of the infant, the mother and baby are believed to communicate through their bodily engagement, adapting and responding to one another (Wynn, 1996).

Critical illness and admission to the NICU immediately after birth necessitates multiple, unusual impingements and multiple caregivers. Hence, this type of early motherhood includes an exhausting and technical watchfulness of the infant, rather than the private time of mutual discovery and enjoyment described by Winnicott (1975) and Wynn (1996). We postulated that the added responsibility of administering painful injections and being unable to protect the infant from this and related impingements, affects the mother-infant relationship in important ways. A qualitative interpretive approach was taken to provide a description of the experiences of mothers and infants engaged respectively in giving and receiving anticoagulants over a prolonged course.
In Qualitative Interpretive approaches the goal is understanding through a synthesized, integrated description of an experience from the perspective of those who live it (Benner, 1994). The context or situation of the person is central to this notion of understanding the meaning of human experience. Benner (1994) argues that by studying others "in context" we can begin to discover what they value and find significant and meaningful. Thus, in order to understand the mother-infant relationship, mothers and infants were interviewed and observed within the setting of their daily lives, as they "lived out" their experiences of the infants' illness and treatment.

Research Questions

This study was designed to illuminate what it is like for mothers and infants to administer and receive anticoagulant therapy at home. To this end, the following questions were posed:

1. How do mothers describe their experiences of administering anti-coagulant injections to their infants?
2. How do infants respond to injections administered by their mothers?
3. How do mothers describe the effects of the anticoagulant therapy on their relationship with their infants?
CHAPTER 2: Design and Method

A descriptive case study design was used to illustrate the experiences of mothers and babies giving and receiving anticoagulant therapy at home. By following each mother-infant pair during the course of therapy, important insights were gained that may have been difficult in a retrospective inquiry. The descriptions and experiences of mothers and infants changed over time, demonstrating complexity and the value of a prospective account. This approach also was consistent with the study's theoretical stance and data analysis strategies.

Sampling Strategy

After approval to conduct the study had been received from the Nursing Review Committee and Research Ethics Board at the joint university/hospital committee, the Hematology Nurse Coordinator identified potential participants who were:

1. Biological mothers who were administering (daily anticoagulant injections) to infants less than six months corrected age.

2. Fluent in the English language.

3. Lived within a 200km radius of the study hospital.

4. The infant did not have any major neurological deficits caused by interventricular hemorrhage (>3), or prolonged asphyxia.

A convenience sample of five mother-infant pairs, who had been referred consecutively to the hematology clinic were identified over a six month period in 1998. The small potential sample size is reflective of the rarity of thromboembolic disorders in this
population. Of the five eligible mothers, one declined to participate, indicating that she felt too overwhelmed by her infant’s illness and treatment, and one otherwise eligible mother-infant pair lived out of province. Consequently, a total of three mother-infant pairs were recruited for the study.

Once potential mother-infant pairs meeting the inclusion criteria were identified, the Hematology Nurse Coordinator approached the mothers in person or by telephone to briefly describe the study using a standardized description of the investigation (see Appendix A). After obtaining approval from the mothers the nurse coordinator released their names and telephone numbers to me. I then contacted each mother by telephone to further explain the study (see Appendix B), answer any questions, and obtain verbal consent. I arranged to meet the mothers and babies in their homes, at a mutually convenient time and date. Both verbal and written explanations of the study were given to the mothers at the first meeting (see Appendix B). The mothers received two consent forms related to the study, one for their participation, and one for the taping of the interviews (see Appendices C & D). All three agreed to participate.

**Data Collection**

Each mother-infant pair was visited on four different occasions dispersed over the treatment period. Two to four audio-taped interviews and one or two observations of the injection procedure were used as the data collection strategies. According to Benner (1994), in interpretive inquiry important data are embedded in everyday practical activities. All human behaviours, which include speech, become a text analogue that is
studied and interpreted to discover the "taken for granted" or hidden meanings (Benner, 1994). Data that constituted the text analogues for this inquiry were generated from three sources:

- Open-ended, focused, home interviews with each mother were used to allow me to elicit their perceptions and interpretations. The number of interviews was determined by the mother's availability and willingness to meet, taking into consideration the number of weeks her infant had left on the treatment. Two mother-infant pairs were followed from the very beginning of anticoagulant therapy, hence they participated in the most interviews (three and four).

- General observations of mother-infant interaction were made on each visit. Systematic observations of each mother and infant before, during, and after the injection procedure were conducted on at least one visit toward the end of treatment.

- Field notes were recorded following each visit, noting the physical home environment, mother-infant interactions, my responses, reactions, and initial interpretations of data.

Because the goal of interpretive inquiry is understanding, multiple interviews were used to review and clarify initial interpretations with the participants and to ask salient questions previously overlooked (Benner, 1994). Open-ended but focused interviews enabled me to invite talk initiated and directed by the mothers, while remaining true to the conceptual concerns of this inquiry (Kaufman, 1994; Kvale, 1996).
The interviews and observations took place two to four weeks apart according to each mother's preference and availability. Interview dates were agreed upon and verbally consented to at the end of each interview and confirmed by telephone one week in advance. On average, each interview lasted one hour and took place on weekdays and weekends. Prior to each interview, tapes and transcripts from the participants' previous interviews were reviewed to identify themes and patterns in a preliminary way. This review process enabled me to clarify my initial interpretations with each mother and to ask questions pertinent to emerging data. Interviews and observations overlapped between mother-infant pairs.

The first interview with each mother began with the completion of a demographic form (see Appendix E), which included information important to the study. This form was pretested on the first two meetings for clarity/understanding and minor revisions were made. Prior to commencing each interview, I reviewed the intent of the study. The interview began with a general, open-ended question to encourage the mother to describe in her own terms, the experience of giving anticoagulant therapy to her baby (see Appendix F). After listening to the mother, I clarified my understanding with her by paraphrasing my interpretation of what she had said. If the mother appeared uncomfortable with this open style, I guided the interview on occasion by making some clarifying comments in all three cases (see Appendix F).

Observations of the mothers and infants in the context of their homes, in addition to observing them during the injection procedure, were conducted to deepen and broaden
my understanding of their experience. Benner (1994) stresses the importance of observing/interviewing participants within the context of the situation, since the sights, sounds, smells and demands experienced become visible in a way not possible outside the situation.

Visits to observe the injections were scheduled to coincide with the infant’s usual injection time so as not to cause unnecessary inconvenience or distress. The observation(s) was scheduled for final interview sessions. This strategy was used to lessen any performance anxiety mothers may have had, given that a rapport had been established through previous interviews. The intent of the observation was reiterated prior to commencing the observation session (see Appendix B), emphasizing that I was not there to evaluate the mother’s skill or performance but to gain further understanding about what the experience was like for her and her baby.

Observation of the mother and infant was organized into three time frames: before, during, and after the procedure. Field notes were recorded on a standard observation guide that I developed for the study (see Appendix G). The observation form was designed to guide my observation of each mother-infant pair. The form was based on a review of the literature, and was piloted over a two week period with infants who were in the NICU, but were not part of the present study. A few revisions were made prior to commencing the study. In addition to noting the setting, I focused on mother-infant gestures and affect, infant behavioural cues and the contextual factors that affected them (eg., deepened nasolabial furrow, brow bulge, eyes squeezed shut, high pitched or
harsh cry, vigorous body movement or withdrawal from stimulus, gestational age, and behavioural state).

Field notes were recorded following all visits. I described the physical home environment, mother-infant gestures, responses to one another and comments or feelings shared by the mother. In addition, I recorded my own responses, feelings, interpretations and insights. This observation assisted my own critical reflection, and guided methodological and theoretical decision making. Lines of pursuit/inquiry were revised to remain congruent with emerging data.

Data Analysis

The interpretation of data occurred in several phases following the strategies outlined in Benner (1994) and Benner, Tanner & Chesla (1996). While verbatim transcription and subsequent interviews were taking place, preliminary data analysis was commenced. I reviewed audio tapes and noted emerging themes and patterns. Field notes were read and analyzed alongside taped and transcribed interviews. The initial approach to organizing the data was guided by the research questions. However, in keeping with the interpretive position, I remained open to assertions made by the text regarding unexpected content and concerns. Each interview transcript was read and reread alongside field notes and observation data to gain a global understanding of each home session. When data collection was complete case summaries were prepared for each dyad. Topics, issues, concerns and events were then collected and summarized for a more detailed interpretation. Consideration was given to the context of each text, noting
preceding and following stories, and where the text occurred in the course of the interview and course of treatment. By systematically moving from the parts to the whole of the text, incongruities as well as unifying repeated concerns were identified and reflected upon.

Thematic analysis was undertaken across and within cases to clarify distinctions and similarities, moving back and forth between portions of the text and portions of the analysis. The term thematic is used to illustrate the importance of meaningful patterns, stances, or concerns versus a focus on words or phrases (Benner, 1994). This shifting enabled me to confront and develop new interpretive insights that evolved in the course of the study. As interpreter, my stance necessarily moved from imaginatively dwelling in the world of the participant to distancing and questioning the participant's world as an outsider, engaging in cycles of understanding, interpretation and critique.

Much of the interpretive process involved the analysis of exemplars. Exemplars convey aspects of a thematic analysis and substitute for operational definitions in interpretive research (Benner, 1994, p. 117). My understanding was enriched through the continual review of examples of mothers' practices. A collection of exemplars using direct quotations were dispersed throughout data synthesis to demonstrate identified patterns of meaning or common situations. Exemplars enhance the reader's understanding by enabling him/her to recognize distinctions within the analysis (Benner, 1994, p. 116).
After compiling a summary of the initial findings for each mother-infant pair, I met with a member of my thesis committee (Wynn), who had also independently read the text analogues that had been generated. New insights about the meaning of the text came to light by sharing our interpretations. We realized that by limiting the analysis to data pertaining to the original research questions, significant details related to the experiences of the participants would be omitted. Consequently, I went back to the original text and developed detailed individual case studies to describe the experiences of each mother-infant pair. This process enabled me to move the analysis from the particular and personal within subject cases, through increasingly more generalized levels of meaning across cases, as described by Kasper (1994). Certain experiences, feelings, and beliefs had qualities that were universal to all mother-infant pairs, yet had individual characteristics. Data were framed according to themes that emerged from the full texts, that were consistent across all three cases.

For the final presentation of data the original lines of inquiry (eg., research questions) were expanded to incorporate these themes. Descriptive names for themes were developed and broadly defined. The purpose of the naming process is to capture patterns of meaning in text rather than using operationally defined codes that may obscure different levels of meaning (Benner, Tanner, & Chesla, 1996). Aspects of the text were then colour coded according to these names. More than one name applied to many portions of text because the lines of inquiry were multiple and overlapping. This naming process was dialogical with the text and members of my thesis committee.
Throughout the project these names and their meanings were reinterpreted and renamed to adequately capture new understandings. Interpretive summaries and full text analogues were then reviewed again, with an orientation derived from the work of Winnicott (1975) and Wynn (1996). Data analysis did not end until the final report was completed. Substantive findings first are presented thematically through multiple exemplars of the experiences of mother-infant pairs, followed by a theoretical interpretation.

**Methodological Rigour**

This study was based on the assumption that the mothers’ accounts and my observations were influenced by mothers’ interactions with me and the context of the interviews. I undertook this investigation as a researcher, with expectations and a historically and culturally rated "preunderstanding" of the mothers’ and infants’ experiences. Benner (1994) describes preunderstanding as essential and unavoidable because this background facilitates a perceptual grasp that contributes to the questions posed and interpretations of the text.

I oriented myself to the experiences of mothers and infants who required daily painful injections by reviewing the research literature about infants and pain, the mother, and the mother-infant relationship. While designing the study, I also spoke with a mother who had a baby undergoing anticoagulant treatment, and to nurses who were experienced in caring for these dyads. This early work assisted me in designing a study that would access the everyday experiences of these mother-infant pairs.
Care in the interpretation of texts was taken by completing multiple readings of particular texts for what they made clear and not so clear, making sense of silences or stories that I expected to hear but didn't. Through ongoing dialogue with study participants, text analogues and members of my thesis committee, my interpretations were confirmed or reconsidered.

Conducting interviews and observations of mother-infant pairs within their homes on multiple occasions allowed for the situated temporal unfolding of events and the emergence of themes and patterns in the data, which helped to establish confidence in analyzing them. Phenomenologists posit that human activities are, by nature, temporal and contextual. Hence, there can always be more than one interpretation of observational and interview data. Through a circular process of moving back and forth between my analysis and the text as a whole, I endeavored to remain "true" to the accounts and experiences of the participants, such that my understanding evolved through the course of the interviews and analysis. Field notes were maintained by including written descriptions of my transitions in understanding. This process helped me to remain "open", to new data to identify and challenge my own "taken-for-granted" background assumptions, allowing the synthesis of data to be criticized and evaluated in terms of it's relevance, coherence, consistency and persuasiveness (Benner, 1994). For example, I had assumed that during the interviews mothers' primarily would focus on the stress of giving injections to their infants. This assumption proved false, forcing me to reconsider what I
had originally thought of as the "injection procedure" and how the treatment trajectory played out in their lives.

Exemplars, including direct quotations from texts, were used as much as possible throughout the presentation of findings to afford readers a deeper understanding of the world of the participants and to evaluate the adequacy that the data synthesis represents (Benner, 1994). My previous experience as a nurse did not involve home care, so I was relatively naïve about many contextual aspects of the study. In addition, I had no vested interest in particular outcomes of the research.

Ethical Considerations

Several ethical issues including consent, risk of harm or benefit to the participants, privacy, confidentiality and anonymity were reflected upon and incorporated into the design of this study. As an emergency nurse, I had a significant amount of experience caring for mothers and their sick infants. This background seemed to enable me to readily establish a rapport with the study participants and I attempted to convey respect to each.

To protect the anonymity of potential participants, they were approached by the Hematology Nurse Coordinator who was uninvolved in the project, for permission to release their names to me. Verbal and written explanations of the study along with opportunities to ask questions, were given prior to obtaining verbal and written voluntary consent. Verbal consent to continue to meet with the study participants was obtained on an ongoing basis, thus allowing the mothers to withdraw from the study at any time.
Mothers were assured that their participation in the study, or withdrawal at any time, would not compromise their infants’ care in any way.

Confidentiality was ensured throughout the research process. Tape recorded interviews were heard only by myself and the transcriber. All transcripts, tapes, data files on computer disks, summaries, and field notes were stored in a locked cabinet accessible only to myself. These data are stored in a locked filing cabinet and will be destroyed six years after completion of the study. Mothers, infants, and other family members were given pseudonyms in the transcripts. Mothers were informed that although they might identify their own words or experiences cited in the research report, it would be unlikely that others would recognize them. In light of the small sample number, the rarity of this problem, and the infants’ ongoing need for follow-up care at the study hospital, special care was taken to disguise and/or omit identifying information to further protect participants (Ford & Reutter, 1990). There was no indication of child abuse or neglect by any person at anytime during the interview process, it was therefore unnecessary, as required by law should abuse have been suspected, to break confidentiality.

All three mothers became emotionally upset on occasion, crying at times when sharing their experiences about personal and sensitive issues. I was empathic to their reactions in all instances, offering support and the opportunity to close the interview. Each mother recovered quickly and chose to continue. I did not feel that continuation would cause the mother undue distress. In response to their requests for information, I acted as a resource for the mothers throughout the course of the study. I referred them to
members of their healthcare team (e.g., nurse coordinator, physician, social worker) when I was unable to address specific concerns. On one occasion, a mother telephoned me at home for assistance in obtaining funding for her son's medication. With the mother's permission, I contacted and informed the Hematology Nurse Coordinator who organized help for this mother.

**Limitations**

The primary limitation of the study is the small sample size. However, the three mother-infant pairs represented a variety of demographic characteristics and infants were typical of those requiring anticoagulant therapy. Given the rarity of DVT/PE in this population, and the time allotted for data collection (six months), the study was only feasible with a small sample. The limited sample size was compensated by multiple interviews over time and observations of each mother-infant pair. This design elicited comprehensive longitudinal data.

The aim of this inquiry was not to produce a number of generalizations about this population, but to understand the phenomenon within the practical lived worlds of the participants (the ways they encountered daily life situations related to illness and care, their concerns and meanings). This understanding may in turn serve to enhance the nursing care of these families and provide a basis and means for future inquiry.
CHAPTER 3: Findings

Characteristics of Mother-Infant Pairs and Settings

The women were all in their early to mid thirties. Two lived in small low rental apartments without laundry facilities, and one lived in a comparatively large single family home with five large appliances. Traveling time to the participating hospital was extensive (one to three hours each way), and two of the women relied on public transit because they had no personal means of transportation. One mother was from the West Indies but had been living in Canada for several years and the other women appeared Caucasian. Two of the mothers lived common-law with the infant’s father and one was married. One woman was a first time mother, the others had one older, school aged child. These older children were not present during any of the interviews.

Prior to the birth of these babies, all three mothers had been employed full-time outside the home in clerical or public service positions. At the time of the study, all three women were unemployed, one was on a maternity leave and the other two had terminated their employment to care for their infants. The financial strain of living on their partners’ income was commented upon by all the mothers. Two of the families had very limited resources and relied upon some form of government assistance. One mother had to store her infant’s medical supplies in sealed plastic containers to prevent contamination from insects that infested her apartment. None of the mothers mentioned having any assistance with sibling care or housework and they frequently appeared tired and drained. The possibility of returning to work outside the home presented considerable conflict to all
women. They worried about leaving their babies with others who would be unfamiliar with and incapable of meeting their special care needs.

All of the infants were boys and ranged in age from one to three months upon entry into the study. All three were full term on delivery but had required immediate transfer to the NICU as a consequence of severe congenital heart anomalies. Two infants were diagnosed at birth, and one infant had been diagnosed by ultrasound at 19 weeks gestation. Each of the babies had been critically ill at birth, necessitating cardiac surgery and multiple invasive medical procedures. Two of the infants developed deep vein thromboses (DVT) during their stay in the NICU and were placed on anticoagulant therapy. One infant was treated prophylactically with the anticoagulant. The length of the infants’ hospitalization ranged from three to four weeks.

Two of the babies appeared small and frail looking compared to other infants their age. Their complexions were usually pale with a bluish tinge. One infant appeared relatively healthy in physical appearance, although he became diaphoretic and tachypneic at times. All three babies generally were irritable, cried frequently, and were difficult to soothe. All of the mothers commented that their infants had been very distressed and irritable after their initial discharge from the hospital. This irritability gradually tapered over the first two to three months at home.

In addition to the anticoagulant regimen, each infant required other medications after discharge. These included cardiotonics, diuretics, angiotensin converting enzyme inhibitors and/or antibiotics. The nature of most of these drugs necessitated some form of
ongoing physical assessment by the mothers. Despite their prolonged hospitalizations and critical health status, all three babies had been breast fed once their conditions had stabilized. Two infants had to be bottle fed prior to hospital discharge because they had been too weak to struggle for breast milk, as reported by the mothers, but one continued breast feeding throughout the study.

For the first two to four weeks following discharge, all three babies required and received daily visits from a home care nurse. Mothers reported that these visits had lasted approximately 15 minutes and involved the assessment of vital signs, weighing the baby, and changing the Insufion© when needed. Different nurses assessed the babies throughout each week. On one occasion, a visiting nurse was present during my meeting with the mother and infant. The frequency of visits was gradually reduced to once per week as the infants’ conditions improved. The nature of each infant’s medical problems demanded routine follow-up appointments on a weekly or monthly basis with the cardiologist either in the office or at the outpatient clinic. These visits were separate from the follow-up visits to the hospital hematology clinic each month.

According to all mothers, the future remained somewhat uncertain for these babies. One infant needed at least two more open heart surgeries to repair his heart anomaly. All three babies required continued monitoring and evaluative tests to determine their progress and the need for additional surgery/medical procedures.
The Interviews

The interviews began within one and a half to three weeks after hospital discharge and took place in participants' homes. Each mother-infant pair was visited (for interview or observation) on four different occasions dispersed over the treatment period. Two of the fathers were present during one of the sessions and participated in the visit. According to the mothers, their partners were involved in caring for the infants, but to a much lesser extent than the mothers.

Despite their very busy schedules and frequent appointments with healthcare professionals both outside and within their homes, all three mothers seemed eager to meet and talk with me throughout the course of their infants' anticoagulant treatment. The interviews appeared to provide an outlet for the mothers to express their concerns and garner support. Each mother voiced her opinions on how the care she received could have been improved for the benefit of future families. The mothers seemed to understand the purpose of the interviews/observations, describing their experiences in detail. Their stories were expressed with a range of emotions from sadness, fear, anger, and frustration, to laughter--exhibiting pride and delight in their babies. Short pauses occurred during the interviews during which the mothers would attend to their babies, adjusting their position, feeding them, or simply cooing at them and smiling.

I began the first interview with the completion of a demographic form. I believed that beginning the interview process this way helped to ease the mother into conversation. Prior to starting the interview the following opening was used:
"I am interested in what it is like for you and your baby now that you're both at home. What has it been like for you to learn to give the blood thinner and assist during the injection port changes?"

This approach provided a context for the interview while maintaining an openness that allowed each mother to talk about what was most important to her. Each of the mothers began by speaking about the transition she experienced in bringing her baby home from hospital. All three mothers struggled somewhat with the open style of interviewing. When I sensed their discomfort, I generated conversation by using questions/topics from the interview guide (see Appendix F) and by following and/or clarifying topics that had been introduced by the mothers. This approach seemed to help them to relax and led to additional thoughts and stories that they shared.

Subsequent interviews were opened by inviting the mother to share any thoughts she had had about the previous meeting that she hadn't had an opportunity to talk about or wanted to expand upon. Observation visits took place on the final meeting with each mother-infant pair. One mother appeared uneasy and chose to have the infant's father give the injection. All three mothers commented that their baby's response was "typical" or characteristic of their usual response to the anticoagulant injection.

**Substantive Findings**

The study findings have been organized under headings that correspond with the original research questions. Additional thematic headings that emerged from the data have been included to capture more fully the experience of the participants.
Mothers’ Descriptions of Giving the Anticoagulant Therapy

All three mothers described how they had been approached and encouraged to learn how to give their infants' anticoagulant injections by nursing staff, in both the hospital and community settings. None of the women had initiated this shift of responsibility for the injections. The rationale given to the mothers for taking on this task was to help them to become more independent in caring for their infants. Two of the mothers had begun giving their babies the injections while they were still in hospital, a few days prior to their discharge home. One mother had begun giving the injections after her son had been home for one week.

Stealing Oneself To Overcome Fear and Hesitancy.

The mothers’ descriptions of the injections and the related care trajectory followed the course of treatment and reflected the burden of responsibility that each felt. Two of the women talked about how they initially had to "push" themselves to give injections to their babies, one commenting that she had even "hated to watch" the nurses put the needle in her son. In the next two quotations, Susan and Emma describe their initial apprehension about learning to give the anticoagulant injections. Susan is referring to her partner (Tom) and the reality that he may not be available to give the injections to their son when he needed them. Tom had started giving the injections to assist with Jonathan’s care and alleviate some of the pressure Susan was feeling:

(Susan) I just didn’t like the idea of actually sticking that needle in him, even though it was through the Insuflon©. I couldn’t do it myself, so finally I said, you
know like, it has to be done, I have to be able to do this because suppose he was not home (referring to her partner), he (baby) needs to get this, this dosage that he needs, right?! So, I gave myself, I said to myself you know, "Okay, I have to do this whether I want to or not!", you know.

(Emma) Squeamish. Um, like um, like you said, you’re taking on the nursing role, whereas you were prepared for this (referring to myself as a nurse, being prepared to give injections). Like with Jacob everything is new, this is my adventure. So, you know, everything is like new and it’s coming fast and furious. So when they suggested that I would have to do the injections and so on, you know, I had, I was a bit apprehensive but I think "Okay it’s for the betterment of his health." So then I just got to steal myself and see how it’s done. So gradually, like I would watch, I would watch and the nurse one day said, "Well you try".

And I tried and you know, it takes a bit getting in there!

In contrast, Sharon reported that she had welcomed the opportunity to learn to give her son the injections. She spoke of her eagerness to be independent with Michael’s care:

Actually I uh, I liked that a lot. I thought you know I’d like to be independent and be able to, you know, care for him myself the best I can and not rely on other people all the time. So, I really wanted to learn. Anything to do with him like I want to know everything!
Becoming An Expert.

Each of the mothers had experienced an initial tension in learning to give the injections. Skill based concerns related to drawing up the exact amount of medication and "getting it proper" had gradually dissipated once they had been giving the injections on a regular basis. Emma’s increased confidence is reflected in the following quotation:

But I think now I’m an expert with getting it in there (inserting needle into Insuflon©). Okay, I manage, I think very well with um, giving him the dosage twice per day. The anxiety of the bubble has lessened (referring to air bubble in syringe). It’s just routine for me now. I draw up three syringes at one time, like one to give at the, that moment, the next half hour and two, one for the night, one for the morning cause it’s in the morning, you know, so I just have it ready and that’s about it. Like when I filter the um, what is it, zero to twelve, whatever the measurement is, I then, if there’s a bubble, I then pull it down into the syringe and then get the bubble out and then go back up to the mark and go from there. So, I’ve gotten better, I say, "Well I can teach this thing now!"

Emma’s focus on measurement and procedure was common among all of the women and reflects the crucial need for a correct dosage of medication. Each of them engaged in daily assessments of their babies from examining the Insuflon© site for bruising/bleeding, scar tissue and/or phlebitis to checking heart rates, colouring, signs of infection, congestive heart failure, or cardiorespiratory distress. One mother worried
about her son's oxygen saturation level and, although she was not able to measure the oxygen saturation herself, she explained that she was careful not to let her son cry for any length of time because his oxygen levels would drop very low.

The following quotations reflect the increased comfort that each mother felt with giving the injections to her infant. At the time of the interviews from which the quotations are taken, the mothers had been giving the injections on a routine basis for two to three weeks:

(Emma) So, I've gotten better, I say, "Well I can teach this thing now!"

(Susan) And now it's, it goes good, I can do it no problem!

(Sharon) Yeah. We're more relaxed now and I think he is too (referring to baby).

So I don't know if we were getting frustrated with each other sometimes (referring to husband) but now it's much more relaxed. It's just a routine to us now. Yeah, it's not like it's a bother, oh damn, gotta give that injection or whatever. Everything's routine. No, it's not hard to give the injection at all!

In addition to becoming more at ease with the treatment, the mothers recognized that their babies were less distressed when they gave the injections as opposed to the nurses. By assuming an active role in the care of their infants they believed they were able to spare them any added or unnecessary pain. The women often described the nurses as "rough" when giving the injections and said that they handled the babies in a rushed or careless manner. The following quotations reflect the mothers' perceptions of the nurses giving anticoagulant in comparison to themselves:
(Susan) But it's like I notice he doesn't even fuss as much when I do it (referring to giving the injection). You know, he doesn't fuss as much, yeah, he's a little more comfortable I guess when, especially when I'm doing it cause he's more with me. And there's a special I guess bond between mom and the kid anyways. But compared to when the nurses, you know, it's a stranger, you know, "Why's she holding me down? What's she going to do to me?" It's always a different nurse, he just doesn't get used to the person, like to feel comfortable with them. You see, so maybe if they did send the same nurse all week, you know, he would get to know the voice, the patch (referring to Insuflon©), you know and this way he would be more comfortable with it. Than having different people touching him all the time, you know, which you know, as long as he's being held, it doesn't really bother him, it's just, you know, they're being a little rough, you know, holding him down.

(Emma) I found at the hospital when they did it, he would cry. When I do it he doesn't cry.

(Sharon) Like some of the nurses that come in, you know some put it in slowly, (referring to injecting the anticoagulant) others will, beforehand and just kind of like push it in!!, it's like, "Oh, go slowly!!"

Each mother had developed a particular way of approaching her infant for the injections that was based on her knowledge of her baby and his specific needs. The observation visits provided some of the richest detail in relation to the mothers’ approach
with their infants. Giving an injection was not a simple matter of inserting a needle into an injection port in the infant’s leg. All mothers developed creative rituals related to administering the anticoagulant to minimize their infants’ discomfort.

**Performing The Injection Ritual.**

The injection ritual spanned over 30 to 60 minutes in all cases and involved three distinct phases of preparation, administration and closure. Forty to sixty minutes prior to the scheduled injection time, each mother would remove the anticoagulant from the refrigerator where it was stored and draw up the appropriate dosage into a syringe. They explained that by allowing the anticoagulant to warm to room temperature, the injection was less discomforting to the baby. All three mothers made a point of breast or bottle feeding their baby prior to the injection. Feeding was described as a comforting measure in order to ensure their babies contentment. Two of the mothers then held and cuddled their baby, talking to them in a soft voice. One mother prepared her son by positioning him in front of the television, so that he appeared to be intent on his favorite program.

Once they felt their babies were "ready" after 10 to 20 minutes of feeding, cuddling and/or distraction, the injection was given. Each of the mothers commented on the importance of injecting the anticoagulant very slowly (and were observed giving the injection over a one minute time frame) so as to reduce any associated discomfort. One mother (Susan) appeared anxious and tense when it came time to give the injection and quickly handed the syringe to her partner. However, Susan had indicated on previous visits that she gave Jonathan’s injections most of the time and was comfortable with
giving them. While her partner gave the injection to their son she watched intently and did not appear to relax until the injection was finished, at which point she began to smile and coo at her baby. The other women appeared calm, focused and proficient. All three of the mothers had been giving the injections twice daily for three to five months at the time of the observations.

Following the injection each of the babies were held, touched and spoken to in a gentle soothing manner. One mother explained that she presses over the injection area for a few minutes to help reduce or prevent bruising and scarring (Sharon). Two infants were bottle or breast fed afterward, one was given a soother. Each of the mothers commented on how good their babies were, that the injections didn’t seem to bother them too much. One mother was clear to emphasize that her son did not have pain during the injections, that she "wouldn’t have that!" (Emma). Another mother commented that she wished there was an oral form of the medication because she found the Insuflon® patch changes and related bruising and bleeding problems to be extremely stressful (Susan).

Dealing With Complications and Problems.

It was particularly noteworthy that, in all three cases there was an unexpected but gradual and certain change in the mothers' perceptions and tolerance of the treatment and related care trajectory. Despite their early descriptions of the injections and treatment as "just routine" or "no problem", after two to five months of the continued therapy the situation appeared to have become very difficult. Typical days were characterized by a host of responsibilities and interruptions from telephone calls to home care, nursing
visits, physical assessments, injection schedules, medication times, and the management of complications. Much of this mounting frustration among the mothers could be attributed to problems arising from or related to the Insuflon®, which the mothers referred to as the "patch". All three babies were described as, and observed to be developing an increasing tendency toward bleeding and bruising problems at the Insuflon® site with the progression of treatment. This complication necessitated more frequent Insuflon® patch changes and resulted in added stress for the babies and their mothers. In the next quotation Susan is describing her distress over the patch:

Well, what was more stressful about it, was not doing the injection, was the thing, the patch, I found really was harder on me, myself. You know, and I was poking and poking at him you know, and sometimes it doesn't even last a week and like every three days he's gonna be poked! You see him crying all the time, you know from being poked all the time and when it does bleed, you know, you need to check under the patch, it hurts him when the injection goes in!

Susan, like one other mother (Emma), was unable to afford to purchase "EMLA®" cream (topical analgesic) to use prior to the Insuflon® changes for her baby. Unlike Emma, Susan was not provided with the analgesic cream free of charge through her physician. She commented that even the removal of the patch, caused bleeding and discomfort for her baby:

It's just to see him going through all this, it's still tough you know. You know, you just want him to be finished with it and over and done with, you know. It's
just for him too, I always see him crying, it’s like why does he have to go through this, you know, he’s been through enough, I mean you know, this just adds on and makes it drag on a little longer for him. You know, feeling pain all the time.

Susan commented during my observation visit that she was looking forward to being off of the anticoagulant as she was tired of the imposition of routine medication times and interrupting Jonathan’s sleep for injections, medications, and assessments. At this point Jonathan had been receiving the heparin for just under three months and was due to be reassessed as to whether the anticoagulant could be safely discontinued.

I just do as I’m supposed to. You know, like watch for this and watch for that, you know, like if he’s blue in the fingernails, or the toenails, around his lips, this area. You know, I always look for this of course, it’s like, I’m just basically like you said, I’m doing what they’re telling me to. You can see the little marks where he’s been poked at before. So, they try to avoid that area and do it in an area that hasn’t been you know, poked at. Where the needle hasn’t been in before, so you know, it’s always hard, and there has to be some fat there as well, right?! Yeah, so um, my boyfriend and I talked about it, we said if there was only some other kind, sort of way they were able to do this, you know. I guess, I don’t know if it has to be done through a needle, if it has to be done that way, maybe, you know, even if it could be done orally or something, I think it would be a lot easier.

As is evident through Susan’s descriptions, finding an area on her son’s arms or legs that was not badly bruised or scarred from previous Insuflon® insertions became increasingly
difficult. This complication was common to all infants in the study and created considerable stress for the mothers. The patch, together with the bruising and bleeding, appeared to serve as a bodily symbol of ongoing pain, suffering, and illness. In the following quotation, Emma is describing her mounting concerns and frustration with the anticoagulant treatment:

Looking forward to the date when he’s going to be off the heparin. Actually last week, we had an anxiety episode where he bled on the Friday. When I say bleed, I had a short flood! So I called the nurse but she didn’t give me much confidence in this instance of this anyway, but, I don’t know, it’s the medical field today! Like um, I’m looking forward for him getting off so we would get out early in the morning and I won’t have to think about "ten-o-clock" anymore (referring to injection schedule).

One of the home care nurses had suggested to Emma that she take on the responsibility of inserting the Insuflon® patch herself. None of the other mothers in the study were asked to insert the Insuflon®. Emma shared some of her feelings around this issue in an emphatic, emotional tone:

I think it’s a nursing procedure and I don’t think I’ll say I’m not going to do it, flat out, but if they can do it, let them do it, it’s their job! It’s just a matter of principle as to the kind of care he’s getting. Where do I draw the line, yes I draw the line!
Emma felt she was already helping out the nurses by doing the daily injections, because it was "inconvenient" for them to come by twice a day. However, she also felt that the "medical field" and health care system, in general, were imposing inappropriately on lay people to carry out what she considered "medical procedures".

In this next set of quotations, Sharon is describing her increasing frustrations with the treatment regime, especially the Insuflox® changes:

So, but it just made me mad because I try to make it as painless as possible for uh, the little guy. I put the EMLA® patch on like before, about an hour or two before they do it (nurses come to change Insuflox®). I put it on at 8:00 am, expecting the nurse to be there. It was like 11:00 o’clock and still there’s no phone call and I said, I better take this off because I don’t think you’re supposed to leave it on too long either. So I took it off, so then by the time she did it at 2:15 or whatever, he was like, he cried and cried. He was freaking out actually, I couldn’t believe it! I was so upset because he was upset.

Sharon also was angry that she and her son had to contend with different nurses with varying levels of expertise and knowledge of his specific care needs. She had learned to assess her son’s injection site for phlebitis, scar tissue, bruising and or bleeding. She conducted these assessments on a daily basis, to ensure his continued well being and tolerance of the treatment regime. In the next quotation she describes her assessment of her son’s leg where the Insuflox® had been and how she began to advocate for him by suggesting to the nurse where to reinsert the next Insuflox®.
Yeah, it took about two weeks to heal, I didn’t want to, I, the first week there was still a lump and then the following week there was still the lump as well, so I said to the nurse, I put the EMLA® just on a different site again on the other leg and I said, "There’s still a lump in there, do you want to just wait till it goes?" and she said, "Oh that’s no problem, that’s a good idea", and then the following week we put it back on, on the leg. It had gone down (referring to swelling in leg).

By our final interview, Sharon appeared completely "fed up" with the injections, Insufion© patch, and related problems. Michael had been on the anticoagulant for five months as a prophylactic measure and the bleeding episodes and tissue damage/bruising had become progressively worse with the continuation of treatment. Her hopes for him to soon be free of this regime were put off by the delay in his next scheduled heart surgery. He would need at least one, and possibly two more surgeries before he would be able to safely discontinue the anticoagulant injections. When Michael’s heart surgeon advised Sharon that her son wouldn’t be ready for another operation for at least seven to eight more months she exclaimed, "Oh my God!, that means longer on the Insufion©!!!", and confessed:

I was getting worried and my husband, he panics more than me, eh. So, he’s like, "What about something oral, can’t we give him something orally?!", and I don’t want to give him, I’m sick and tired of these needles, you know. I’ll be glad, I’m getting fed up. That’s why I was, we were, I was hoping for the next surgery next month.
When Sharon notified the nurse coordinator at the hematology clinic about her concern with regard to the increase in bleeding episodes and what she described as Michael’s intolerance of the treatment, the nurse suggested to her that she may have to give the injections directly instead of using the patch. This suggestion seemed to intensify Sharon’s anxiety and distress, she appeared completely overwhelmed when relating this story:

So I’m like, "Oh my God, what am I going to do?!?" So I called (names nurse coordinator) at the hospital and I tell, I left her a message and I told her about (referring to increased bleeding, bruising) and she says "Well, maybe you might have to circulate it, like injecting into, right into the skin." Rather than the Insufloν©, and I’m, "Oh no, I hope we don’t have to do that to him eh?!?!" So, I said, "Oh my God!!", I was getting so worried, "What am I going to do, do I have to start giving him injections?!?!" And, and then the nurse (home care nurse) the um, the nurse said, "No, don’t worry, we’ll, you know, we won’t resort to that, we’ll keep trying to find a spot, (referring to trying to find an area on the baby’s body that was not badly bruised or scarred from previous Insufloν© patches in order to reinsert a new one) even if it’s over a bit", or something right.

Even though all of the mothers described the "patch" as one of the most distressing components of the anticoagulant treatment, the thought of giving injections directly, compared to using the Insufloν© patch, was described as very threatening and extremely stressful. Sharon felt "tied" to her home as a result of the constant surveillance and
management of complications. In this next quotation she describes her son’s Christening party as being interrupted by a bleeding episode:

You feel so kind of tied to your home, you know, you can’t go anywhere! I called the nurse at about 5:30 in the afternoon, there was still lots of people here and stuff (referring to her guests for the baby’s Christening) and I said it’s bleeding, can the nurse come tonight and change it?, so she called back, she goes "I’ll be there in half an hour". Well that didn’t give me time to put an EMLA® patch on, eh. So when she came he was screaming when she shoved in the needles again. So, and they always say, "Oh it’s just because I’m holding him down, that’s why he’s crying" and I’m like, "No, it’s hurting him!" Yeah, yeah, sure, I’m not stupid, I know it’s gonna hurt him, Jesus Murphy!! So then, so then yeah he screamed and I’m like, "Oh my God!", I think I was just so exhausted from the day.

**Worrying About The Infant’s Future.**

Each of the mothers frequently expressed concern over the future well being of their babies as a consequence of their heart problems and critical illness at birth. Anxiety related to their survival and quality of life presented a daily challenge for these women and their families that was compounded by the stress of the treatment regime, related complications, and daily surveillance. The mothers’ fears were legitimate. Although each of the infants had survived life-threatening illness, their futures remained somewhat uncertain, they would require ongoing monitoring and medical care. The anticoagulant
therapy was the only available option for these infants, and was essential to their survival.

In this next quotation Susan is talking about her nagging fear that her son could die:

Actually yeah, you know, it still bothers me, I still think about that, that something can go wrong, just, you know at this point, even though he is doing good, you never know, tomorrow, you know what can happen. Yeah, and I just don’t want to have to actually deal with such a thing. It would be the hardest thing, it would be really hard to deal with that.

The daily injections and related difficulties with bleeding and the Insuflon© patch heightened Susan’s anxiety as evidenced in this quotation:

The other day I was cutting his nails and I thought he was asleep and um, this really upset me that I did this, I was cutting his thumb nails and um, as I was going to snip, I thought he was asleep and he moved and I cut a little piece of his skin off and he just could not stop bleeding! I go, "Oh my God, is he ever going to stop bleeding?!" I wrapped his arm up, so I think maybe no air gets to it. It just, oh God, I was like, "Oh my God, I’m so sorry, I’m so sorry" I kept saying to him, eh.

Susan talked about the relief she anticipated feeling when her son would no longer require the anticoagulant injections. She had been giving the injection for three months at this point:

Yeah, I’ll feel a lot more relieved, like he won’t have to go through this pain anymore. You know, even for myself, I won’t have to see him hurting anymore,
you know. That’s going to be a big relief. It’s like at this point you say, like that’s enough now, you know, like he’s been through hell! Um, you just want it all to end, and you know, let him live his life and not hurting no more.

Emma often expressed concern as to what the future might hold for she and her son. She would imagine little scenarios in which she might find her son not breathing, and attempt to plan ahead how she might handle such a crisis. The future she described was full of unknowns as to her sons chances of survival and quality of life.

They sleep so still, you know, so, you want to, "Is he breathing?", you know. And then I think, "What am I going to do?!" So, I said, "What am I going to do if in fact I do that and he’s not breathing?" So, I thought, call 9-1-1. Jeez, I just deal with it! Nobody has said to me yet children with this problem, they don’t live very long. Do I want to know that?, maybe. But I would like to know is he going to live well, that would take worry off me.

The home care trajectory (home care visits, injections, patch, anticoagulant, managing complications) exacerbated these fears and played on her sense of security. Problems related to the Insuflon© patch and bleeding episodes seemed to increase in frequency with the progression of treatment.

Well I know heparin is blood thinners, obviously, the blood will be thin and be able to bleed more easily, but again all these things are new to me! If I see blood, I’m thinking, it, when it started, "Oh my God, will he bleed to death if I don’t hold this?!", because I had to hold, for forty-five minutes!
Sharon struggled daily with concerns related to her son’s health and future well-being. Her anxiety is evident in this next quotation:

You know anything could happen. My God your heart’s pounding and it’s like, how are you going to stop him from crying. And we tried everything. He (referring to MD) just says "Well don’t let him cry too long because his saturation drops down in the 50’s when he’s getting really upset" eh. So then I, so that made us all paranoid!

The home care trajectory appeared to add to her burden of worries, particularly as time passed. Michael was experiencing more and more frequent bleeding episodes from the Insuflon© patch over the course of treatment. This necessitated more frequent patch changes from once per week to every few days.

Oh my God I was getting so panicky because none of them, they kept bleeding all the time, eh, none of them were taking. (referring to Insuflon© patch) I was worried that maybe he wasn’t tolerating it anymore or something. So, as this one was bleeding, or started to bleed it, we took it off, this one started to heal up, no it was this one, this one started to heal up, cause it took a while with that mass eh?

So, we put it back in this leg and thank God it lasted ten days!

The diagnosis of a heart anomaly, critical illness at birth, and an unpredictable future, combined with the routine of daily injections and necessary surveillance placed an enormous responsibility and burden upon each of the mothers.
Infants' Responses to Injections Given By Their Mothers

Observation visits took place in the participants’ homes at regularly scheduled morning injection times during my final meeting with each mother-infant pair. At the time of data collection, the infants varied in age from three to six months. All three babies were delivered at full term and had similar histories of prolonged admission to the NICU, requiring cardiac surgery and a number of invasive tests and procedures. Prior to the injection, each of the babies was alert and content, they had all been recently fed and had awakened from a nap within the previous hour. All of the babies were held and cuddled by their mothers before the injection. While receiving the injection, one infant was positioned lying on his mother’s lap (Jacob), one was in a lying position on a sofa (Jonathan), and one was sitting upright in an infant seat while "watching" television (Michael). None of the infants exhibited any of the identified behavioural pain responses (deepened nasolabial furrow, brow bulge, eyes squeezed shut, high pitched cry, vigorous body movement, withdrawal from stimulus) during the anticoagulant injection. Their mothers confirmed that this was a "typical" response, and remarked on how "good" their babies were when receiving the injections. The infants were alert and appeared content during the injections, seemingly unaware. Their bodies appeared relaxed and were still. One infant (Jacob) cried briefly after the injection was completed but settled once his mother sat him up from a lying position. Two of the babies were breast or bottle fed following the procedure, one was given a soother. Their mothers held, touched and spoke
to them in a gentle soothing tone. All of the mother-infant pairs appeared relaxed and content at this time.

Of particular significance, is that each mother indicated that their babies were distressed during routine injections when administered by a nurse instead of themselves. On a separate occasion, I observed one mother-infant pair (Susan & Jonathan) while a visiting nurse gave the injection. The baby had just had an Insufilon® patch inserted, and responded with all of the behavioural pain responses previously described, as well as a taut tongue and open mouth. EMLA® cream was not used prior to the insertion of the patch. The injection was quickly given following the insertion. Michael again exhibited all of the identified pain responses, in a less robust manner. He initially was content and alert when with his mother. She had been giving him his bottle until the nurse was ready to begin. Michael began sucking on his fists when his bottle was taken away. He became more restless, wiggling about once the nurse picked him up and positioned him on the sofa. His mother assisted in holding him still for the nurse. He settled within three to five minutes of being held and cuddled by his mother following the procedure. This observation took place one day after the visit in which Michael was calm and relaxed during the injection that was administered by his father. The nurse commented that Michael was more upset today than usual and his mother agreed. Susan commented that she had given him only part of his bottle before taking it away for the nurse to insert the patch. She believed that this probably made him more upset.
Given that all of the babies were described as being very distressed and crying when nurses gave the injections, the absence of a behavioural pain response when mothers gave the injections does not seem attributable to the phenomenon of a habituated response or learned helplessness as described in the literature (Evans et al., 1997; Henrikson & Birks, 1997; Johnston & Stevens, 1996). This finding does however, accentuate the importance of contextual factors and their influence on infant pain response. The following quotation from one of the mothers emphasizes this point:

(Susan) But it’s like I notice he doesn’t even fuss as much when I do it (referring to giving the injection). You know, he doesn’t fuss as much, yeah, he’s a little more comfortable I guess when, especially when I’m doing it cause he’s more with me. And there’s a special I guess bond between mom and the kid anyways. But compared to when the nurses, you know, it’s a stranger, you know, "Why’s she holding me down?, What’s she going to do to me?" It’s always a different nurse, he just doesn’t get used to the person, like to feel comfortable with them. You see, so maybe if they did send the same nurse all week, you know, he would get to know the voice, the patch (referring to Insuflon©), you know and this way he would be more comfortable with it. Than having different people touching him all the time, you know, which you know, as long as he’s being held, it doesn’t really bother him, it’s just, you know, they’re being a little rough, you know, holding him down.
All of the mothers put a great deal of time and effort into making the injection routine as unobtrusive as possible. As previously discussed, each mother had developed a ritual of preparation, administration and closure that spanned over 30 to 60 minutes. The familiarity of their touch combined with the comforting measures of feeding, warming the anticoagulant to room temperature, cuddling, and waiting until they believed their infants were "ready" for the injection, appeared to ease the associated pain and discomfort.

The Mother-Infant Relationship

The extensive demands of coping with critical illness and the burden of responsibility in caring for these babies seems to have left an indelible mark on the mothers and their infants. The nature of their relationship was shaped and continually altered by the trajectory of care from birth through hospitalization and coming home. The following pages have been arranged and titled to reflect this experience which one mother described as an "adventure". The effects of the injections and care trajectory will be addressed within this frame.

Accepting The Circumstances.

Each mother reported feeling overwhelmed by the news that her baby had been diagnosed with a potentially life threatening congenital heart anomaly. Two of the women had been unaware of any problem until the delivery of their babies, suddenly finding themselves and their infants in a state of crisis. In this next quotation, Susan is
recalling her initial shock upon learning of her son’s illness and the lack of support she perceived from hospital nursing staff:

Like I carried him for all those months, you know and not knowing that anything was wrong and I was expecting to have a healthy baby. You know, as far as I was concerned I thought he was supposed to be healthy and then this happened to me and they’re telling me I didn’t understand it! (referring to nursing staff) You know, especially they, I mean they must have known by the record I had a cesarean section and I was drugged up as well (referring to pain medication). It’s hard to like, for it to hit you at the beginning!!

Susan’s son had had two cardiac arrests within hours of his birth. After expecting a perfectly healthy baby she was forced to confront issues related to his immediate survival. She struggled to overcome feelings of guilt, believing that she was somehow responsible for Jonathan’s illness:

I cried a lot over what happened and then this, it’s not your fault, sometimes you think well, was it my fault because I was working in a bar area. When I was working in the bar, I said, well, maybe because in the beginning when I didn’t know I was pregnant, you know, maybe I had some drink and maybe this could have sort of affected him.

Emma recalled a very traumatic delivery experience in which she felt her son had been snatched away from her without any explanation:
And they took him away and there I am expecting him to come back and I’m not seeing him. Someone came and said he wasn’t pinking up, maybe after an hour. So, now I’m in hysterics, not screaming or anything but my nerves are shot, cause I’m wondering now "What could it be?" Because just the week before we had our hospital visit and I’m saying, well, my child won’t be in there because I’m thinking it’s you know, kids with jaundice or premature kids go to the nursery.

Well, low and behold!

She also struggled with feelings of guilt and anger, convinced that someone was to blame for her son’s illness.

I was not prepared to be pregnant, you know, so and all through the pregnancy I can say I gave the dad a hard time. Abortion didn’t enter my mind because it’s not me, but I can’t say I was overwhelmed with joy! But like I say the Lord saw fit for this year, so here we are with Jacob. So, then you have all these concerns about him. I don’t even know his family uh, (referring to partner) what type of illnesses would have existed there. And I look into my own, what’s happening on my side and the doctor says, "Well you can’t blame anybody because these things happen", but I still think, I still think genetically maybe lifestyle maybe because I know um, his dad, would um, consume alcohol. For myself, when I went to bury my dad, they would have the wake and so I drank alcohol then, not knowing that I was pregnant, so that could be a factor, I don’t know, I’m still looking for answers.
Unlike the other mothers Sharon learned of her son’s heart anomaly during her 19th week of pregnancy. She believed this knowledge helped her to make the adjustment more easily:

Oh my God, yeah, it was really, you know, it was hard to find out at that time, it was really shocking, and hard to adjust to, but I was uh, I was glad that we knew ahead of time anyway so we could be prepared. Like, we had met with a social worker at (names hospital) and she took us for a tour of the, you know ICU to prepare us about what we were going to be seeing and showed us a baby hooked up to some machines and stuff. But, I, I was glad instead of being shocked at the time, you know you think you’re having a healthy baby and then all of a sudden wham, your baby has this and let’s ship him here!

All three babies had to be transferred to the participating pediatric hospital. Because of their critical illness and NICU admission, initial contact with their mothers was severely limited. In all three cases, the mothers talked about not being able to hold their babies as a significant source of stress for them. In this next quotation Emma is recalling her son’s transfer to the NICU at the participating hospital:

Before he left they brought him down for a visit and he squeezed my index finger and I said, well, you take care, he went off (transferred to the pediatric hospital). So, there all night, not sleeping, I just cried.
Emma felt overwhelmed by her son’s illness and admission to the NICU. She desperately attempted to sift through what she termed as "all the medical jargon" in order to grasp what was happening:

Oh, overwhelming, overwhelming, I had so much questions, I still have questions as to how could it happen, you know, who you’re going to blame thinking about um, what was happening in my life when he was conceived, you know, stuff like that, you know.

Susan wasn’t able to hold her son until a week and a half after his birth. Although very excited and anxious to hold Jonathan she recalled feeling intimidated by the wires and tubes he was connected to while in the NICU:

I just finally got to hold him, you know, just for like a short period. I, actually I wasn’t very comfortable with it at first because I was afraid, what happens if something gets disconnected here, you know, this can hurt him here in some way, you know. So, the first nurse wrapped him up and then, put him secure and then I held him for a while, it felt good to hold him. The first time was really good, it actually brought tears to my eye, you know. I got to hold him, it felt good. And I guess he probably loved it as well, you know to feel some security, you know.

Susan described herself as "crying all the time" during Jonathan’s hospitalization, fearful "he may not make it." Although still recovering from a cesarean section, she made every effort to travel by bus daily for two and a half to three hours to see her son:
I was still in a lot of pain from the cesarean. I could barely stand up and barely walk, but I still went to see him, I said, you know, "He needs me", he needs to know that his mom is there. And I can't even believe I made it through all that!

Susan talked about having a "special connection" with her son, even though her initial physical contact and caring was limited to brief touches through the isolette amidst a myriad of pumps, tubing, and wires. She recalled an awkwardness in learning what "mothering" she was "allowed" to do while Jonathan was in the NICU, from asking permission to hold her own baby to changing his diapers.

So, the diaper was not changed and we didn't know that we were allowed to do it ourselves. We didn't know if we can touch him, like to move him around. You know, but then they told us we could have, so then we, you know, we said okay, next time we're there, you know, no problem we'll do it ourselves but we just didn't know, you know!

We'd ask, can we hold him?, you know, is it okay if we hold him? But we did not pick him up straight ourselves. One of the nurses would bundle him up in a blanket first and then she would give him to us.

Since she was unable to be with her son as much as she wanted to, Susan kept his picture under her pillow at night as a source of comfort.

Even though Sharon had learned of Michael's heart anomaly well in advance of the delivery she also found his hospitalization to be a highly emotional ordeal. She talked
about only being able to hold her son for 15 minutes before his transfer to the participating hospital.

It was emotional, seeing him hooked up to everything. Yeah, I found it very emotional but the nurses were all very nice and it’s good to know that he had one on one care there. But it was hard seeing him hooked up to everything and you know, not being able to hold him. We could touch him, his hands, his feet or his head and stuff. And then um, then he had to go in an oxygen tent thing, so we couldn’t touch him, it was hard to get at his head or his face, so we could just touch his arms and stuff.

Sharon felt that she had to be present to protect or guard her son during his hospitalization from what she perceived to be a "constant barrage of insults". She believed that the longer he was in hospital the more at risk he was for infection and additional invasive tests. After Michael was transferred to a cardiac step down unit from the NICU, Sharon was able to "room in" with him. She did not leave his side for two weeks:

It just seemed like they were, the longer he was in hospital, the more things that he was catching and stuff, you know. So, we’re just, "Let’s just get out of here!" But in there, we were, the surgeon was telling us one thing and the cardiologists were telling us another thing, you know, we were like not getting a straight answer from anyone!
Sharon felt considerable distress over the number of painful invasive tests that Michael was subjected to while in hospital, she believed many were unnecessary:

Especially that spinal tap they did, there was no anaesthesia, no nothing!!, they just put a needle in his spine and I, you know, it doesn't make sense to me, what are they?, I don't know.

When it was suggested to her that her son may have to undergo another lumbar puncture Sharon refused. "I said no you’re not! I’m sorry but you’re not going to do that to him again, he’s not going through that again!" Sharon did not feel comfortable in leaving her son at all, the opportunity to "room in" with Michael had consumed her.

Oh God, cause I was, two weeks, he was on the floor there and I could stay in the room with him, I was there the whole two weeks, I didn’t come home at all, I just wanted to be there with him, cause you know, the nurses had maybe three patients to look after and so, well, what if he’s crying and no one can get to him right away and, well, at least I’ll be there and like I wasn’t leaving the room at all, not even to eat, he (referring to husband) was picking me up food and stuff, I just didn’t want to leave him!

The critical nature of each baby’s condition brought with it a number of challenges for the mothers and their infants. Each baby underwent several invasive tests and surgical procedures as a consequence of their illness. Physical contact with their mothers was almost impossible during the first few weeks of life. The majority of human
touch they experienced was procedural in nature. Each mother had to adopt a style of mothering that "fit" within the hospital structure and routine.

Enduring Transitions.

Once arriving home with their babies, all of the women indicated that they went through a difficult two to four weeks. During this time, they described a period of transition in getting to know and feel more comfortable with their babies. All three infants had been generally irritable and difficult to soothe, particularly during the first few weeks home. This irritability created considerable distress and anxiety for their mothers. Emma believed she had suffered from postpartum depression which was exacerbated by Jacob's illness and irritability:

I know I was going through postpartum depression, I know because with my first girl I was into everything. I was a single, single mom, no help and I would get up in the morning, do my stuff, go to drop in centres, go visit moms. With Jacob, no energy. Yeah, I think with his stressful birth, probably that's why, um, I'm not totally back to my normal self. But day by day we make strides, yeah.

Jacob was extremely irritable most of the day and night for the first month that he was home. Our visits were often interrupted by his sharp cries and discontent, to which Emma responded with apparently endless patience. She would frequently change his position in her arms, offer him breast milk, or gently pat his back or bottom until he settled. She talked about gradually becoming more familiar with what worked best for her son:
Cry a lot, like you know, like he would be up, he would get up at midnight and he’d be back to sleep at four. So I would be there rocking and doing all these...trying to soothe him. I’d even have times when he would be screaming and I would be going, Ooooooh! So, eventually I took him to bed with me, when he would fuss I would just give him the breast and he would go right back asleep, he just probably wants something to suck on. You know, even though he’s not sucking, he just needs to nuzzle on something. So now we are good friends.

Breast feeding played a very significant role for Emma and Jacob. She believed breast feeding was essential to nurturing their relationship:

I think it’s very important for us to have that closeness. I do want to stay keeping him on (referring to breast milk) because I think it’s good for him, the antibodies will be working with him and I don’t know, for that um, socialness that we have. Just to be closer for now. I still want to continue having that closeness because I know when Tisha was weaned (referring to her daughter), I felt detached, like I lost her.

The "closeness" that Emma refers to was evident throughout my visits to their home.

Jacob was never seen outside of his mother’s arms. He would play at her breast, focused and watching her intently. Emma would frequently break our conversation to coo at him. Although often tired looking, Emma constantly attended to Jacob, feeding him, cuddling and rocking him in her arms. This bodily tending and caregiving appeared central to their relationship which Emma described as an "adventure".
Every experience in life, you learn from, that's what I think. And I never encountered tragedy until this year. My dad died and then Jacob was born with this heart defect and so now Jacob is an ongoing process. It's not like it happened today and it's going to end. It's continuous, continually being altered, that's the adventure. Yeah, so you learn to deal with it, you accept it, well for myself, I accept it and we're going to move on from there, yeah. And build on that, be positive I think, very positive about his future, that he is going to have one.

Susan talked about feeling panicked each time Jonathan would cry during their first three weeks home together. Jonathan was very irritable during this period and she described him as "crying all the time". She worried that something might be seriously wrong related to his health, "I just didn't know what was wrong!!" During what would normally be pleasurable moments of mothering such as giving him a bath or undressing/changing him, Susan found Jonathan to be very distressed, "he would cry like crazy, he just didn't like it at all!!" She attributed this behaviour to his experience in the NICU, in which most of the physical contact he received was for painful procedures -- "I guess he knew, he had some sense still that he was gonna still be hurt. Cause that's all they did at the hospital, was basically poke at him all the time!" Once she had begun to learn Jonathan's particular patterns and cries, Susan described feeling more at ease. This took her approximately one month.

After a while, you know, we got used to having him home and because his condition you know, we got more comfortable with it, so you know, we wouldn't
jump up every time he made a noise. You know, and before we were more
paranoid about it. So, like I know him a little more now, so I know what, you
know, how he, how he reacts, different reactions that he does, you know, the
movements, like you know. You get to know your child.
The "special connection" Susan initially felt between she and her son became much
stronger once they were home together:

Yeah, but not as strong as when he came home, when I get to hold him all the
time, yeah, he's in my arms and you know, you talk to him, yeah. Yeah, but now
he's doing really good and he seems to understand a little bit more of course
(speaks with pride, smiles).

I asked Susan to elaborate on what she had meant by her term "special connection".

Although somewhat difficult for her to articulate she manages to convey the significance
of their relationship and the agency of her baby, as follows:

Um, I don't know now, I just find that um, how can I say it? It's just, you just
feel it, it's just, it's really strange I can't explain it really, it's just a feeling you
have, like you know, your child knows you and your child needs you, you know,
it's just a different kind of love, it's not like a love like you would love your
husband or you know, it's a certain sort of love for a child. Yeah, and it's just a
lot different and you just feel like he understands you more than he understands
anybody else.
Being able to hold her son appeared to be an essential part of establishing this "connection" that Susan described. Holding was seen as a significant part of the work and pleasure of mothering her baby. "And um, I noticed he, like when I don't hold him very much then I miss him. It's weird but it's like, it's a lot of work but just the same you miss it when it's not there, because you know you're always so used to holding him."

During my visits Jonathan was often nestled securely in Susan's arms. She would pat his bottom and coo at him amidst our conversations. He appeared calm and content while she held him. They were never more than arms length apart. Even while he lay resting in his bassinet, Susan would gently stroke his head, adjust his blankets, and slowly rock him back and forth.

Susan believed that it was because of this unique connection she shared with her son that he was more comfortable when she gave his injections herself.

I guess because he knows your touch and I, I think he would, he can feel you, you know, he knows it's his mom, right. Yeah, he knows, he just calms down and yeah, he takes it pretty good. Well even like when she's (referring to nurse) doing it to him, like giving the shot and I talk to him, he still fusses. But, when I do it and I talk to him and I'm holding him there, he seems very, he's very relaxed. Even sometimes with his dad he still fusses with his dad as well. But, I guess cause he knows his mom, it makes it better for him. And even when he cries and cries and dad takes him and dad can't make him stop and then he goes, "Here mom you take him." And he stops like just seconds!
Sharon found her son Michael to be very irritable during his first few weeks at home. He would cry frequently and was not easily consoled. "But at first he was, I think maybe he was getting used to the surroundings as well because he was a little bit crying a lot more and just, I don’t know if it was being scared or what but he’s okay now." When I asked Sharon if she had noticed whether Michael was most upset during his changes or baths she agreed emphatically, but hadn’t made the connection before. She had already begun to adapt her approach in order to accommodate him. "If you talk to him calmly while you’re doing it (referring to bathing/dressing), then he’s okay." Michael had been home for two weeks at this point, she began to notice he was settling in. "So, he’s more comfortable. He’s realizing that this is home."

Sharon took great pride in getting to know her son, his particular little ways and preferences:

Little things he’ll do are uh, he’ll cry and you know Dave (partner) will say, "Well what’s wrong with him, Why is he crying?" and me, you know, I’m like, "He probably has a little burp, sit him up" and sure enough he burps you know and I’m like, "See" and he, "How’d you know?!" I said, "I don’t know, I just know." So, I said, "Well, you know you find these things out when you spend the whole day with each other." But, you know he gets cranky, when he gets cranky I know he’s tired, he needs a sleep. Like before when he first got home, it’s like, "Oh my God, why is he crying?! I don’t know what to do!!" Now at least you know why he’s crying, he needs to be picked up.
During my visits, Michael was always in close proximity to his mother. He would often be nestled in her arms while she fed him or rocked him rhythmically back and forth. If he were sitting in his swing chair or resting in his bassinet she would frequently break her focus from our conversation to glance over at him, smiling or talking to him. Michael appeared content and relaxed when in his mothers arms. It was important to Sharon to feel recognized for all of the devotion and thought she put into mothering her son. She became very excited when she realized that at three months of age, Michael recognized her as distinct from others:

I find he's starting to really recognize me. I didn't really notice him recognizing me before, but lately I think he is. He'll be with somebody else, he'll start, you know, putting the lip-- so, that was, yeah, he's sweet. He's gonna be a smart little guy I think. But yeah, and I really noticed him knowing me now. So I like that, it makes me feel good, you know, you work so hard with him. Yeah, he'll look for me when someone else picks him up he'll look where I am. Yeah, and then he'll see me and he'll watch me and he'll smile. Yeah, it makes me feel good and happy. Cause I'm always saying to my friend, "I don't think he knows who I am." She goes, "He knows you, don't worry about it." Cause you don't know they'll, they'll go to anybody that's going to give them a bottle sort of thing, you know, at that stage.

Sharon was very protective of Michael and was anxious to be independent with his care. She hesitated to accept any offers of respite from others:
I said, I don’t know if I’m just overprotective or I just, you know, but I don’t know, I said, I’m sure people are wanting to relieve me, you know, let me have a break but he’s only three months and I don’t want a break yet, you know. Even when Grandma comes over too, it’s like, you know, she’ll be helping me and once he starts to cry I’ll go, "Okay I’ll take him now."

Sharon appeared to struggle in finding a sense of normalcy, she talked about her fear of exposing Michael to any infection or germs that might jeopardize his health. Her concern for his welfare forced a ritual adherence to vigorous hand washing before she touched her son. Her hands had become red and sore looking. This anxiety gradually dissipated with passing months.

Anytime just before I go to hold him I have to wash my hands, just in case I’m touching something but even though I’ve not, I haven’t even been out of the house, you know. So it’s like, "Oh my God", so we’re um, my hands are so dry because I wash them so much, see--they are red!

Sharon’s concerns regarding infection were also shared by Emma who felt the need to isolate her son from others:

I tended to keep him away from everybody. Before I was afraid that maybe he would catch something in the air, or something from somebody, but I can’t prevent that, if he has to catch something he catch it. It’s the world we live in I think, it’s only natural but I was kind of protecting him, wanting him to be in this invisible bubble. But I can’t do that, so, I’ve let go of that.
Sharon was the only mother to directly express concern related to the effect of the injections and treatment on her relationship with her son. She had been giving the injections and managing Michael’s care for the greatest amount of time (five months) compared to the other mothers (three months). On our final visit she talked about her feelings related to the injections.

That’s my main concern. Making him go through any added pain. You know, cause he’s looking at me when I give it to him, (referring to the injection) you know, and I'm like, "Oh well I don’t want to", you know—look at me and think I’m gonna give him pain, you know all the time.

Although Emma took great offense to the nurse’s suggestion that she begin to insert the Insufion® in addition to giving her son the injections, she did not relate her concern to the impact it might have on her relationship with her son. Instead she emphasized what she termed as her "political" concerns about health care workers pushing their responsibilities on lay people. She appeared to focus on what she considered to be "normal" about her relationship with her son and related it to mothering her daughter:

No. No, actually, I see Jacob, if I didn’t know he had a heart problem, he would be normal. Um, he eats well, you know, he goes to sleep, he wakes up. So, that just makes me remember when I had Tisha. That’s how she behaved, so it’s just normal.
Emma and Susan may not have directly expressed concern over the effect of the injections on their relationship with their babies because they did not perceive any threat to the closeness that they shared with their infants. Sharon had been giving the injections to her son for a full two months longer and the end of treatment was unclear and indefinite to her because of the delay in Michael’s heart surgery. The stress and exhaustion that each mother-infant pair endured as a consequence of the treatment trajectory was apparent through the narratives and observations in all cases.

Making Up For Lost Time.

When each mother was asked how the experience of her son’s illness/treatment had affected her outlook or changed her behaviour, all of the women talked about being more attentive to, or "spoiling" their babies. This attentiveness was evident during my observations. All of the mothers’ efforts centred on the comfort, contentment and well being of their infants, seemingly to the exclusion of themselves. Their descriptions of personal time consisted of brief trips to the grocery store, taking a nap or hot bath and going to the hairdresser on occasion. Although each of the mothers often looked tired and drained, their devotion to the care of their infants seemed inexhaustible. In this next quotation Susan is talking about "spoiling" her son:

He is spoiled so, like when he wants to be held, he’ll cry and cry and cry till you pick him up. I’d say that I pay a little more attention, closer attention to him now, because of what he’s gone through, his operation and everything. And I will not
let him cry as long. Like I’m more, I listen a little more and if he stops crying, I’m like, well, I better go check him just in case, you know.

When I asked Susan what she meant by "spoiling" she offered this explanation:

I hold him more and you know, tell him I love him all the time, and you know, cuddle him a lot, more than I would if he hadn’t gone through what he’s been through. Like I had another child as well and I didn’t spoil him because I know once you spoil them when they’re a child then that’s it, there’s no going back after that. So, he is a little more spoiled and my boyfriend tells me that, but that’s again because of what he’s been through and I can’t help it.

Spoiling appeared to be Susan’s way of compensating for the lost time and traumatic beginning she and her son shared.

I almost lost him, you know, so um, I feel like I have to give him extra attention you know because he didn’t have it in the beginning as well and you know, what he’s been through you think, you know he needs that extra comfort and you know I think so, I don’t know how everybody else thinks about the situation but if they’ve been through it, this is how I feel. And I just can’t help it!

Sharon talked about the attention and love she doted on her son. She struggled with others perceptions of her "spoiling" Michael:

I love being a mother and stuff that’s so, I don’t know if I love him more or if that’s what you’d say spoil, maybe I am but, um, like if he’s crying, a lot of people say, "Why are you going to him when he’s crying?!", and you know, like
they think okay, maybe that’s spoiling or something but I’m like, well you can’t
spoil a baby and I don’t want to let him sit and cry you know. So I don’t know if
they’re judging me or thinking I’m spoiling him, but I don’t think he’s spoiled.
You have to see what’s wrong with him!!

Sharon believed that Michael felt more secure as a result of the extra time and attention
she spent in caring for him. Although perturbed by comments from family and friends
that she was "spoiling" her son, Sharon continued to mother Michael in the manner she
felt was best for him. She attributed part of her attentiveness and concern to his medical
condition. She explained that if Michael were left to cry for prolonged periods, his
oxygen saturation levels would drop very low. Sharon was clear to point out that even if
this were not the case she still wouldn’t leave him to cry, she believed it was important to
attend to him and see that he was okay.

Emma indicated that she spends more time with her son in comparison to the time
she had spent with her daughter when she was an infant. She did not elaborate on how
she would spend this extra time with Jacob, nor did she use the term "spoiling" like the
other mothers had. However, during my visits she never put him down for a moment.
I’m really aware of maybe what I didn’t care about before, I’m paying more
attention too. I think I’m paying more attention to Jacob. I’m confident that he’s
all right, you know, but then I still say this little prayer that "I hope you do okay
just get better and stronger."
Running Interference.

A significant part of each mother's role appeared to be a form of running interference between her baby and the health care staff. In all cases the mothers shared stories of their experiences with home nursing staff, who changed from week to week. Nurses were described as helpful on occasion but were mostly perceived as strangers contributing to their distress.

Initially at home and learning to cope on her own, Emma felt assured that an "expert nurse" was coming in to assess her son. As the care and treatment progressed she became increasingly disillusioned and dissatisfied with the nursing care. The burden of responsibility lay more and more heavily upon her shoulders. Emma felt that she and families like hers were being "imposed upon" to perform medical procedures. She saw herself as "helping out" the nurses by giving her son the injections. During our final interview Emma was completely exasperated with the home nursing staff. She had called to alert them that her son was having problems with the Insuflon© site, the patch was bleeding frequently and needed to be changed. After six days of incessant phone calls to home care and "no shows", a nurse finally changed the patch on his regularly scheduled visit the following week. No one came during her time of crisis.

I don't expect when I call that someone is going to be here like 911, I don't expect that. But I also don't expect excuses! It makes me think like, maybe his condition isn't serious. I don't know, maybe they take it very lightly, but I take it very serious! I don't know you guys are the experts (referring to myself as a
nurse). So, when she was leaving last night I said, "If I have a problem, he wouldn't bleed to death, right?" The hole would, I have to reassure myself, well maybe the hole is so tiny he wouldn't bleed to death (referring to needle insertion site from Insuflon©). Which may be logical, but I don't know that at first, the blood is thin, it may be just running. (Emma's concerns are legitimate, infants on anticoagulant therapy are at considerable risk for bleeding).

As far as when I called the company back and she said that we didn't have an order for it. Well, I say incompetence right away because you know I don't have any and you, you took a list, you know so. (referring to nurse forgetting to order the injection supplies and having to call the manufacturer to see what happened to them).

Rather than enjoying a supportive system of care, Emma often felt the nurses added to her stress. Emma did not have many supportive relationships to draw from. Her immediate family lived out of the country and she was still mourning the death of her father who had died unexpectedly during her pregnancy. She rarely mentioned her partner and only commented on the tension between them. Emma used Jacob's follow-up appointments at the hospital as an opportunity to talk to other mothers. In this next quotation Emma is talking about her need to be held and comforted by her mother, who was unable to be with her:
But sometimes I think too, what I need is a mother. I have no mother here, no sister. So sometime you know you need somebody to hold you, not just the father. Not him, you know you need more than that, I don’t have the more.

In this final quotation Emma is talking about her need to be strong. She felt she had no one else to rely upon.

Um, I might be presumptuous in saying I’m strong but I know I’m strong, I have to be strong. You know, I have to handle whatever situation comes along, so when Jacob was born with his defect of course I’m dying inside but I have to handle it, I have to come home and cook to get some energy for myself. I think that um, whatever there was to be done, I had to do it, there was nobody else.

Susan found the home nursing visits to be helpful. She felt more confident about Jonathan’s health and well being when a nurse came to check on him. However, she also perceived the nurses as strangers, intruding upon her life with her son:

Oh, it’s always different, yeah. Something like three days in a week he’ll get the same nurse then it will be another lady after that and it’s, he just doesn’t get used to the person, like to feel comfortable with them. You see, so maybe if they did send the same nurse all week, you know, he would get to know the voice, the patch, you know and this way he would be more comfortable with it. Than having different people touching him all the time, you know, which you know, as long as he’s being held, it doesn’t really bother him, it’s just, you know, they’re being a little rough, you know, holding him down.
However, in this next quotation, Susan is anticipating what it will be like once the nursing staff are no longer required to do home visits, concerned that she will feel panicked and run to her doctor's office unnecessarily:

Yeah, but it's just you know, I'm sure I'll be nervous every day. I don't want to run to the doctor's you know all the time with him and say, "Can you check my kid?", you know, they're going to think I'm crazy, right?! They're going to say, "Oh my God, go home woman!" You know lock the doors when they see me coming. But uh, you know, you will, I will feel nervous once nobody's coming anymore.

Susan had mixed feelings toward the nurses. She and her son relied upon them to monitor his health, and yet they were also seen as part of the problem. During my visits to their home, it was obvious that Susan desperately needed someone to talk to. Although she found the nurses helpful in checking Jonathan's physical status, she did not feel comfortable in talking to them about the stress she was under. On one occasion a home nurse arrived during my visit with Susan and Jonathan. She was "in and out" within 20 minutes. Susan described this as a "typical" visit that consisted of a highly task oriented approach of assessing Jonathan's vital signs, weighing him, and changing his Insufion© patch. The nature of this visit was characteristic of the nursing visits experienced by the other mother-infant pairs in this study. Emma referred to them as "just routine, in and out" visits which she contrasted to her interactions with her family physician, whom she
described as being thoughtful of her emotional, physical and mental health needs in addition to her son’s well being.

Sharon became increasingly frustrated with home nursing staff over passing months. The lack of consistent staff and their varying skill levels/expertise created a considerable amount of added stress. Michael often had a different nurse every week.

I was a little, with the home care nurse yesterday I was a little ticked off. So, this Monday was a holiday for this week, so they came on Tuesday. So they’re usually at the place before nine in the morning, somewhere before nine or maybe just shortly after so about nine, but they usually, they call me first to tell me they’re on their way, right. So anyway, nine o’clock came and went and we hadn’t heard from anyone so I called the, the phone number to find his chart and I said, "Are we on your list for today?", because he has to get his patch changed and we’re just a little worried right and they’re like, "Oh yeah, you’re on the list and I’ll tell the nurse to call you", so that was nine o’clock. She didn’t call me until one-thirty! I couldn’t believe it. And when she called I went, she goes, I go, "Oh my God!" and she goes, "What?!" and I go, "I’m usually seen first thing in the morning", and they make me wait around all day long, I was so mad! So, then she says, "I’m on my way." So she showed up at two fifteen and oh my gosh, she was like a big tall lady, big, probably about 60 years old with a tight, tight bun in her hair, you know. I’m like, I’m like, "I’m going to give that nurse heck when she gets here!" Then you’re afraid to speak when she walks in! I said, "Oh my God,
I'm not going to say anything she's gonna flatten me or something!!" So, but it just made me mad because I try to make it as painless as possible for uh, the little guy. I put an EMLA® patch on like before, about an hour or two before they do it (referring to nurses changing Insuflon®). I put it on at eight o'clock in the morning, expecting the nurse to be there. It was like eleven o'clock and still there's no phone call and I said, I better take this off (referring to EMLA® patch) because I don't think you're supposed to leave it on too long either. So I took it off, so then by the time she did it at two fifteen or whatever, he was like, he cried and cried. He was freaking out actually, I couldn't believe it! Oh God, I was so upset because he was upset.

The lack of consistency in nursing care made it difficult for Sharon to establish confidence and trust in the nurses responsible for her son. In this next quotation she relates her upset with a nurse who had not taken care of Michael before:

She came in and she's never seen him before in his life, she walked in "Oh is he ever blue!", I don't think--that's exactly what he looked like yesterday and she tells me he's blue!, "Oh is he ever blue!" I'm like, "Excuse me?!" She goes "The last nurse here wrote that he was pink, he doesn't look pink to me!" And I'm like "Well the other two nurses have seen him ever since he was in the hospital and I'm sure they put he was blue when he first got home but he looks probably a lot better to them." And she's told me he's blue, and I'm like, "Oh for God's sake!!" and then he had an appointment with the pediatrician yesterday afternoon too and
I told him that the nurse had said he was blue and he goes, "Oh, there's supposed to be a little bit of blue because that's his, his problem" or whatever, I mean obviously we know that, but for her to say...

Sharon made a point of watching the nurses closely during their visits. On one occasion she and her husband had to advise the visiting nurse that she had drawn up an incorrect dosage of heparin. The less often the nurses were needed, the happier Sharon was. "Now it's been like, the same nurse, I'm down to once a week (referring to number of nursing visits). Once a week visits! I'm so happy, I've graduated!!"

During our final visit, five months into the treatment, Sharon spoke a great deal of her need for additional support. She suggested it would be helpful to attend a support group with other parents who were experiencing similar problems.

Like, because I see (names doctor) there and you know, he's busy so he doesn't have much time to you know, spend with me kind of thing so--Yeah. And yeah, even if I could talk to someone who's been through it. Like doctors know about it, but it's not like their child is the one with the problem.

Sharon's social worker put her in touch with a nurse from the cardiac unit at the participating hospital. Being able to speak to someone who was supportive and knowledgeable helped to comfort Sharon, and allay some of her concerns:

So, I called the nurse and she--pause--like I said it takes him a while to finish (bottle feeding her son), um, she, she suggested a nurse and at (names hospital) that works in the cardiac part, she's kind of in charge there and she called me back
and, just talking to her made me feel so much better! She’s like, "Well you know", she was just saying that, I, she asked me what he was doing and I said, and she goes, "Well, his heart is weaker than most kids so that’s why he’s drinking slower and it takes him a while to get, to finish his milk" and, and I said, "Well, that’s true" and then she said that he, she says that he needs the calories just because his heart’s working so much harder than a normal heart too, so he’s burning all those calories. And I’m like, yeah, that’s true. And I didn’t even think of these things, right, so I felt so much better after I talked to her!

Although Michael’s cardiologist had an office conveniently located close to their home, Sharon would have preferred weekly trips to the out patient clinic instead. She believed this outing would enable her to meet and talk with other parents and nursing staff.

Sharon looked forward to Michael’s monthly follow-up visits at the hematology clinic for this very reason. Despite the support of her husband, friends, and family, Sharon felt a tremendous burden as the treatment progressed. Rather than seeing improvement she was routinely confronted with issues related to the Insuflon® patch such as bleeding, that served as a constant reminder of Michael’s health problems.

**Theoretical Interpretation**

The mother-infant pairs in this study did not begin the early phase of their relationship with the intense bodily closeness and mutual engagement described as ideal by Wynn (1996). The nature of the infants’ acute medical illnesses necessitated their immediate separation from their mothers at birth for various diagnostic invasive tests and
procedures that were most likely painful and exhausting. Mothers recalled being fraught with worry, unable to hold or comfort their newborn infants. Winnicott (1975) emphasizes the magnitude of such early experiences and their influence on future development of the child. Infants are dependent upon their mother’s ability to achieve a heightened sense of awareness and attunement to their needs. By entering a temporary phase of "primary maternal preoccupation", the mother provides a "setting" in which the infant may begin to develop (Winnicott, 1975).

Given the extraordinary circumstance of these mothers’ and infants’ beginning weeks together, the ability of the mothers to achieve this state and tend to their infants had been very limited. Mothers recalled struggling with surrounding wires, tubes, and machines in order to touch or hold their babies while in the NICU. They recalled learning to adapt a style of mothering that fit within the routines of the intensive care unit and sought permission and assistance to hold, feed and care for their sick infants. Despite the number and intensity of obstacles confronting them, all of the mothers spoke of a dedication and commitment to their babies that exemplified Winnicott’s (1975) notion of a "devoted caring". Amidst their feelings of distress, exhaustion, and fear, all of the mothers recalled feeling a deep obligation to "be there" for their babies who "needed" them, spending several hours in travel to see them, usually after sleepless nights. Winnicott (1987) argues that mothers, through a devoted caring, establish a bodily sense of constancy for their infants, so that even when alone, the baby would have an awareness that he/she had someone who cares.
The initial weeks at home from presented new challenges for the babies and their mothers. The infants were described as having been very irritable and "crying all the time". The mothers recalled feeling distraught, unsure of themselves and their baby's needs, all the time worrying that "something was seriously wrong". The mothers talked about "getting to know" their babies once they arrived home--their particular needs, cries, and ways. Winnicott (1987) recognized the importance of care giving to the mother's ability to begin to know her infant and adapt to his/her needs. Central to this experience is the mother's holding of the baby, which Winnicott (1987) describes as the "prototype" of all infant caring. Because of the acuity of their infants' illnesses and hospitalization, this period had been delayed until the infants arrived home, three to four weeks after their birth.

Wynn (1996) carries this notion of learning to care for one's baby, beyond that proposed by Winnicott (1987). Wynn (1996) argues that rather than primarily adapting herself to the infant's psychological and biological needs, the mother and the infant come to know one another through a co-active bodily engagement. Holding (physical and psychic sheltering of the infant), in this sense, becomes a simultaneous "holding and being held", so that holding is formed as much by the infant as by the mother (Wynn, 1996). During the first few weeks of life, mothers and infants had very little occasion to begin to know one another in this way. The infants had been introduced to a world of mostly procedural touch and technical care while in the NICU (Perreault et al., 1997). Once discharged home, infants appeared to experience a transition period in which they
began to discover and inform their mother's care and holding. Mothers spoke of a gradual familiarity with their infants, and their infants with them. Babies were described as "smart" or "bright", being able to "understand" their mothers "more than anyone else" and vice versa. Mothers appeared (to the researcher) to demonstrate a thoughtful and skilled comportment (bodily approach) with their babies that helped the infants to overcome their early reactions of distress when being bathed or changed. The "special connection" and "closeness" that developed between these pairs was reciprocal, and co-constituted through their holding of one another, what Wynn (1996), following Merleau-Ponty (1962), refers to as a "chiasmic relationship".

Upon beginning this inquiry, my assumption was that the mothers would have difficulty in sharing a reciprocal relationship with their infants. The daily administration of painful injections was expected to mitigate against reciprocity. This assumption was not the case. Each mother recalled feeling a deep responsibility to assume this form of care for her infant. Two mothers described "pushing" themselves to overcome their initial distress and anxiety. All of them struggled through their initial awkwardness to develop a highly skilled ritual of care, particular and specific to their infants. The "special connection" and chiasmic relation between the mothers and infants appeared to enable the mothers to give the injections and care for their babies in a way that lessened their pain and distress although it was never easy. Winnicott (1987) argues that during this period of primary maternal preoccupation, the mother almost loses herself in identification with her baby, so that she knows specifically what the baby needs. She
assumes the baby's vulnerability, feeling herself into her infant's place (Winnicott, 1987). Although the mothers were unable to shield their babies from the experience of various "impingements" associated with their illness and care (Winnicott, 1975), each played a very important "mediating role" in protecting and sheltering their infants (Wynn, 1996). Impingements may be internal or external events such as pain, hunger, loud noises, strangers or being held in an insensitive manner (Winnicott, 1975).

As time passed, mothers learned to cultivate a milieu of skillful practices attuned to the needs of their infants (Wynn, 1996). They spoke with pride when relaying stories where they described their ability to perceive and appease their infants, better than anyone else. Infants appeared relaxed and contented when in their mother's care. During periods of irritability and distress, their mothers displayed apparently endless patience, empathy, and skill in consoling them. Wynn (1996) describes this attunement as a kind of "pre-reflective" caring and holding of the infant, informed by their bodily interplay with their mothers. Because of the nature of their infants' health care demands, mothers were also obliged to learn a highly conscious and technical component of care, that appeared to be interwoven with the pre-reflective caregiving described by Wynn (1996). They described an exhaustive and vigilant watchfulness that consumed their daily lives. Mothers talked about feeling "tied down" by the medical treatment trajectory and their infants' condition. Persistent and worsening complications related to the Insuflon© "patch" became almost unbearable, inescapable reminders of their infants pain, suffering, and illness. Mothers' voices were filled with anguish and concern when describing the
need for repeated re-insertions of the Insuflon®, and the associated bodily wounding (multiple bruises, "lumps", "holes", and bleeding). The babies' "tiny" fractured bodies were vivid, and real images to their mothers, who seemed to feel their pain and discomfort (Wynn, 1996).

Despite exhaustion and feelings of being overwhelmed, mothers went to extraordinary lengths to comfort their babies. Several hours of thought and skilled attentiveness went into making their days more bearable and the home care trajectory less threatening. Even though the treatment regime forced an unnatural and routinized existence, mothers allowed their infants' particularities and preferences to guide their caring. They spoke of how their infants liked to be held and reassured through their touch and gentle tone of voice. The pain of injections and patch changes appeared to be assuaged through feeding, cradling, distraction and devoted holding (Winnicott, 1975; Wynn, 1996). The intensity and duration of the treatment trajectory, combined with the vulnerability of the infants, appeared to extend the period of primary maternal preoccupation beyond the usual two months. Three to six months following the birth of their infants, mothers remained consumed with their babies needs and care, seemingly to the exclusion of themselves. They did not talk about their relationships with their other children and partners, or how the treatment might have impinged upon their time or relationships with these loved ones.

When asked how their infants' illness and care had affected them and their babies, all of the mothers struggled to answer. They had been so caught up in their babies, there
was little time to consciously reflect on the meaning of the experience. All of the mothers talked about "spending more time" with their infants or "spoiling" them. This "extra time" was evident during my visits, in which mothers were engaged in a constant attendance and holding of their babies. Winnicott (1975) addresses this phenomenon as a "making up for what has been missed". Women who have had difficulty at the earliest stage, or "missed the boat" become involved in a prolonged period of adaptation to need or "spoiling" (Winnicott, 1975). The mothers felt that their infants needed this extra attention "to feel more secure", given "all they had been through". Apart from "making up" for the traumatic beginning they shared, it would seem that the mothers were responding to an essential need communicated by their babies, whose health remained precarious.

Babies are highly dependent and affected by everything that happens (Winnicott, 1987). Winnicott (1987) reveals that they are continually having experiences that "add up in their memory systems" to either give confidence in the world or a lack of confidence and sense of unpredictability. The early experiences of the infants while in hospital provided little if any reliability. They were touched and handled by a number of different caregivers. Many of their first introductions to human contact were highly technical, invasive, and painful. Monitors beeped and alarmed around them. These experiences seemingly left an impression, as the infants were first described as being very distressed and irritable, almost distrustful of their mothers touch during bathing or changing. With passing weeks, the infants began to settle, secure in their mothers'
holding. Wynn (1996) argues that the infant's body becomes habituated through a "sedimented bodily knowledge" gained through his daily encounters with others and otherness. His movements are intentional, intelligent, and interpretive in a non-reflective way (Wynn, 1996). Infants came to know and find comfort in their mothers, through their daily positive interactions. Through movements, gestures, and cries, the infants informed their mothers holding and practice, just as their mothers informed and transformed their experiences of touch, pain, and being in the world.
CHAPTER 4: Discussion, Implications and Conclusions

Discussion

The main purpose of this inquiry was to develop an understanding of the early mother-infant relationship when mothers assume responsibility for giving babies, who are born with significant health problems, painful injections over a prolonged period. Through focused, open-ended interviews and observations of three mother-infant pairs during the course of treatment, important insights were gained into the lived worlds of the participants. Mothers’ experiences of this illness and care trajectory were continually altered and reinterpreted with the passage of time.

All of the mothers recalled the early weeks that followed the birth of their babies as "overwhelming" and an "emotional ordeal". The infants required direct admission from the delivery room to the NICU, as a result of congenital heart anomalies that necessitated a variety of surgical/invasive tests and procedures. They remained in hospital for three to four weeks. The acuity of their illnesses limited and defined the nature of physical contact they had with their mothers, who described how they had struggled with equipment, wires and tubes, when attempting to "touch" and "hold" their babies. Mothers described this period as particularly stressful because none of them had been able to hold their babies for more than a few moments immediately following their birth. Although all mothers recognized that the NICU was essential to the survival of their infants, it was retrospectively described as a threatening and confusing environment where the babies were exposed to "germs" or "infections", and "basically poked at all the
time". Mothers remembered feeling a deep obligation to "be there" for their infants in order to protect and comfort them. One mother recounted how she had traveled daily by bus for two to three hours in order to see her son. All mothers stayed with their infants for several hours of the day and night. The intensity of parental stress associated with NICU admission and acute neonatal illness has been documented by other investigators, supporting these findings (Affonso, et al, 1992; Hatton et al., 1995; Hayes et al, 1993; Shandor Miles, 1989; Shandor Miles, Funk, & Kasper, 1991; Wereszczak et al, 1997).

All infants required the continuation of anticoagulant injections on discharge.

Once at home with their babies, mothers recalled feeling some relief from psychological distress, even though the first few weeks had been very stressful. All of the women described their infants as "irritable" and "crying all the time" for the first two to three weeks after discharge. They recalled feeling unsure of "what was wrong" or "what to do", feeling "panicked" each time their babies cried. Routine bathing, changing, and care was described as very distressing to the infants. Mothers described spending the first few weeks at home "getting to know" their infants and becoming more familiar with their particular needs and preferences. The babies appeared to have experienced a similar period of transition in which they began to discover and inform their mothers care and holding through bodily gestures and cries. The early weeks of life spent in the NICU circumscribed much of this opportunity for mothers and infants to come to know one another. Mothers talked about how they had learned to approach their babies in a way
that calmed and appeased them. The infants gradually settled and appeared to have found comfort in the familiarity and reliability of their mothers' holding.

Other researchers have found infants and toddlers with congenital heart disease to be perceived as irritable and difficult to soothe, having lower thresholds to stimulation and feeding problems (Gardner, Freeman, Black, & Angelini, 1996; Goldberg, Simmons, Newman, Campbell, & Fowler, 1991; Hinoki, 1998; Kolbrun Svavarsdottir & McCubbin, 1996; Lobo, 1992; Marino & Lipshitz, 1991). All of the mothers in this study reported difficulties breast feeding their babies. Two mothers reluctantly had resorted to bottle feeding because they believed that their infants were "too weak" to "struggle" for breast milk.

In addition to coping with stresses associated with their infants’ temperaments and precarious physical conditions and routine care, all of the mothers recalled struggling through their initial awkwardness in assuming responsibility for administering the injections. Two mothers described having to overcome feelings of anxiety and "squeamishness". They talked about pushing themselves to provide this form of care because their babies' lives depended on it. As their knowledge and comfort level improved with passing weeks, each mother developed what appeared to be a highly skilled and thoughtful approach to giving the injections. They described and demonstrated a detailed ritual of preparing, administering, and completing the injection procedure that was specific and guided by their infants' individual needs. The early descriptions of awkwardness and "getting it proper" were replaced by descriptions that
the task had become "no problem" and "just routine". Every mother commented that her baby was more content and less distressed when she gave the injections herself, as opposed to visiting nurses. Their babies were described as being more familiar and comfortable with their touch and handling compared to nurses who were perceived as "strangers", "holding down" their babies, and "being rough" while "shoving" in needles. The "special connection" and "closeness" that mothers shared with their infants enabled them to engage in a reciprocal, bodily communication that guided their actions. When I observed the infants during injections given by their mothers, none of them exhibited any of the behavioural indicators of pain (deepened nasolabial furrow, brow bulge, eyes squeezed shut, high pitched cry, vigorous body movement, withdrawal from stimulus, taut tongue, open mouth). They appeared calm and contented, their bodies relaxed and still during the injections. Mothers confirmed that this response was "typical" and remarked on how "good" their babies were.

The absence of behavioural pain indicators is not likely attributable to a habituated response or learned helplessness (Evans et al, 1997; Henrikson & Birks, 1997; Johnston & Stevens, 1996) as mothers emphasized that infants continued to demonstrate considerable distress during injections and Insulflon® changes that were done by nursing staff. I observed one infant while a nurse gave the injection and changed the Insulflon® device. The baby exhibited all of the pain behaviours (deepened nasolabial furrow, brow bulge, eyes squeezed shut, high pitched cry, vigorous body movement, withdrawal from
stimulus, taut tongue, open mouth) in a robust manner. This finding accentuates the importance of contextual factors and their influence on infant pain response.

A comparable study of parents learning to care for infants and toddlers who required daily insulin injections reported that the children were very distressed during injections given by their parents; they cried and actively struggled (Hatton et al., 1995). Parents also reported that their children became progressively worse and more upset with increased age (Hatton et al., 1995). In contrast to mothers in the current study, mothers of diabetic infants did not describe a "close" and "special connection" with their babies. Instead, they spoke of mourning the loss of the "ideal mother-child relationship", and "diminished bonding" (Hatton et al., 1995). The relational disturbances between these mothers and their children and the non-life-threatening nature of diabetes may account for the contradictory findings between the two studies. In addition, the age differences, illness severity, and the use of an Insufion© injection device might have influenced infant pain behaviours. In a study with older infants and children, mothers commented that their children behaved "better" for the nurses than for themselves, during renal dialysis and tracheostomy care (Haverstock, 1992). Infants and children were generally more "uncooperative" and screamed and cried when their mothers attempted to "perform skills" on them (Haverstock, 1992). These findings may conflict with the current investigation because of the differences in the children's ages, differing procedures, and levels of expertise among the mothers. Also, children in Haverstock's (1992) investigation knew
that technical skills were not a part of normal life, in contrast to the infants in the current study who began life with painful procedures.

Mothers' perceptions of and tolerance for carrying out the treatment gradually began to change during the course of this investigation. After two to five months of the continued therapy the situation had become much worse. Mothers described spending most of their time managing complications arising from the anticoagulant and Insuflon© device. Bleeding episodes and bruising became more frequent, requiring Insuflon© changes several times per week instead of one. A typical day was characterized by rotating around injection schedules, giving medication, nursing visits, calls to home care staff, and managing complications related to the "patch" (Insuflon©). During my visits, mothers talked about feeling "tied" to their homes and appeared consumed by their infants' illness and care trajectory. The Insuflon© patch and resulting "bruises", "lumps", and "holes" on the babies' bodies seemed to represent physical symbols of the babies' ongoing pain, suffering and illness. Although the mothers had initially felt assured that an "expert" nurse was coming in to check on their babies, they grew increasingly skeptical of the knowledge and competence of home care nurses. Nurses varied from week to week, many were described as unreliable and unfamiliar with the infants' care needs and temperaments.

The weight of responsibility appeared to lie more and more heavily with the mothers, who spoke at length about associated stresses and their need for better care and support. None of the women mentioned having any form of outside assistance for
housework or homemaking activities. One mother talked about "needing a mother", to be "held" herself. These findings corroborate those of other investigators who have noted the complex and persistent demands placed upon women caring for chronically ill children in the home (Hatton et al, 1995; Leonard, Brust, & Nelson, 1993; McKeever, 1992; Spalding & McKeever, 1998; Sterling, 1990).

Mothers did not convey significant concerns about their relationships with their infants nor were any problems observed. All of the women described a "closeness" and "connection" with their babies that was evident during the interviews and observations. Mothers and babies were always within close proximity, engaged in feeding, soothing, and holding gestures. Mothers often would break their focus from the interviews to gaze at their babies or attend to them. One mother indicated that a visiting nurse had suggested she begin inserting the Insuflon© device herself. This mother was very emotional and emphatic about not performing this task. She talked about having to "draw the line", and referring to the nurse, that inserting the Insuflon© was "their job". An unexpected finding was that this mother related her concerns about inserting the Insuflon© patch to the quality of care she was receiving and not to any potential threat to her relationship with her son. When asked how the treatment trajectory had affected their relationships with their infants, all of the mothers commented that they "spend more time" with their babies and "spoil" them. Two mothers related their extra doting and attention to their infants' acute illness and difficult beginning, as if they were attempting to compensate. Throughout the study, all of the women relayed fear and anxiety about
the future well being and survival of their infants. One mother described how she imagined little scenarios where she might find her son not breathing, and attempted to plan ahead how she might handle such a crisis. This fear of death has been noted in other studies with parents of infants with congenital heart disease (Gardner et al, 1996; Goldberg et al, 1991; Hinoki, 1998; Kolbrun Svavarsdottir & McCubbin, 1996). During a final interview with one mother, she commented that she was concerned her son was "watching" her while she gave the injections, "thinking of her as giving him pain". This mother had been giving the anticoagulant for the greatest length of time (five months). Concerns about the impact of performing technical skills on infants and children have been frequently cited by mothers in other studies with chronically ill children (Hatton et al, 1995; Haverstock, 1992; McKeever, 1992; Spalding & McKeever, 1998). Mothers in these studies also expressed concern about how their relationships with other children and partners had been damaged. This concern was not voiced in the current investigation, although all mothers inferred that there was some nonspecific tension with their partners.

Despite the complexity of the infants’ illnesses and treatment regime, mothers spoke very little if at all, about their own informational needs related to the care of their infants. It was not clear what discharge teaching had been done, or if any follow-up teaching had been provided in the community. However, ongoing support and education appeared to be missing, although vitally necessary. Mothers described using their routine clinic visits as an opportunity to talk to nursing and medical staff as well as other parents about arising questions or concerns. Our interview sessions seemed to serve a similar
purpose, and I acted as a resource at times, to assist mothers to find appropriate resources. Stinson & McKeever (1995) found that mothers of infants with cardiac disease had many unmet information needs prior to hospital discharge that necessitated that the research protocol be violated by ensuring mothers received information. Mothers in that study recommended the need for repeated reviews and printed reference information which would appear to support current study findings (Stinson & McKeever, 1995).

In summary, mothers and infants endured many stresses as a consequence of the illness and care trajectory that gradually became worse with the continuation of anticoagulant therapy. Most stresses associated with this treatment were specifically related to the Insufion© patch which apparently had become a symbol of ongoing pain, suffering, and illness for mothers.

Implications For Nursing Practice

The findings of this study have important implications for nurses and other health professionals engaged in the care of mothers and infants with severe health problems. Interventions to reduce the complexity of the care trajectory for mother-infant pairs might foster well being and adjustment. Mothers and their babies must be "held" (supported and cared for) by nurses and other health providers in order to buffer the effect of various unavoidable impingements related to illness and care (Winnicott, 1975).

Mothers in this study were anxious to talk about their concerns and needed someone to listen. Despite their hectic schedules they all said they looked forward to the interviews and willingly set aside time to meet with me. Mothers generally described
visiting nurses as highly task oriented, unfamiliar, and unreliable, with questionable expertise or competence. During routine home visits and clinic appointments nurses could get to know the mothers and babies, encourage them to share their concerns and assess their coping skills. Information needs regarding the infant’s illness, management/care and future, should be reassessed at these times in order to provide ongoing guidance and support. In order to allay mothers fears regarding the survival of their infants, nurses could include mothers in their assessments of the infants and take the time to point out noticeable improvements such as weight gain, changes in vital signs and colouring. For further reassurance, they could also recognize and compliment mothers’ skills and quality of care. To foster a better relationship with these families, a highly skilled primary nurse from a specialized pediatric team should be assigned to them. This form of primary care would enable nurses to become familiar with the individual needs and concerns of mothers and their babies. Nurses would be better able to provide care with confidence and knowledge that would help them establish a rapport and trust with the mothers.

The issue of nursing competence and reliability is critical. Mothers reported feeling "tied" to their homes and described various occasions in which nurses arrived several hours late, too early, or didn’t come to assess their infants when they needed them. This problem created considerable distress for both the infants and mothers.

Mothers reported using EMLA® cream to prevent pain during Insuflon© changes but it’s efficacy was eliminated when nurses arrived several hours late or too early. The safety
and effectiveness of EMLA® is affected by and dependent on the length of application (Acharya, Bustani, Phillips, Taub, & Beattie, 1998; Benini, Johnston, Faucher, & Aranda, 1993; Garcia, Reichberg, Brion, & Schulman, 1997; Taddio et al, 1997). It is unclear whether nurses lacked the necessary knowledge about infant pain and the use of EMLA® cream or if there were broader staffing and workload issues that contributed to this scheduling problem. One mother described waiting six days for a nurse to come and assess her son and change the Insuflon© device. This visit only occurred after repeated phone calls to home care to inform them that her son's leg had become badly swollen and was bleeding around the injection site. Another mother voiced her concern about the potential for medication errors, as she had observed a nurse draw up an incorrect dosage of anticoagulant for her son. Reports from mothers related to the quality and safety of home nursing care would suggest that there are many contributing factors. These are serious competence issues, mothers need to know who to call to deal more effectively with this type of situation (eg., case manager).

Based on these findings, a comprehensive evaluation of the quality of care provided through home nursing services is needed. Parents in the community should be an active part of the evaluative process as well as nurses and other health professionals delivering care. The increasing complexity of patient care needs in the community demand that nurses maintain and even increase their professional competency and accountability through continuing education and certification programs. Swanson & Naber (1997) developed a creative program where NICU nurses were cross-trained to
deliver care to neonates in the home. This program provided a smoother transition for mothers and infants upon discharge and improved families’ satisfaction with nursing care (Swanson & Naber, 1997). The structure and funding of community care programmes must also be considered if significant changes are to be made. Under current funding restrictions and standards, nurses are expected to reduce the number of visits with each family by encouraging their acquisition of technical skills and self reliance (personal communication, February 4, 1999). The issue of how extensively dollars are allocated for care of these babies also needs to be considered. In focusing on reducing costs the human costs to families are being overlooked. Findings of this study and others clearly indicate that mothers carry a tremendous responsibility for the care of children with special needs. A comprehensive examination of current services would help to effect change.

Pagers or cellular telephones could be provided to lessen mothers’ experiences of feeling "tied" down, so that mothers would be free to leave their homes with the assurance that they wouldn’t miss a call from their nurse, or vice versa. Further support for mothers could be facilitated through the organization of a parent support group. Mothers indicated that talking to other parents during clinic appointments was helpful and reassuring. Access to other parents through a telephone support line could provide a convenient and practical adjunct or alternative to support groups in order to better accommodate parents busy schedules and available resources. Two mothers had no means of personal transportation and relied on public transit. Different specialty clinics at the participating hospital could work collaboratively so that follow-up appointments
could be scheduled on the same day. This collaboration between clinics would reduce the amount of planning and travel involved for mothers and their sick infants.

It is essential that nurses and other health professionals take individual family resources, living conditions and personal circumstances into account. EMLA® cream should be supplied as a fundamental component of the treatment regime. One mother indicated that she was unable to afford EMLA® for her baby and was forced to do without. Given the long-term consequences of pain in neonates, nurses and other health professionals have a moral and ethical obligation to protect these infants from unnecessary pain. None of the mothers mentioned having any outside assistance for housework, child care or homemaking activities. The need for respite services and household assistance should be assessed and arranged for these families. Leonard et al. (1993) suggest that mothers’ distress levels may be alleviated through the provision of household help when caring for technology dependent children.

Nurses could encourage and support mothers in becoming more involved with their infants while in hospital, to lessen the shock and transition for both mothers and their infants when they are discharged home. This involvement must reach beyond the acquisition of technical skills, to include an opportunity for mother and infant to actively engage and come to "know" one another. This process may be enhanced by encouraging mothers to hold their infants through skin to skin contact, commonly referred to as "Kangaroo Care". Researchers have demonstrated that this form of holding and intimate
contact between mother and infant has improved mothers’ feelings of competence and infant well being (Bier, et al., 1996; Tessier et al., 1998).

Gentle massage for infants might assist them in overcoming the stresses associated with procedural touch, giving them a sense of pleasure and security. Mothers and their partners could be encouraged and taught how to provide this therapy. Massage for infants and children has been attributed to reducing pain incidence and severity, reducing stress/anxiety, improving clinical outcomes, and enhancing parental feelings of wellness (Field, 1995; Field et al, 1998; Field et al, 1997; Hayes, 1998; Scafidi & Field, 1996). It would appear that infant massage could provide many possible benefits for these mother-infant pairs and nurture their relationship. However, empirical research investigating this phenomenon is necessary.

Implications For Research

Although the findings of this study reflect the experiences of a small number of volunteer participants, the results are important to consider when exploring the experiences of other mother-infant pairs in the hospital and community. The insights gained through observations and open-ended interviews support the use of a qualitative approach. The rapport established between the mothers and the investigator led respondents to express highly personal thoughts, feelings, and perceptions, that may have been difficult to capture through traditional quantitative methods.

Other avenues of research could be explored to better our knowledge, understanding and ultimately improve the care provided to these families. A larger scale
exploratory study comparing infants’ reactions to mothers and nurses during painful therapeutic procedures would be useful in furthering our knowledge of the effects on mother-infant pairs. A prospective cohort design incorporating open-ended interviews and participant observations along with repeated measures of infant pain, maternal distress, competence, and quality of life would provide a comprehensive examination of this phenomenon that may be used to support changes in policy and practice.

The experiences of other family members such as partners and siblings could be studied to further our understanding of how families as a whole are affected and manage daily life. Mothers in this study appeared exhausted and drained, one reported that she had suffered from postpartum depression. Research evaluating mothers’ physical and emotional health needs, nutritional status and documentation of sleep/rest patterns could assist caregivers in promoting wellness and preventing harmful health changes.

Research evaluating the quality of home care services is needed to address issues related to standards of care. The experiences of mother-infant pairs in this study raise serious questions as to the training and expertise of home care staff and the quality and safety of care for infants with rare complex disorders. Parents and children, along with nurses and other health providers need to be an active part of this evaluative process.

Further research to develop less invasive alternatives to current medical management of severely ill infants is necessary. Mothers in this study commented on their distress over the number of invasive procedures their infants required and emphasized the need for an oral form of anticoagulant.
Parental knowledge, attitudes, and beliefs regarding infant pain and how they may impact current and future practices would be relevant and should be explored in future research. Broader issues of research transfer and utilization must also be taken into account if we are to improve the quality of life and quality of care among mothers, infants and their families.

Conclusion

Important insights into mothers’ and infants’ experiences of giving and receiving anticoagulant at home have been identified in this study. The findings accentuate the intensity and complex nature of care giving activities and practices that mothers assume and adapt to protect and comfort their babies. Significant changes are needed to address the human costs and consequences of transferring the responsibility of care to mothers.
References


Abstract.


Appendix A

Letter to the Hematology Nurse Coordinator Outlining Her Role in the Project

Dear Hematology Nurse Coordinator:

The following is an outline of your role in my study that we have previously discussed. Upon approval of my proposal by the Nursing Review Committee and the Research Ethics Board, I will request that you identify potential study participants according to the inclusion criteria of the project:

1) The biological mother is fluent in the English language.
2) The mother and infant live within a 200 km radius of the city.
3) The infant will be no greater than six months corrected age.
4) The infant receives daily injection of anticoagulant that is administered by his/her mother, and weekly Insufion© hub changes in the home setting.
5) The infant does not have any major neurological deficits (ie: due to intraventricular hemorrhage >3 or asphyxia).

Approximately 2 weeks before I expect to interview each mother, I will request that you contact the potential participant by telephone. Points to include in the conversation are:

- Tracey Irvine, a graduate student from the Faculty of Nursing at the University of Toronto would like to speak with you about her research study.
- She is interested in what it is like for mothers and infants when mothers give anticoagulant injections at home.
- May I give her your name and telephone number so that she can explain the study further and you can ask questions? You may then decide whether or not you want to meet with her.

I also mentioned previously that you would be the contact person at the hospital, if any participant wishes supportive resources after the interviews/observations. I will contact you only with the mother’s permission.

Thank-you for your assistance.

Sincerely,

Tracey Irvine RN BScN
Appendix B

Information Form

Research Title:
Giving And Receiving Anticoagulant Therapy At Home: A Description Of Mothers’ And Infants’ Experiences

Investigators:
Primary Investigator
Tracey Irvine RN, BScN (Master’s of Science Candidate), University of Toronto, Faculty of Nursing.
Thesis Supervisor
Patricia McKeever, RN, PhD, Associate Professor, University of Toronto, Faculty of Nursing.

Purpose of the Research:
The reason I am doing this study is to gain a better understanding of what it is like for mothers and infants when mothers give their babies medication by injection. I hope to improve nursing care and support of families by understanding and describing this experience.

Description of the Research:
You will be asked to take part in two to five interviews (based on how often you can meet with me and when your baby started the program) while your baby is receiving the heparin. During one of the final interviews, I would like to watch you give the drug to your baby. This visit will take place at a time you would normally give the drug. Whether you decide to take part in the study or choose not to, you and your baby will continue to receive high quality care at the participating hospital. I will ask you to sign two separate consent forms, one for agreeing to take part in the study and one for me to audio-tape the interviews.

Interviews and Observation:
The interviews will take about one hour, and will take place in your home every two or three weeks, at a time and date that is convenient for you. I will begin by asking you some questions about your background and your baby’s health. I will then ask you to tell me what it is like for you to give your baby the injections at home. You may talk about your experience any way you like. There are no right or wrong answers. I am interested in hearing about your experiences, what you find works best for you and your baby. I will tape record the discussion so that I don’t have to write everything down and so that I won’t forget anything you tell me. You are encouraged to share any feelings or stories regarding what it was like for you to learn to give the needles and assist in changing the
injection port. You may describe how you feel this has affected you and your baby, if at all.

**Potential Harms (Injury, Discomforts, or Inconveniences):**
There are no harms associated with taking part in this study. It is possible some mothers will find it stressful or difficult to talk about their feelings and experiences. If you become uncomfortable and wish to end the interview at any time, you may do so. Should you wish to talk to someone for assistance, with your permission, I will ask Karen Charpentier to contact you.

**Potential Benefits:**
You and your baby will not benefit directly from taking part in this study. Mothers and babies in the future, may benefit from the information learned in this study by helping nurses and health professionals to be more sensitive and aware of what is helpful and/or not helpful for them.

**Confidentiality:**
Confidentiality will be respected and no information that discloses the identity of you or your baby will be released or published without consent unless required by law. The research consent form will be kept with your baby’s health record.

**Participation:**
Participation in this study is voluntary. If you choose not to take part in this study, you and your family will continue to have access to the same quality of care you have received in the past. You may withdraw from the study at any time.
Appendix C

Consent Form

I acknowledge that the research procedures described above have been explained to me and that any questions that I have asked have been answered to my satisfaction. I have been informed of the alternatives to participation in this study, including the right not to participate and the right to withdraw without compromising the quality of medical care at the participating hospital for me and for other members of my family. As well, the potential harms and discomforts have been explained to me and I also understand the benefits (if any) of participating in the research study. I know that I may ask now, or in the future, any questions I have about the study or research procedures. I have been assured that records relating to me (my baby) and my (baby’s) care will be kept confidential and that no information will be released or published that would disclose personal identity unless required by law.

I hereby consent to participate.

-------------------------------------------

Name of Participant

Signature

The person who may be contacted about the research is: Tracey Irvine who may be reached at telephone number:

-------------------------------------------

Name of person who obtained consent

Signature

Date
Appendix D

Sound Recording Consent Form

Research Title:
Giving And Receiving Anticoagulant Therapy At Home: A Description Of Mothers’ And Infants’ Experiences

Investigators:
Primary Investigator
Tracey Irvine RN, BScN (Master's of Science Candidate), University of Toronto, Faculty of Nursing.
Thesis Advisor
Patricia McKeever, RN, PhD. Associate Professor, University of Toronto, Faculty of Nursing.

I hereby consent to be audio-taped during participation in this research project. I understand that I am free not to participate in this part of the study and that I may withdraw at any time without altering the quality of health care received at the participating hospital by me or members of my family.

Name of Participant ____________________________ Signature ____________________________

The person who may be contacted about the research is: Tracey Irvine who may be reached at telephone number:

Name of person who obtained consent ____________________________ Signature ______________ Date ______________
Appendix E

Demographic Form

Today’s Date? Year ☐ Month ☐ Day ☐
Mother’s Date of Birth? Year ☐ Month ☐ Day ☐
Marital Status? Single ☐ Married ☐ Common-law ☐ Divorced ☐ Separated ☐
Are you currently employed? Yes ☐ No ☐ Full-time ☐ Part-time ☐
If yes, what is your occupation/activity? __________________________
If no, were you employed prior to your infant’s birth or illness?______________
If yes, what was your occupation/activity? __________________________
How many hours/week do you work? _____ Did you work? ____
What kind of delivery did you have? C-section ☐ Vaginal ☐ Induced ☐
Are you currently breast-feeding your baby? ☐ Bottle Feeding ☐
Did you ever breast feed your baby? Yes ☐ No ☐
If you were breast feeding your baby what made you decide to stop?

________________________________________________________

Do you have other children? Yes ☐ No ☐
If yes, how many? # _____
What are their ages? __________________________
How would you describe your health (emotional/physical)? ________________________
________________________________________________________

Date of infant’s birth? Year ☐ Month ☐ Day ☐
Gestational age of infant upon first admission to hospital? _____
Original health problems of infant: ____________________________________________
Current health problems of infant: ____________________________________________
Current medications infant is on: ____________________________________________
Current treatments infant requires: ____________________________________________
Was admission to the Neonatal or Pediatric Intensive Care Unit required? ________
If yes, how many separate admissions were there? ______________________________
When was your baby discharged from hospital last? Year☑ Month☑ Day☑
When did you start giving the injections? Changing the Insufilon©?
Who taught you how to do this? Was it suggested you learn how to manage the injections? If yes, by whom?
Mother initiated learning how to give injections Yes☑ No☐
Mother initiated learning how to change Insufilon© Yes☐ No☐
How often does your home care nurse come to see you and your baby? Is this sufficient?
Do you find her visits helpful? (if yes, why; if no, why?)

Since your infant’s birth, how many weeks has he/she spent in hospital? 
Was your infant born prematurely? Yes☑ No☐
Gestational age of infant at birth?
How would you describe your infant’s temperament (content, irritable, easy going)?
Appendix F

Interview Guide

Interview 1:
- Explain the study (see Appendix B), obtain consent or decline to participate
- Discuss and complete demographic form
- Arrange subsequent interview dates and times at the end of the interview

Opening Question:
I am interested in what it is like for you and your baby now that you're both at home. What has it been like for you to learn to give the blood thinner and assist during the injection port changes?

Subsequent Interviews:
Verbal consent or decline to participate will be obtained at each subsequent interview. Following the initial interview, additional interviews will begin by asking the mother if there is anything she would like to talk about that she didn't have an opportunity to during the last meeting. Any of my own questions, or interpretations in regard to the previous interview will also be clarified with the mother. The interview will then commence by asking the mother what she would like to talk about today. The following interview topics/probes will only be used if the mother appears uncomfortable with this open style of interviewing. The next meeting time and date will be confirmed with the mother at the end of each interview.

Interview 2:
- Describe an experience(s) that you felt changed your thinking/understanding in a way that has influenced how you look after your baby.
- Compared to when you first began giving the medication to your baby, how would you describe your level of comfort and ability to give the medication?
- How do you think your baby feels about you providing this treatment?
- Describe how your baby reacts/responds to you now, is it different than when you first began to give the medication?

Interview 3:
- How could the experience of caring for your baby have been made easier for you, your baby, and family members? (before/after discharge from hospital)
- Advice for a mother in a similar situation.
- Relationships with health care professionals.
- How she spends her "free" time, what she does to relax.
- Relationship with significant other.
Interview 4:
- Observe mother and baby while mother administers the anti-coagulant
- Observe mother and baby while the nurse changes the injection port
- Refer to observation form (Appendix G)
- How do you get ready to give the medication to _____ (infant’s name)?
- How do you prepare yourself to assist the nurse in changing the injection port?
- How do you prepare your baby before giving the medication? Changing the injection port?
- What do you find the most difficult/stressful?
- What do you find the least difficult/stressful?
- How do you feel during these treatments?
- How does your baby respond during these treatments?
- Was this a "typical" experience for you and your baby? (comment that my presence may have influenced behaviours/interactions)
- What do you do after the treatment?

Interview 5:
- Is there anything that bothers you more now than when you first started giving the medication or assisting with the injection port changes?
- What (if anything) became easier for you?
- Is there anything else you would like to share with me, talk about that you didn’t have an opportunity to talk about in the previous interviews?
- Review demographic form questions again to acknowledge for any changes.
- Thank mother for allowing me to talk to her about her experiences (for participating in the study).
- Provide an age appropriate small gift for her baby.
Appendix G

Observation Form

Date: ________________

Procedure: Insulfon Change □ Injection of Anticoagulant □

Before:
• How does mother prepare herself (What does she do? What does she talk about?)
• Mother’s affect, appearance
• How does mother prepare her baby?
• How do mother and infant respond to one another?
• Infant state irritable □ content □ sleeping □ alert □ other □
• Note infant’s gestational age

During:
• Where does procedure take place (i.e.: kitchen, bedroom)?
• Describe what the room is like
• Who is present nurse □ mother □ father □ sibling □ other □
• Describe role of mother, nurse, spouse etc. (who does what)?
• Who holds the baby? nurse □ mother □ father □ other □
• How is the baby positioned?
• Describe affect of mother (other family members if present)
How do mother and infant respond to one another?

Behavioural state of infant: irritable☑️ alert ☐ sleeping ☐ content ☐ other ☐

Infant response during procedure: deepened nasolabial furrow ☐
brow bulge ☐ eyes squeezed shut ☐ high pitched cry ☐
vigorous body movement ☐ withdrawal from stimulus ☐

After:

What does the mother do (ie: hold, comfort baby)?

Mother's affect, appearance

What does she talk about?

Infant state irritable ☐ crying ☐ settled ☐ quiet ☐ other ☐

Do they stay in the same room or move to a different room?

How do they respond to one another?

How long after the procedure does the baby appear to settle?

How long after the procedure does the mother appear to settle?

Was this a "typical" response?