

**MATERNAL EXPERIENCE  
OF THE BIRTH OF A CRITICALLY ILL BABY  
AND IMPACT ON SENSE OF SELF**

by

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## ABSTRACT

The purpose of this research was to explore how the experience of having a critically ill baby impacted upon participants' sense of self as mother. A qualitative methodology, interpretive description (Thorne, Kirkham, & McDonald-Emes, 1997), was selected as a way of describing the experience and its impact on sense of self, seeking to gather commonalities, while preserving the unique aspects of each individual's experience.

Participants were eight women with children currently aged two to six years, who had been critically ill at or closely following birth. At the time of the study, all children had a good prognosis and were functioning within developmental norms. During audiotaped interviews, the participants described their experience of having a critically ill baby, and of how that experience impacted upon their sense of self as mother.

Data analysis involved repeated immersion in individual audio tapes and transcripts in an attempt to become intimately familiar with the individual cases and to enable the production of relevant common themes (Thorne et al., 1997). Results indicate that the birth and hospitalization of their baby represent an intense emotional experience which continues to feature strongly in the memories of all eight women. Common themes experienced by the women during this time were shock and chaos, characterized by feelings of grief, guilt, powerlessness and fear. Participants spoke of drawing from external and internal resources in their attempts to cope with the stress of having a critically ill baby. In answering the question of how the experience impacted upon their sense of self as mothers, participants reflected upon how the experience changed their overall sense of selves, including their inner selves, relational selves and mother selves. Results are considered in relation to previous and future research and clinical practice.

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## CHAPTER ONE

### Introduction

*With time this internally created self appeared as real to us as the outside world glimpsed through the senses. Like air, it is always there; like the body, it has its limits. It is something that can get hurt, but it can also soar; it grows, and its powers slowly expand.*

*Mihaly Csikszentmihalyi*

The birth of a baby is potentially one of the most moving events in a woman's life. When a woman gives birth to a critically ill child, an experience that was expected to be full of joy instead becomes a time of terror, grief and uncertainty. It may, as well, be a time of profound transformation in the mother's sense of her self. The experience of having a critically ill baby can lead to severe psychological stress for the mother (Affleck & Tennen, 1991; Gordeuk, 1976; Greaves, 1997; Kratochvil, Robertson & Kyle, 1991; Miles & Holditch-Davis, 1997; Pederson, Bento, Chance, Evans & Fox, 1987), may compel her to use a gamut of individual coping strategies (Affleck & Tennen, 1991; Klaus & Kennel, 1982; Pederson et al., 1987; Smith, 1986), bring her through an intense emotional experience (Gordeuk, 1976,; Miles & Holditch-Davis, 1997; Pederson et al., 1987), alter the way she sees her child, and affect the mother-child relationship (Greaves, 1997; Kratochvil et al., 1991; Miles and Holditch-Davis, 1997).

Missing in this literature, however, is a description of how the mother perceives a transformation within her self as mother. In what ways does her view of her self as mother change from the way she imagined herself to be prior to this experience? What form does her evolution take? The question I considered in this research was, how does the experience of having a critically ill baby change a woman's sense of herself as mother?

McMahon (1995), in her account of the impact that children have on women's lives, points out that, until recently, there has been little research on women's experience of motherhood.

McMahon (1995) examined the impact of children on women's lives, believing that that past perspectives of motherhood were wanting in their lack of the women's voices, their explanations of their own experience. In attempting to hear this from the mothers, she initially sought to discover to what degree motherhood was an important source of identity for women. A closer look at her data, however, revealed rich accounts of transformations in women's self-conceptions, which later came to be a focus of her research. She recalls feeling, "haunted by the data, which repeatedly pointed to the tremendous significance of children and motherhood in women's lives" (p.6).

It is this quality of transformation, described by McMahon (1995) which I find interesting; the internal shifts which occur throughout the life span and, specifically, those which affect the sense of self in response to unexpected, critical events. I hoped to hear women's descriptions of the impact of the birth of their critically ill child on their sense of themselves as mother.

### **Purpose of Study**

The central purpose of this study was to seek to answer the question, "How does the birth of a critically ill baby affect a woman's sense of her self as mother?" The data which arises from this study is intended to contribute to the growing literature on the development of the self, and more specifically in this case, on one's sense of self as mother. A woman's "mother self" represents, of course, only one facet of one's identity, yet, as indicated by McMahon (1995), it is a facet of profound importance to many women. With this study, I attempted to explore the internal processes that occur within the self during and after critical, life-changing events and to uncover some of what we know of ourselves, and of our own process of self change.

This research is intended also to add to the body of clinical literature which describes the experience of mothers who have critically ill babies. Each year, two to nine percent of newborn babies require specialized care in a neonatal intensive care unit (NICU) (Goldberg & Divitto, 1995). Because of the increase in sophistication of the medical systems required to sustain the lives of these babies, this rate is on the rise as smaller and sicker babies survive preterm birth (Wereszczak, Miles & Holditch-Davis, 1997). More and more parents will be affected by the critical nature of the experience of having a baby admitted to the NICU. They deserve to have their experience more closely examined.

## **CHAPTER TWO**

### **Literature Review - A Foundational Forestructure**

The method I have chosen for this research, Interpretive Description (Thorne, Kirkham & MacDonald-Emes, 1997), emphasizes the importance of constructing an analytic framework from a critical analysis of existing theoretical and empirical knowledge of the phenomenon to form the "foundational forestructure" for the new research. This framework serves to orient the research in terms of theoretical assumptions and preconceptions, yet does not restrict the findings, as, "it typically will be challenged as the inductive analysis proceeds" (Thorne et al., 1997, p. 173).

To develop a foundational forestructure for this study, I have thus chosen to present empirical and theoretical knowledge regarding the following: the literature which addresses the issue of parenting a critically ill child; some selected theoretical perspectives on self, on motherhood, on how the self might change, and how crisis affects the self. Finally, I provide a rationale for this research

#### **Parenting a Critically Ill Child**

The birth of a critically ill child impacts upon a mother's life in many ways, ranging from the practical, to the emotional, to the spiritual. One wonders how this event, with its constellation of sequelae, impacts upon a mother's nascent view of her self as a parent. The birth of a sick child has been shown to impact upon such systems as a mothers' and fathers' emotional state (Affleck & Tennen, 1991; Greaves, 1987; Klaus & Kennel, 1982; Miles & Holditch-Davis, 1997) and the relationship with the child (Goldberg, 1988; Gordeuk, 1976; Klaus & Kennel, 1982; Kratochvil et

al., 1991; Miles & Holditch-Davis, 1997), both of which take part in the development of the mother's self-concept. It is for this reason that I have chosen to provide an overview of the literature which seeks to describe the emotional impact upon the mother as a result of the birth of a critically ill baby, as well as some of what may occur in her relationship with the child.

Many of the studies cited use both mothers and fathers as subjects or participants. Even though I am looking only at the maternal experience of this phenomenon, I have chosen to include those studies which used the parental dyad because I found them to be well designed and to yield information which I believe to be applicable to this study.

The reader will notice that the literature review contains mostly references to preterm births. Goldberg and Divitto (1995) point out that each year, two percent to nine percent of newborn babies require specialized care in a neonatal intensive care unit, and the majority of these are babies born prematurely. The literature review reflects this fact, in that most of the citations reflect work done in the area of parenting children born preterm.

### **Emotional Impact**

Miles and Holditch-Davis (1997) summarize research findings from over two decades of research on the topic of parenting the prematurely born child. Their summary includes a review of the emotional response of the parents, as well as the impact on parent-child interaction. Many of these studies did, predictably, indicate psychological distress in parents of premature infants, ranging through anxiety, helplessness and loss of control, and fear, uncertainty and worry about their infant's outcome. Also commonly reported were guilt and shame, depression and sadness, and a sense of failure and disappointment. This section will highlight some of the findings from these and other studies, focusing on the emotional impact of having a critically ill child from birth.

Pederson et al. (1987) attempted to describe the dimensions of stress perceived by mothers of critically ill preterm infants by interviewing 130 mothers of infants with gestational ages less than 38 weeks and who were admitted to a NICU. The infants were categorized by a morbidity index which reflected the severity of the infant's medical course in the hospital. In the sample of babies, 53% were classified as well and 47% were classified as ill. The following demographic variables were also noted: maternal and paternal education, maternal age, children in household, and maternal marital status. Near the end of their infants' hospitalization, the mothers were given structured interviews which included questions about differences in their experiences from those anticipated with a full term birth, and their feelings and concerns when visiting their babies. The researchers coded the resulting transcripts for the presence or absence of various stress categories which were developed on the basis of previous research on the stresses of preterm birth. These categories were as follows: emotionally upset, crying, psychosomatic symptoms, disappointment, alienation from the infant, resentment at being separated from infant, inconvenience in visiting her infant, concern about her infant's survival, concern about long-term prognosis, and need for special preparations.

Pederson et al. (1987) found that having a preterm infant is emotionally stressful for most mothers, even for the mothers of the well preterm babies. The category which was reported by most mothers (68% of "well" premies, and 95% of "ill" babies) was "emotionally upset," which the authors described as including feelings of sadness, guilt and shock, difficulties in functioning, such as anxiety or insomnia, crying during the interview, and inability to discuss the events surrounding her infant's hospitalization. The next three most frequently reported categories were "special preparation" (52% of "well", and 83% of "ill"), which was described as the need for

special preparations after discharge, anticipating that the infant would require more physical care and monitoring than expected, and anticipating the need to be protective because of the infant's vulnerability, "uncertain of survival" (24% of "well" and 78% of "ill"), and "alienation" (32% of "well" and 56% of "ill") which was described as feeling helpless because she had no control over the infant's care or well-being, feeling that the infant was not hers, not feeling like a parent, worry about whether she would be able to feel close to her infant after discharge.

The uncertainty of the infant's survival, as reported by Pederson et al. (1987) creates a high incidence of fear which has been identified by other investigators. Blackburn and Lowen (1985), for example, sent questionnaires to 36 mothers asking them to identify their feelings when their children were admitted to the NICU for reasons associated with prematurity and found that the predominant emotion identified was fear.

The fear experienced by the mothers and fathers with children in the NICU seems to be aroused in part by the uncertainty of their babies' survival. This uncertainty has the potential to lead parents to anticipate the actual loss of their child, creating a state known as "anticipatory grief" which involves grief reactions similar to parents whose infants died (Benfield, Leib and Reuter, 1976, cited in Brooten, Gennaro, Brown, Butts, Gibbons, Bakewell-Sachs and Kumar, 1988). Yu, Jamieson and Astbury (1981) gave a questionnaire to 20 parental pairs whose infants had been admitted to the NICU in an attempt to discover the psychosocial factors affecting the parents, including a measure of anticipatory grief. They found the grief reactions to include feelings of sadness, difficulty sleeping, loss of appetite, preoccupation, anger, guilt and hopelessness. Cramer (1982, cited by Klaus and Kennel, 1982) suggests that mothers may withdraw from the relationship with their child until they feel confident of the infant's prognosis.

From Cramer's interviews with mothers of premature infants, he noted that only one mother out of thirteen sent birth announcements, and none prepared a crib until the child made definite progress.

The ongoing impact of the grief response has also been alluded to by researchers such as Fraley (1986), who distributed a forced-choice and open-ended questionnaire to thirty-nine mothers and eight fathers of premature children in an attempt to understand the relationships between children who had been born premature (at time of study, ranging from 1 month to 28 years) and their parents experiencing chronic sorrow. Fraley (1986) describes "chronic sorrow" as the periodic feelings and thoughts associated with grief, loss, and fear which parents of premature children have throughout their child's growth and development. She noticed that these emotions resurfaced when their child experienced developmental or situational crises or stressor events such as illness, surgery, the discovery of another medical problem, another child crawling, walking, or talking earlier than their child, the manifestation of behavioral problems or a chronic illness, and the need for day care. Maternal expression of self-blame for their child's early birth was also evident throughout their child's life.

### **Neonatal Intensive Care Unit (NICU)**

Many researchers have explored how the Neonatal Intensive Care Unit (NICU) is itself a factor which contributes immensely to parental stress (Affleck, Tennen, Rowe & Higgins, 1990; Miles, Funk and Kasper, 1992; Miles and Holditch-Davies, 1997) both at the time of the event, and persisting for many through the child's later years (Affleck et al. 1990).

Miles and Carter (1983, cited by Wereszczak et al., 1997) developed the Parental ICU Stress Model, which hypothesizes that parents experience several stressors when their child is

admitted to the NICU. They list these stressors to include environmental stimuli from within the NICU, including sights and sounds, the child's appearance and behaviour, staff communication, and parental role alteration; situational factors related to the child's illness, such as severity and uncertainty about outcome; and personal factors such as parental personality, family characteristics and parental resources including cognitive appraisal of the situation, coping patterns, and support received from staff and family during the hospitalization.

Jeffcoate, Humphrey and Lloyd (1979) also found evidence for the stress involved with the change in perceived parental roles when the baby was in the NICU by interviewing two groups of 17 families, those with pre-term infants and a control group with full-term healthy babies. The babies' ages at the time of the interviews ranged between 6 and 20 months. The investigators asked mothers from both groups when they first felt the baby was theirs. All but one of the control group mothers felt their baby belonged to them within the first few days, whereas half of the mothers from the pre-term group did not feel this until after they had taken the baby home. The authors suggest that this latter response may have been even higher but for the impact of social desirability.

A scale developed from the Parental ICU Stress Model, the Parental Stressor Scale: Neonatal Intensive Care Unit, was used to evaluate how 23 couples responded to the hospitalization of their premature baby in the NICU (Miles et al., 1992). They found that the greatest source of stress was the drastic alteration in parental role expectations, the second greatest amount of stress in relation to the sights and sounds of the NICU, followed by the infant's appearance. Examples of changes in parental role expectations were that they were unable to take a direct part in caring for the baby, were unable and or felt reticent to hold the baby, felt unable to

protect and nurture the baby, and were forced to endure separation from their baby. Parents may perceive the medical staff as providing the total baby care that they had expected would be their role. For example, Casteel (1990) points out that the usual caregiving activities of feeding, dressing, bathing, and comforting the infants that the mother and father had expected to perform are now being performed by a nurse.

The baby's appearance may also be upsetting for the parents because the child is often in pain or discomfort, is perceived to appear frightened or sad, appears to be weak and limp and is the recipient of foreign and seemingly painful needles and tubes (Miles et al. 1993). This image of vulnerability may feed into the fear and uncertainty that parents experience at this stage of their baby's life, perhaps even persisting into their child's later years.

In a study conducted by Wereszczak, Miles and Holditch-Davis (1997), 44 mothers of prematurely born three-year olds were interviewed about their child's hospitalization in the NICU and about their own experiences as parents during the neonatal period and subsequent years. Mothers were asked about their memories of their infant during their child's hospitalizations, what it was like for them as a parent during that time, how it was for them when they took their baby home, and how often they currently think about the NICU experiences. Data analysis focused on the mothers' recall of their experiences and their responses during the neonatal period when their child was in the NICU, and findings were examined in light of the hypotheses developed earlier from the aforementioned parental NICU Stress Model, with allowance for the emergence of additional findings. The researchers found that three years after the birth of their premature infant, mothers reported vivid memories of the stress they experienced at that time, particularly those related to the size, appearance and behaviour of the child, the pain and procedures endured

by the infant, and uncertainty about the infant's outcome. Alterations in parental role featured highly in the mothers' remembrances - 94% recalled the frustration of parenting an infant in the NICU. The mothers in Wereszczak et al.'s study (1997) felt detached from the role of caregiver, being unable to nurture their new baby. A "few" mothers felt that their concern that the infant might die prevented them from initially bonding with their infant. Staff relationships were mentioned frequently as a source of stress as were prenatal factors (including high-risk pregnancy or birth and experiences with infant loss), although these had not been hypothesized. A family stressor which emerged for some mothers was disturbance in family support. Twenty-five percent of the mothers felt they could not rely on members of their family for support through this crisis. Mothers remarked on positive attitude and behaviours of the nursing staff to be a source of support, as well as the stress management strategies of downward comparison, the search for meaning in the crisis, and normalization.

Wereszczak et al. (1997) comment that, "it is not surprising that parents can readily recall painful images of their experiences and their feelings related to their infant's birth and hospitalization in the NICU" (p.39), and continue by citing Horowitz (1982) as suggesting that painful memories of a stressful life event will intrude into consciousness until the event is integrated and the memories are no longer actively stored. However, environmental cues which act as reminders can keep the event from settling into the past (Silver et al., 1983, cited in Affleck, Tennen, Rowe, and Higgins, 1990). Wereszczak et al. (1997) suggest that with preterm birth, however, resolution of the intense memories may be difficult due to the presence of the child in the mother's daily life. The authors suggest that further research is needed to explore the long-term impact of these parental emotional responses on the parent-child relationship.

The study by Wereszczak et al. (1997) is well conceptualized, and contains thorough and detailed findings which cover environmental stressors (infant's appearance, alteration in parental role, staff behaviors, NICU environment), and situational stressors (uncertainty and perception of severity, postnatal effect of prenatal stressors, personal stressors, resources).

Affleck et al. (1990) conducted a research program on mothers' adaptation to the crisis of newborn intensive care and tried to discover what this may mean for them and for their child's future well-being. One hundred mothers took part in a longitudinal study of their adaptation to the birth, hospitalization, and early home care of infants who had been treated in the NICU. The infants involved in the study were almost all born prematurely with serious medical problems. The mothers were asked, six months after discharge, to describe any memories they had of their child's hospitalization in the NICU, to rate them as emotionally painful, pleasurable, or neutral, and how harmful or helpful those memories were. The majority of mothers believed their memories to be in some way helpful because they reminded them of the personal gains they had made during that time, reminded them of their child's special needs, reminded them of how precious their child was, and helped them to appreciate how much progress their child had made. However, the authors also found that having a child on the NICU presents severe threats to a parent's psychological well-being to the extent that mothers who had the most painful memories of their NICU experience also reported the least attachment to their child. Affleck and Tennen (1991) expand this finding by discussing the impact of various coping styles on appraisal of the situation, and found that the children of parents who were able to construe some benefit from the experience had better developmental outcomes.

### **Effect on Relationship with Child**

The above overview of the parent's emotional response to the birth of a critically ill baby begs the question, what are the long-term effects on the nature of the mother-child relationship, and consequently, on the formation of the mother's maternal self-concept?

Several researchers attest to the complexities involved in trying to answer this question. Kratochvil, Robertson and Kyle (1991) conducted a report designed to reveal whether mothers and fathers of children who had been in neonatal intensive care felt that the initial illness and separation had had a long-term effect on the parent-child relationship. The study involved the mothers and fathers of nearly 600 children who, because of difficulties in the neonatal period, were identified and followed for eight years. The parents attended extensive follow-up services and assessments, the final one being when the child was eight years old. At this time, parents were administered questionnaires which they were encouraged to complete in their own words, with no time or volume limit. Forty percent of the parents felt that their experience had a long term impact on the relationship with their child. Of that forty percent, most parents felt that their relationship with their child was more distant due to the child's illness and early separation, but about a third indicated that they felt closer to their child due to their earlier experience. A small portion of the responses indicated that the parent felt that the child was different, or deficient in some way, making the parent-child relationship difficult. Kratochvil et al. (1991) refer to the work which has been done in trying to determine whether a "critical" period for bonding exists between a mother and her child immediately following delivery. It now seems clear that this notion has no empirical support, the authors explain, as human nature is more plastic and too complex to be determined by a single event.

Goldberg (1988) has done a great deal of work in studying attachment formation between infant and mother when complicated by the baby's medical problems. She studied prematurely born infants, developmentally delayed preschoolers, and infants with cystic fibrosis, and found that medical problems of the infant do not necessarily disrupt the development of secure attachment to the mother. Goldberg (1988) comments that, "these studies indicated that the propensity to form a secure attachment is not easily disrupted, and the majority of parents with ill or handicapped youngsters are sufficiently resilient to adapt to their situation in a fashion that provides the conditions for normal development of infant-mother relationships" (p.185).

So, although the eventual status of mother-child attachment may show similar patterns between ill and healthy child populations, many researchers believe that a different process is at work in the establishment of a mother-infant relationship when the child has been born critically ill. Some researchers have found that any differences between the emotional adjustment of mothers of preterm infants and that of mothers of healthy newborns are short-lived (Jeffcoate Humphrey and Loyd, 1979; Miles et al., 1992; Trause & Kramer, 1983). Affleck and Tennen (1991) point out, however, that, "these between-group comparisons... obscure individual differences in mothers' short and long term adaptation to the crisis of newborn intensive care" (p.6). Although my study is not quantitative in methodology and will thus not specifically highlight differences and similarities between two populations, it is nevertheless the above quoted individual differences in mothers' short and long term adaptation to the crisis of newborn intensive care which I hope to discover.

Many researchers have attempted to more fully understand the process of interaction between a mother and her critically ill child following the birth event. Miles and Holditch-Davis

(1997) present a review of the literature on this issue which reflects conflicting findings regarding the impact of a child's birth status upon future parent-child interactions but do summarize their findings by suggesting that parenting the preterm infants may be, "More work and less fun" (p.258) than parenting full-term babies. That is, due to the increased needs and demands of a critically ill child, the parent is faced with particularly difficult challenges. Goldberg (1988) also believes that the development of these interactions follows a different pattern from that existing between parents and full-term infants which is in part due to the tendency of medically fragile infants to be more difficult to care for and less rewarding to interact with. For example, in the first year of life they tend to be less responsive, vocalize less, avert their gaze more often, and show less positive affect than full-term infants, resulting in less mutually satisfying social interactions (Miles and Holditch-Davis, 1997).

Kratochvil et al. (1991) also emphasize that, "when the capabilities for interaction are delayed, as with preterm or seriously ill infants, development of social interactions does not take place automatically or spontaneously and may be further diverted by anxiety and fear for the life of the infant" (p.97). In reaction, therefore, to a challenging situation in which the mother's emotional status is stressed and her child presents unique difficulties, social interaction styles of preterm and full-term mother-infant pairs differ (Goldberg & DiVitto, 1983). For instance, mothers of prematurely born babies tend to stimulate and protect their infant more than do those of full-term healthy babies (Miles and Holditch-Davis, 1995). Yet, even though a particular pattern of interaction between a mother and her ill infant may seem abnormal by current cultural standards, it likely does have adaptive utility, resulting in healthy attachment between mother and child (Goldberg, 1988).

Miles and Holditch-Davis (1997) interviewed mothers three years after the child's birth and discovered that mothers continue to have intense emotional memories of their experience which persist into the third year of the child's life. They defined a resultant style of parenting which they labelled as "Compensatory Parenting" and which involves, "increased stimulation, attention, and protection and difficulty with limit setting" (p. 258). They suggest that this style of parenting has both benefits and disadvantages for the child in that a better developmental outcome can be predicted from the increased stimulation, yet the perceived vulnerability of their child could raise problems related to discipline and resentment among siblings. Miles and Holditch-Davis (1997) suggest that more work must be done on discovering which parenting behaviours are altered in these circumstances, and the extent to which changes in parenting behaviours affect developmental outcomes.

Insecure forms of attachment between a mother and her medically fragile baby do, of course, occur, but this may happen more in mothers with other challenges due to personality variables, lack of social support network, or financial stress (Goldberg, 1988). Goldberg (1988) points out that factors such as parents' and family characteristics, family functioning and reaction to the child's problem do impact upon maternal attachment to an ill or handicapped child, resulting in vulnerability to attachment problems.

For example, Wille (1991) investigated the impact of preterm birth and perinatal medical status on mother-infant interaction and quality of attachment in a predominantly low socioeconomic status sample. In this study, 54 mothers and their six month old premature infants were first observed in a laboratory setting, and assessed using a second-by-second monadic phase system derived from Tronick, Als, and Brazelton (1980). At twelve months of age, the children

and their mothers were evaluated via the Ainsworth Strange Situation (Ainsworth & Wittig, 1969) in a laboratory playroom. Preterm birth was found to predict quality of attachment in this sample with a greater proportion of the preterm infants being rated as insecurely attached. Wille (1991) points out that this effect has not been found in middle-class intact families, thus suggesting that socioeconomic status may moderate the impact of preterm birth on infant-mother attachment.

The above attests to the pain, the loss, the wounding that the birth of an ill child presents to the mother. However, it is important to note that some authors have reported on the more positive feelings which may also arise from such an experience. Gordeuk (1976), in a literary review of mothers with medically compromised infants, states that the child with an abnormality often is held in "favourite status" among mothers. Affleck and Tennen (1991) found the majority of the participants in their studies of mothers of medically fragile newborns described at least one benefit from their experience. Examples of benefits included becoming closer to their husband and other family members, learning lessons about the priorities of life, enhancing their ability to empathize with others in need, creating other positive personality changes, and causing them to see their child as more precious because of his or her closeness to death.

In a study investigating the affects and cognitions of mothers and fathers of preterm infants, Casteel (1990) identified, along with the "negative" responses of anxiety, fear, helplessness and sadness, the "positive" affects of amazement, confidence, love and well-being. Amazement responses were characterized by expressions of wonder about their infants and of a pleased surprise; confidence responses were expressions of trust in the caring abilities of the nursing and medical staff; love responses were expressions of unsolicited concern for their infants,

and well-being responses were expression of happiness, good-feeling or pleasure about their infants.

It does appear that a woman's world is turned upside down from the time she receives news of her newborn's condition, and, to a certain extent, on into childhood. Consumed initially by a profound emotional state and challenging demands from the baby, in what way does her parent self evolve? The following will address this question by providing a theoretical overview of concepts of self, and of the impact of crisis upon formation of maternal self-concept. However, lest the sceptic wonder how the birth of a critically ill baby constitutes a crisis in any way different from that which most first time parents describe, I shall briefly give an overview of a comparative study by Jeffcoate et al. (1979), using semi-structured interviews, which compared the response to stress as experienced by two groups of families, a group of parents of preterm infants, and a control group of parents of full-term infants. The researchers found that the experiences of the pre-term group of parents differed appreciably from those of the control group and had left a deep impression on many parents. The authors allowed that, due to the qualitative nature of the study, a comparison is difficult to demonstrate. Nevertheless, they conclude that the pre-term group of parents suffered more emotional stress, delay in attachment, and management problems following the child's discharge from hospital. Emotional stress arose from a sense of failure, shame or guilt at producing a pre-term baby, anxiety for the baby's condition including fear of death, and loss of expected parental role.

### **The Self - Some Definitions**

The earlier section on parenting a sick child attests to the research that has been conducted in exploring various aspects of a woman's internal and external life in response to having a sick child. Little work exists specifically on how a woman perceives her maternal self as developing and changing in response to the birth of her critically ill child.

To assist in making sense of the findings of my study, I have chosen to explore and define the two concepts represented in my research question, drawing from the feminist and constructivist literature to do so. First, I discuss the construct of "sense of self as a mother," exploring various definitions of "self" as well as "mother," followed by a discussion on change of self.

#### **Sense of Self as Mother**

To begin addressing what is meant by "sense of self as mother," a definition of self would be in order. It is important in a discussion of a definition of self to emphasize that "self" is in part a culturally dependent construct (Jordan, 1997). Various cultures, differing in their existence in time, on the globe, or in a society's hierarchy, differ in their definition of self. Here in the West, the concept of self enjoys much attention in psychological literature, perhaps because it has held a position of importance in Western thought in general. Miller (1984) writes that, "indeed, it seems entwined in the roots of several delineations of the fundamental human motive or the highest form of existence, as in Maslow's self-actualizing character" (p. 1).

As such, although much attention has been given to the self, there is no one agreed-upon definition of the self. Traditionally in the west, however, the most widely accepted conceptualization of the self is that as an entity separate from its context, and contained unto

itself, contained and separate from other entities (Jordan, 1997). Modern American writers who have studied psychological development have conceptualized the self as moving toward maturity through a series of stages, "separating ... out from the matrix of others" (Miller, 1984, p.1), to arrive ideally and eventually, into an autonomous, individuated and separate state.

Critics of this point of view of self as separate and contained, notably those of feminist thinking, point out that, "this is a profoundly de-contextualized self" (Jordan, 1997, P. 16). As such, there is an effort being made to emphasize the importance of the existence and quality of relationships in the development of self. Writers such as Miller (1984) have been motivated to reexamine the concept of self primarily because they believe that the Western definition of self is incongruent with the way in which self is experienced by women. Jordan (1997) refers to this way of thinking about the self as the "relational being," and credits feminists with succeeding in bringing this perspective into focus. She emphasizes the relational nature of women's sense of themselves, and encourages a more relational paradigm for the study of all self experience. Miller (1984) believes that women develop in the context of other people, and encourages a model of self which assumes that, "freedom and maximum use of our resources - our initiative, our intellect, our powers - can occur within a context that requires simultaneous responsibility for the care and growth of others. . . ." The inclusion of interconnectedness in a definition of self is a relatively new and compelling perspective, and one that has obvious advantages in understanding how women, and certainly mothers, come to know themselves.

How, then, can we say that one "knows" oneself? In what ways do we experience a *sense* of ourself and how do we communicate that to others? Miller (1983) states that when psychologists speak of a sense of self, they refer to a construct meant to describe an internal

mental representation, or "self schema" (Markus, 1983). Constructivists theorize that as we develop, we gradually build an awareness of who we are by constructing a self schema from the information gathered in our unfolding life experiences. The development of self-knowledge is seen as a self activated process in which there is an interplay of cognitive growth, emotional differentiation, attachment processes and family patterns of interaction (Mahoney & Lyddon, 1988). In addition to this, social constructivists emphasize the importance of our history, our culture, and our perceptions in the building of our self knowledge.

Also adding to the many factors which play into the construction of the self at any moment in time is the important human capacity for imaginative and creative thought (Lyddon, 1995). The ability to use the creative and symbolic means of language, myth, metaphor, and narrative feature strongly in our constructive processes. The very act of relating a story about a particular experience changes the way one sees one's self in that event, as suggested by Rosenwald and Ochberg (1992) who explore the way that autobiographic narratives play a significant role in the formation of self. They argue that the telling of one's own story may be liberating, in that it may free one from the constraint of psychic and social obstacles. I would thus expect that the part of this research which involves the interview process may result in a further evolution and construction of the women's sense of her self as mother.

Through this active interplay with their environment, then, individuals are constantly creating models of themselves, and shifting their view of themselves accordingly. Constructivists endorse a form of relativism, in which reality is not singular nor stable, but is dynamic and subjective, with no externally defined true meaning or value. The meaning of one's reality is seen as being contextual, interrelational and subjective.

Historically, however, western psychologists have focused on those elements of self-knowledge that can be measured by the study of observable external events. The way in which research on self-knowledge has been conducted and analyzed frames the way the self is conceptualized. It would follow that a given researcher would gather information about an individual's self schema based on the questions asked of that individual. Markus (1983) points out that in the past, researchers have focused primarily on self-descriptions of demographics, roles, and characteristic behaviour, resulting from such questions as "Who are you?" and "What are you like?" Consequently, past study in self-knowledge has been limited to those features of self which tend to be relatively static, and which comprise one's "social identity." Surely, though, there is more to learn from individuals themselves about the nature of their experience with their selves. What is needed, Markus (1983) suggests, is interest in those parts of the self which might be called "dynamic" and which feature self-knowledge of preferences and values, of goals and motives, those elements of self which have the capacity to evolve and change.

Considering the variability in defining self, it is difficult to agree on one definition of sense of self. The above characteristics of self suggested by Markus (1983) in the preceding paragraph might constitute a definition of sense of self. As well, Ruddick (1989) refers to a sense of self when she speaks of the intellectual capacities that are developed, the judgments that are made, the metaphysical attitudes that are assumed, and the values that are affirmed by women in their experience of being a mother. There is however no explicit mention of the role of relationships in these conceptualizations. Jordan's (1997) concept of relational being achieves this purpose, suggesting that women's sense of their self is that of being *connected* with others, or a connected self, at the level of goals, values and beliefs, as well as at the level of feelings and body experience,

is a valuable addition. Miller (1984) concurs with this emphasis on relationship and connection. She writes that the "felt sense of self" (p.4) endures, but is inseparable from interaction with others. Jordan's is the first conceptualization of sense of self which I have seen which includes cognitive, affective, relational and physical elements.

Finally, the research question demands that attention be given to what is meant by "self as mother." As an echo of earlier paragraphs, it is appropriate that attention be given to the role of culture in defining mother. In this discussion, the term culture encompasses where a woman is situated historically, geographically, and socially (this latter category including sexual, developmental, personal history and socio-economic status). Throughout the ages, and across the world, as well as between individuals who share common culture, "mother" will hold varying meanings.

Certainly in our current western culture, what it means to be a "normal" mother is powerfully influenced by society's message which is communicated and informed largely by media. The television images, the labels on baby food, the front covers of parenting magazines lead us to expect that our babies will be round and pink and healthy. They also suggest that as mothers we will develop a lasting and loving bond with this perfect and perfectly dependent infant. We will from the first moment and forever after be willing and able to provide all that is needed to create a content and normal child. There are many flaws in these messages, the obvious ones being related to the appearance of the baby, that the "normal" baby is healthy, strong, and round, and in our own perception of and ability to tend to our child's needs. The more subtle flaw is that we, as mothers, are active in and solely responsible for the creation of our child. In fact, as McMahon

(1990) writes, "I invert the idea that mothers create children, and suggest instead that children create mothers" (p.20).

The cultural messages sent to mothers, such as the one described above, writes Boulton (1983), are an amalgamation of the prevailing theories of motherhood. Boulton (1983) states that the nature of women's experience as mothers is the subject of much controversy, both in the culture at large, as well as in academic institutions. She outlines two theoretical camps which take opposing views of the experience of mothers. One of the camps is comprised of the biologically based theories which emphasize the importance of physical reproduction, maternal care of the young, and the mother-child bond. This perspective is represented by the psychoanalytic and the ethological schools of thought. The other is made up of socially based theories which note the importance of social institutions in meeting human needs and in shaping human behaviour. Implicit in this perspective as it relates to motherhood is the view that society is the chief agent in shaping a woman's sense of herself as a mother and that the desire and capacity to look after children are largely socially created. The focus here, although a woman's personality and history are accepted as also being influential on her experience of motherhood, is, "on the way the role itself is institutionalized in society and therefore on the social conditions which can make it generally rewarding or distressing" (Boulton, 1983, p.18).

Many other writers also focus on the impact of culture on prevailing notions of the meaning of motherhood. In the forward to a collection of essays on motherhood, Lamott (1999) dispels the notion of a "normal" mother. "Somewhere along the way," they write, "we figured out that normal is a setting on the dryer" (p.xi). Unfortunately, letting go of the idealized image of "normal" motherhood may be more difficult than that suggests. Ruddick (1989) discusses

motherhood as a political force, and examines the ways in which motherhood is conceptualized. She points to the tremendous influence of culture on the way we think about motherhood in general, and specifically on the way mothers think of themselves. "The language of solitary thinking," Ruddick (1989) writes, "is necessarily public in the sense that it is governed by public criteria of meaning and truth. . . thought does not transcend its social origins" (p.15). Thus, a woman's expectations, values, thoughts and feelings about what it means to be a mother are subconsciously shaped and deeply affected by the messages transmitted by her culture.

Ruddick (1989) believes that each culture burdens motherhood with its own unique sets of demands which, when stripped away, leave the basic and universal demands of mothers as being for the child's preservation, growth and social acceptability. Most specifically, the first demand, preservation of the lives of children, "is the central constitutive, invariant aim of maternal practice" (p.19). She explains that how a mother sees herself in terms of conducting her maternal practice, "the intellectual capacities she develops, the judgements she makes, the metaphysical attitudes she assumes, the values she affirms" (p.24), establish criteria for determining failure and success, how she sets priorities within her "discipline," in short, how she evaluates and thus experiences her self as mother.

Given the existence of changing cultural ideals and differing theories regarding what it means to be a mother, one singular definition of "sense of self as mother" is elusive, at best. For the purpose of this study, therefore, a definition of sense of self as mother culls the above discussed contributions (Jordan, 1998; Markus, 1983; Miller, 1984; McMahon, 1995; Ruddick, 1989) into the following: One's sense of self as mother is that part of a woman's self schema which reflects her cognitive, affective, metaphysical, relational and physical behaviours as they

pertain to the preservation of the life of her children. One proviso is appropriate here, that it is possible for a woman to have a self schema as mother unrelated to the relationship she may have with her own offspring, or even if she has no children. A woman may, for example, feel "maternal" toward any person or thing toward which she is inclined to create, nurture or protect. The above definition, however, is framed by the choice of participants for this study, all of whom spoke of the children to whom they gave birth.

### **The Changing Self**

Although this research attempts to gain some insight into the changes in self which women experience as a result of giving birth to a critically ill child, at this point in the discussion I would like to give credence to the enormous transformative powers of motherhood, given *any* type of child which blesses the event. In her thorough examination of the impact of children on a sample of mothers in her study, McMahon (1995) found that the women experienced themselves as new persons by becoming mothers, and that this experience of self-transformation was the dominant theme in the experience of motherhood. "I invert the conventional idea," she writes, "that mothers produce children and look instead at how children produce mothers" (McMahon, 1995, p.3). The women described themselves as having changed in both external and internal ways, "in the practical details of everyday life and in the way they experienced themselves in the world" (p.147). She found that this new identity went beyond the learning that is expected of taking on a new role in life - it catalyzed, "not merely a change of behaviour but a change of *heart*" (p.129).

### **Change Through Crisis**

The following researchers and theorists conceptualize this transformation from the perspective of the child being "different" from what is generally defined as "normal." Of course, in post-positivist thinking, "normal" is an invalid concept because, like the society which defines it, the norm is constantly shifting. However, culture does persist in communicating an ideal of what is the "normal" child, and mothers, to a great extent, absorb that norm into their expectations of their unborn baby.

Schlossberg (1985) sees a crisis as a watershed in the development of identity, "the crisis of identity is reawakened whenever the individual experiences a major transition" (p.22). She attributes this to the way our hopes and dreams - the imagined possibilities of what may be - are a key to our identity and must be reevaluated in response to a crisis. Applying this to the woman who has an unexpectedly ill child, one can see the transformative possibilities for her identity as a mother. For example, a woman may spend the nine months of gestation, if not a portion of her life to that point, building her life around her expectations of having a baby. During the third trimester of pregnancy, parents encounter one of the developmental tasks of pregnancy (Als, Lester & Brazelton, 1979, cited in Casteel, 1990) in which they think about and imagine their parental roles. When this process is interrupted, parents follow a different cognitive and affective path, because, "of course, if the infant were still in utero, these experiences would not be available" (Goldberg & DiVitto, 1995, p. 213). Casteel (1990) conducted a descriptive study to determine the thoughts and feelings of mothers and fathers of preterm infants while the infants were in the NICU and following the infants' discharge from the hospital to the homes. The thirty six parents, interviewed as a dyadic unit, were interviewed when the infant was 5 days old in the

NICU, and again after the infant had been in the home for 5 days. Casteel (1990) found that the younger the gestational age of the infant, the harder it was for the parents to talk about being a parent, except in general, non-specific terms.

Adding to the difficulty in conceptualizing one's self as a mother, the mother likely does not, confined as she may be by cultural and personal historical context, carry an ongoing image of a critically ill newborn. Indeed, Markus (1983) points out that the empirical research indicates that individuals resist information that is counter to prevailing self-schemas. The self-schema as mother thus shapes the individual's expectations of this anticipated role. Of course, no event ever plays out exactly as anticipated. But, the birth of a critically ill baby likely presents a greater divergence from expectations than does a new-born that fits its culture's defined norms. If that baby is born "defective," the anticipated identity of the child and thus of the mother is either modified or lost completely, and a time of grieving of the unattained self as mother takes place, followed by the construction of a new self-schema (Romney, 1984). Schlossberg (1985) believes that this is an important time in the building of a new self-schema, in that the time of grieving, "is a time of questioning and of regrets, a time of thinking almost obsessively about what might have been" ( p. 25).

Romney (1984) examined the phenomenon of families who had experienced the birth of a child with a congenital defect by exploring two major groups of theories about parenthood: parenthood as a development stage, and parenthood as a crisis, and examined the phenomenon of families who had experienced the birth of a child with a congenital defect. She underlines the difficulty that parents have in coming to terms with the birth of an infant with a malformation by pointing out that there is an immediate experiencing of a sudden loss. Their hopes and dreams of

the perfect baby have not materialized, and in some cases, they must instead face their worst fears and fantasies. The mother must thus encounter the symbolic loss of the much hoped for, ideal child, as well as the physical loss of the baby. For the mother, the birth of a premature baby would resemble this experience in a similar way, "The premature infant is quickly taken away from the mother in the moments following birth. Reactions to this separation are universal ... Mothers experience a void, an amputation" (Cramer, 1982, cited by Klaus and Kennel, 1982, p.184).

Affleck and Tennen (1991) point out that a key feature of the crisis of new-born intensive care is that it threatens, and in some cases, permanently damages parents' cherished assumptions about themselves and the world. They report that half of the mothers in one of their studies had not even imagined that their baby would need intensive care after delivery, and that the intensive care crisis shattered their expectations of their pregnancy's outcome. One participant in the Affleck and Tennen (1991) study lamented that despite all of her conscious attempts at making sure that, "everything would be perfect ... something like this happens to turn your whole world upside down" (p.7). Miles and Holditch-Davis (1997) also suggest that the sources of distress for parents appear to be related to the loss of their expected parent's role. Werceszczak, Miles and Holditch-Davis (1997), for example, found that one of the primary stressors for mothers of 3-year old prematurely born children was related to alterations in their parental role and their expectations of the infant's behaviour, appearance, and suffering.

The researchers cited above view the crisis of a new-born in intensive care as involving much loss - loss of anticipated identity, of anticipated role, and of assumptions and expectation of

self and the world. Many writers have also found, however, that such an event involves the search for meaning and the acquisition of perceived gains.

For example, Affleck and Tennen (1991) attempted to illuminate ways in which parents found meaning in their crises, and found that such "victims" have the capacity to rebuild their worlds by reframing the situation in a way that brings a sense of mastery over their lives and meaning to their challenge. By struggling to answer the "Why Me?" question, people creatively find answers that bring order and purpose to an otherwise senseless event. In their work, in which they attempt to discover how parents of premature babies search for meaning in their crisis, Affleck, Tennen and Rowe (1994) asked mothers if they ever wondered "Why Me?" in response to being faced with the crisis of having a critically ill newborn. The largest category of answers allude to the belief that God had a plan for them. This attempt to see their experience as a test of faith was associated with positive mood and responsiveness to the child.

Collins, Taylor and Skokan (1990) have found many ways in which people construe benefits from victimizing events. They review the positive outcomes of victimizing events and suggest that when people encounter damaging information and circumstances, they reduce the negative implications so as to be viewed as unthreatening as possible, and attempt to offset them with perceived gains such as finding meaning, or perceiving the self as a better, stronger person. Thus, the researchers point out, "the process by which illusions are maintained can actually lead to more positive beliefs than those held prior to victimization" (p.265).

Affleck and Tennen (1991) report that mothers of medically fragile new-borns frequently report that the event brought them closer to their spouse and family, taught them lessons about the priorities of life, enabled them to better empathize with others in need, and caused them to see

their child as more precious. These changes in parental beliefs seem to have an impact on the children, as those mothers who claimed that they experienced such benefits from this event had children who showed superior development during the two years following discharge from the hospital.

The mothers discussed above seemed to have created meaning and derived benefits from their crises which enabled them to function in adaptive, positive ways. Sometimes, however, the meaning-making does not go so well, and this can impact upon the children's well-being in unfortunate ways. For example, some researchers (Kratovich, Robertson, & Kyle, 1991) have found an increased prevalence of low birthweight children among physically abused children, perhaps due to the increased difficulty in caring for and interacting with a critically ill new-born, and a lack of positive coping abilities. Jeffcoate, Humphrey and Lloyd (1979) cite evidence from a number of studies which show a high incidence of prematurity or neonatal illness among infants who were subsequently neglected or abused. Greaves (1987) also indicates that the way in which mothers perceive their situation has a direct impact upon their stress levels, which in turn affects their behaviour. His analysis of the effect of rational-emotive parent education for mothers of young children with Down Syndrome indicates that the elevated stress levels that these mothers experience are related to "irrational beliefs" and that the findings of his study, "provide support for the role of a philosophic change in this group of mothers being a covariant with a reduction in stress" (p. 264). In these cases, then, the "self-as-parent" is being constructed in a way that could negatively impact upon parenting behaviour and thus upon the child. It is important to add here that other factors, such as low maternal support, financial burdens, and personality factors have

been shown to play into the picture of abuse as well, and that it is not simply the birth of an ill baby that causes an abusive reaction.

In an attempt to consolidate and make sense of the research on posttraumatic change, particularly that involving personal growth, McCann and Pearlman (1990) have built a theoretical framework called Constructivist Self Development Theory (CSDT). Saakvitne, Tennen and Affleck (1998) critique CSDT and posit that it is designed to be a theory of self which explores the impact of trauma on self-development and which can explain both negative and positive changes which result following a traumatic event. It borrows from constructivist and psychoanalytic theory by accepting that personality development is the result of interaction between core self-capacities (related to early relationships, and ego resources) and constructed beliefs and schemas.

The authors suggest that there are five areas of the self which reflect ways of organizing experience, and which are expected to be affected by traumatic events. These are 1. Frame of reference (one's usual way of understanding self, the world and spirituality); 2. Self-capacities (the capacity to maintain a benevolent inner connection with self and others); 3. Ego resources (the ability to be self-observing and use cognitive and social skills to maintain relationships and protect oneself); 4. Central psychological needs (safety, trust, control, esteem and intimacy); 5. Perceptual and memory systems. The authors suggest that following a traumatic experience, change arises from the individual's attempt to integrate the event and its context and consequences into these five areas.

Saakvitne et al. (1998) suggest that the way an individual perceives and experiences an event affects the way that event is integrated into the individual's sense of self. Thus:

The uniqueness of an individual's response to trauma is determined by the particular meaning ascribed to the trauma, the individual's experience of self, age and developmental stage, biological and psychological resources, interpersonal experiences and expectations, and his or her social, cultural and economic milieu. The similarities of responses across individuals reflect common values, biology, expectations, and needs that would lead to shared attributions, meaning, and adaptations (p.281).

Saakvitne et al. (1998) also discuss the difference between intentional (or deliberate) and automatic change. An example of automatic change could be the revelation experienced by an individual in the aftermath of a traumatic event, or the instinctive need to create meaning following a traumatic event, which leads to changes in enduring beliefs about identity and worldview. Intentional change is referred to that which requires conscious attention and effort. One of the differences between these two types of change is that intentional growth may need time to develop, whereas automatic change tends to emerge rather suddenly, like an epiphany. They note the substantial body of literature which addresses the issue of gradual change, indicating that positive psychological adaptation to trauma unfolds at a gradual tempo. There has been little attention paid, however, to the dramatic transformations that occur more suddenly. Saakvitne et al. (1998) quote a study by Miller and C'deBaca (1994) which explores "quantum" changes in individuals in crisis or facing prolonged adversity. Most of the individuals in this study described dramatic changes in their personal meaning systems and view of the world, and in their personal goals which became less achievement-oriented and more spiritual. Saakvitne et al. (1998) also refer to earlier research which suggests that abrupt change is preceded by despair, humiliation and conscience pangs.

CSDT suggests that when an individual experiences trauma, her frame of reference, or lens through which she sees the world, is affected, and she strives to make meaning of the changes which she perceives. Consequent changes in self-perception, interpersonal relationship and philosophy of life occur. The degree to which the traumatic event challenges beliefs about self, the world or spirituality effects the degree of change experienced. They point out that CSDT not only predicts positive transformation, but the development of maladaptive beliefs as well. Furthermore, Saakvitne et al. (1998) emphasize that there is no simple division between those who experience growth from trauma and those who are harmed by trauma, and that caution should be exercised against imposing onto trauma survivors the cultural bias of "getting on with it and getting over it."

### **Rationale**

The body of literature covering the experience of parents who have critically ill babies is vast. The bulk of the above literature review focuses on parenting premature babies, reflecting the larger body of literature which also focuses on parenting premature babies, perhaps because preterm births represent the majority of admissions to NICU's (Goldberg and Divitto, 1995).

This study features a different approach to the issue in a number of ways. First, although investigators have examined parental emotional impact of the NICU (Affleck et al., 1990; Brooten et al., 1988; Casteel, 1990; Fraley, 1986; Jeffcoate et al., 1979; Miles et al., 1992; Pederson et al., 1987); maternal recall and impact of the NICU experience ( Affleck et al., 1990; Miles et al., 1991; Wereszczak et al., 1997); critically ill child-mother relationship (Goldberg, 1988; Kratochvil et al., 1991; Wille, 1991), none of these reported on the mothers' perceptions of the impact of the experience on their sense of self. Although one could argue that cognitions and emotions do

contribute to a sense of self, there seems to be missing a more complete investigation committed to exploring the impact of this type of critical event on a woman's sense of self as mother.

Another way in which this research departs from the existing literature is the point in time that the research is being conducted. The children in this study will range in age from 24 months to six years. The vast majority of the literature review focuses on the parental experience within the first year of the child's life (Affleck et al., 1988; Brooten et al., 1988; Casteel, 1990; Goldberg, 1988; Miles et al., 1991; Pederson et al., 1987; Trause et al., 1983; Wille, 1991). Exceptions to this are the study conducted by Kratochvil et al. (1991) which investigated parents' view of parent-child relationship eight years after neonatal intensive care, and Wereszczak et al.'s study (1997) which focused on maternal recall of the NICU when the child was three years old. The researchers who chose to study this phenomenon within the first year of the child's life probably did so because this is the time during which the preterm infant acts and looks more different than term babies, and access to parents may be more feasible. However, because the self is constantly changing, this research represents a work in process. Static or moment-in-time descriptions of parental responses do not tell a story of a process of change. Another reason why mothers of older children were chosen for this study is because awareness of sense of self represents a cognitive function which perhaps can be better articulated after time has smoothed the edges of the crisis, when the heat of the moment has died down.

A third way in which this study is different is in its attempt to hear the mother's voice in her account of this phenomenon via the use of qualitative methodology. Most of the studies included in the literature review used both mothers and fathers as subjects or participants, and of those which focused only on mothers, most used coding of maternal-child interactions

(Goldberg, 1988; Wille, 1991) and instruments designed to measure affect (Brooten et al., 1988; Thompson et al., 1993). In these examples, investigators framed and limited the way the women were able to articulate their reactions to the experience via methodological means. Two teams of investigators used interviews to focus on maternal emotional responses to preterm birth near the end of their infant's hospitalization and mothers' recall of newborn intensive care before six months after NICU discharge (Affleck et al., 1989; Pederson et al., 1987). So although these latter researchers provided greater opportunity for the mothers to use their own voice in the discussion, they limited their findings to the first half year of the child's life.

Finally, another way in which this study adds a new piece to the literature is in the area of self research. A review of the literature did find theoretical work on the impact of crisis on self-concept (Saakvitne et al., 1998), but did not find any work which examined the mother's perception of changes in self following the birth of a critically ill child.

Regarding my choice to examine only mothers in this study, I would argue that a mother's experience is necessarily and fundamentally different from that of a father's, this difference being a function of both biology and sociology. Both perspectives are worthy of investigation, and the study of a man's sense of himself as a father would be a fascinating topic of study. However, with this study, I chose to help close the gap in the literature by choosing to focus solely on a mother's sense of self.

## CHAPTER THREE

### Methodology

#### Ways of Thinking About the Self and the Changing Self

Markus (1983) points out that relatively little work has been done to examine the actual contents of self-schemas, and suggests that even self-description questions such as, "what are you like," may yield rich information about self-knowledge. Beyond this type of information, however, Markus (1983) comments on the lack of research which tells us what people know of their own goals and motives, personal standards and values (the dynamic components of self), and how they are represented and communicated within self-knowledge.

Furthermore, Saakvitne, Affleck and Tennen (1998) point out that one of the major limitations in the current literature on posttraumatic growth is the focus on moderator analyses versus descriptive inquiry. In moderator analyses, the researcher searches for moderational factors which influence psychological adaptation in the face of adversity. The authors claim that researchers in this area tend to rely on the same moderational and mediational "suspects," primarily personality moderators, and examine how these influence posttraumatic adaptation. They note that although much has been learnt from this method of inquiry, "there is also the distinct risk of learning only what one already suspects" (p.287). What is thus needed to add to the literature on posttraumatic growth is a descriptive approach to thriving.

Integral to the development of knowledge about an individual's self concept is awareness of the person's lived experience, including details of their roles, their values, their motives, their context. Hearing the individual's voice in this way represents a direction away from positivism

and externally applied labels and diagnoses, and toward a description of an experience from the perspective of those who live it.

Descriptive inquiry, which seeks to answer a "how" question (e.g., how has the experience changed you?), is useful in permitting the individual to find personal meaning in the question, and to convey subjective meaning in the answer, allowing the researcher to uncover the complexity and variability of an experience. Description of one's experience necessarily involves highly personalized narrative elements, reflecting the progressive scaffolding of current experience upon historical experience. However, many personal stories have many elements in common with those of other individuals who have had similar experiences. This "dialectic between the general and particular, between commonality and individuality" (Thorne, Kirkham & MacDonald-Emes, 1997, p. 171) must, in my view, be respected in a methodology designed to develop knowledge about the experience of self. With this in mind, I have chosen the qualitative method of Interpretive Description (Thorne et al., 1997) to explore my topic of research.

Interpretive Description was initially developed as a methodology specifically suited to the nursing profession to best explore issues related to human health and illness. Thorne et al. (1997) describe the methodology as being, "grounded in an interpretive orientation that acknowledges the constructed and contextual nature of much of the health-illness experience, yet also allows for shared realities" (p.172).

#### **Personal Assumptions/Biases**

In order to enhance the validity of this research design, Thorne et al. (1997) emphasize the importance of reporting biases, those inherent in both the individual researcher's frame of reference as well as professional discipline and their possible manifestations. In my tri-faceted role

of researcher, counsellor and mother of a child born critically ill, I necessarily hold assumptions and preconceptions which I assume to have had the potential of affecting the way in which I listened to and interpreted the stories told to me by the participants in this study.

Regarding the role of counsellor, my training as a counselling psychologist has helped me form, for example, the opinion that meaning can be found in suffering, that people strive to grow through change and that we are able to locate a source of strength within ourselves in troublesome times. This may have influenced the way I interpreted the interviews, perhaps listening for accounts of positive and more difficult consequences of their experience, as well as reports of quite different developmental paths from the time the baby was born to the time of the interview.

As a mother, I expect my own experience of having a child who was born critically ill to have had the strongest impact on my point of view. My child was born nearly six years ago when, during a weekend visit to Chicago in my thirty-first week of pregnancy, I went into premature labour and gave birth to a four pound baby girl. Although healthy at the time of birth, her lungs failed within hours and she was ventilated for five days and hospitalized for five weeks. My husband needed to return to work, so I spent my days and nights alone walking back and forth the short distance from my rented apartment in downtown Chicago to the hospital where our baby was struggling to survive and to grow. Although I knew nobody in Chicago, I managed to cultivate a relationship with the nursing staff in the NICU which was, with a few exceptions, supportive and helpful. Our daughter is currently thriving and well within developmental norms for her age. I believe that the experience of giving birth under such critical conditions and of watching her spend her first five weeks surrounded by the machinery of the NICU, and the

meaning that I made of those experiences, have created lasting changes in the way I experience myself as a mother.

The stories which I envisioned as I was conducting the above literature review resonated strongly with my own, from the intense emotional impact of the birth and following days, weeks and months, to the NICU experience, to the immediate and lasting effect on my relationship with my child. I am aware that, because so many details which I read were details of my own experience, I likely have made a tacit identification with all those who share a similar experience. Even as I was writing about my baby in the previous paragraph, I was tempted to insert the personalized adjectives of "tiny," "perfect," "fighter," and "precious." I am aware that the moments in my life as a mother which I stop to celebrate, or which I would rather see disappear, are so very often superimposed upon an image of my daughter at her sickest moments in the neonatal period, thus affecting the way I am as a mother. I realize, however, that these are *my* words and images which attempt to communicate *my* story of *my* lived experience. These adjectives and vignettes don't necessarily belong to everybody or anybody else with a similar experience. I attempted to exercise caution when listening to the stories of the participants in order to avoid transposing the meaning that I make of my own experience onto that of theirs.

Additionally, there were many elements of my personal experience which shaped the way I made meaning of the event. Aside from my own personality and historical factors, the child that I had as described above was my first born, I was thirty years old, university educated, in a healthy marital relationship, not suffering poverty or substance abuse, and although I knew no one in Chicago at the time, felt supported by telephone calls from family and friends at home. I assume

these factors to have been instrumental in the development of my view of the experience and how it impacted upon me.

Further to my personal experience with the phenomenon being explored, the very act of being a mother in this culture, as discussed above, must influence the way I see my self as parent. Ruddick (1989) stresses the impact of one's 'social origins' on one's way of being as a mother, noting that the way in which a mother views her self is profoundly affected by the zeitgeist of her time. Ruddick (1989) points out that mothers in the current western culture are distinguished from, "most of the world's mothers past or present" (p.55) by the fact that most of us can choose to have children, and they are expected to survive. However, she comments that mothers, as diverse from one another as they may be, all share the awareness that their children's survival depends upon protective care.

### **Journaling**

In Doing Qualitative Research (Ely et al., 1991), one of the authors reflects that:

I was profoundly engaged in making final meaning of my study; so much so that it took me a while to get the distance I needed to be a bit more clear about what it was that touched me so deeply...the task of searching for meaning as one writes begins with the crucial task of discovering ourselves, and our understanding of others in the final analytic presentation can only be as profound as the wisdom we possess as we look inward upon ourselves (p.177).

She goes on to advise, "as you write, keep yourself actively up front. To be personally passive in ethnographic research may be dangerous to the health of what you are doing" (p.177).

Knowing the risk of being influenced by biases, following each interview I followed the suggestion of Thorne et al. (1997) to keep a reflective journal as a way of documenting my own internal process as it relates to the gathering and analyzing of data. I took notes regarding my reaction to the interview, to the participant's story, and to the moments when I felt most empathically aligned, realizing that this might be a time when I imposed my meaning on that of the participants. Additionally, I noted thoughts which occurred to me between interviews.

### **Participants**

#### **Criteria for Participation**

In keeping with the chosen methodology's theory of sampling, " which encourages us to sample from the most predictable variations within the theme we are studying" (Thorne et al., 1997, p.173), I initially intended to choose participants that appeared to be the most varied along such dimensions as socio-economic status, marital status, and ethnicity. My rationale for this was to be able to attain the most potentially complex interpretation of patterns relevant to the topic of study, while at the same time guarding against misinterpretation of the meaning of the findings. However, the participants which were recruited for this study showed similarity in the above dimensions as almost all were Caucasian, all were entrenched in Western culture, all were married at the time their child was born, and all were of middle or upper-middle class. However, as would be expected in a gathering of eight individuals, much variability existed at less evident levels. For example, there was variation in number of siblings, hospitals at which the ill child was born, previous experience with trauma, age of child, age of mother, among others. Thorne et al. (1997) de-emphasize homogeneity of the sample population due to their belief that this type of research

does not seek to obtain generalizable results, but to hear the individual lived experience of the participants.

The women who participated in this study defined themselves as having had a critically ill child in the neonatal period. The criteria of "ill child" was defined as such: children who spent a period of time during the neonatal period in the NICU, children who currently have a good prognosis and are functioning within developmental norms, and children between the ages of 24 months and 6 years. This age span has been chosen in order to capture a wide variation in change in concept of self over time. However, I chose not to include younger children due to my hunch that mothers of children younger than 24 months, might still be very much in the emotional phases of the experience, and may not have had the time necessary to move into a more reflective state of the impact of the experience on them. I chose not to include children over the age of six believing that once the child leave for full-day school at the age of six, the mother and child might enter into a different phase of their relationship.

The medical condition necessitating admission to the NICU included prematurity (before 37 weeks gestation) or organ disease. Goldberg (1995) states that two to nine percent of newborn babies require specialized care in the NICU annually, and the majority of these are babies born prematurely. This proportion of premature babies was represented in the participants who took part in this research, as five of the eight mothers had premature babies, the other three had babies with organ disease.

### **Characteristics of Participants**

Because qualitative research seeks to understand the lived experience of each research participants, an overview of each individual's context, or a "thumbnail sketch" is provided. I have

chosen to describe the following characteristics of each participant: age, number and ages of children, marital status, ethnicity, hospital in which the child was born, condition of child at birth, length of stay in NICU, and current health of child.

Most of the participants stated that they were comfortable with the use of their and their child's own names when quoted or discussed in this study ("I have nothing to hide," being the common response to my query of this). I did, however, decide to provide them all with pseudonyms, and to refer to their children, when necessary, with the first initial of their names.

Alex is a Caucasian, 28 year old mother of two children, a daughter, five years, and a son, two years. She was married at the time of the birth of her children and is now separated from their father. She is employed as a health food distributor. Her first child was born eight weeks prematurely by Caesarean section, following a protracted, four day labour. The baby remained in a large metropolitan hospital for four weeks and was discharged with no prominent concerns for her future health. She currently is a healthy, active five year old with no evident developmental delay. Her son was also born prematurely, although his hospital stay was not so lengthy. He, too, enjoys current good health.

Bonnie is a 37 year old, Caucasian mother of two children, a daughter, four years, and a son, one year. She is married, and currently not employed, although she has worked as a high school teacher. Her daughter was born full term at a large metropolitan hospital, but with a severe diaphragmatic hernia, in which there was protrusion of abdominal contents into the thorax through a defect in the diaphragm wall. The baby was hospitalized for fourteen days, undergoing several surgical procedures, and will continue to have annual X-rays for the first ten years of life. She is currently a healthy, active four year old with no evident developmental delay. Her son was

born and remains healthy, although a false positive test in utero indicated he was suffering from Down's syndrome.

Joanna is a Caucasian woman in her late twenties, who has one two year old son, and is pregnant with another son. She is married and is not employed, although she has worked as a molecular biologist. Her son was born two weeks post-term and evidently healthy at a large metropolitan hospital, but was diagnosed at nine days with several heart defects. He immediately underwent surgery and was sent home for two weeks, at which point his condition began to deteriorate. At that time, he was suffering from severe congestive heart failure and it appeared he would need a heart transplant. She and her husband were told that her child might not survive the airplane trip to California, where the transplants are done. He did survive, but remained in critical condition while they waited for his heart. They sustained profound disappointment when a promised heart turned out to be unsuitable, and finally received a heart which was, "the perfect match." He remained in the NICU for six weeks, enduring a complication known as a chylothorax which occurs when one of the lymphatic vessels is cut during surgery. After discharge from the hospital, Joanna and her husband and son remained in California, where the child needed to be monitored, for another three months. They still have some concerns from a vascular condition related to all of the medical procedures. He is being followed regularly, and there remains the need to be extremely cautious about potential infection due to his immunosuppressed condition. He is currently a healthy, active little boy who is developing normally.

Jana is a 37 year old Caucasian mother of four children. She is married, works with her husband who is minister of a church, and is working to complete her teaching degree. The eldest

is a seven year old boy, the middle children are five year old twin boys, and the youngest is a three year old boy. The twins were born prematurely at thirty weeks at a large metropolitan hospital. One of the boys was discharged three weeks later, the other one approximately six weeks later. This boy needed oxygen at home, and after three weeks needed to be readmitted for another three weeks. Both boys are currently doing well, but there are concerns regarding Attention Deficit Disorder. The first-born son has been diagnosed with mild autism.

Justine is a 39 year old Caucasian mother of one six year old boy. She was married at the time of her baby's birth, and is now divorced from the father. She works as an adolescent psychiatric nurse at a large metropolitan hospital. Her baby was born at 36 weeks by Caesarean section at a large metropolitan hospital and remained in the NICU for two weeks. He is currently developing normally.

Jasmine is a 41 year old Caucasian mother of three children, 21 years, 17 years and two and a half years. The older two children were those of a former marriage. Her youngest child, a son, was born prematurely at thirty one weeks, in a large American metropolitan hospital. She is living with and in a committed relationship to the father of her son and is self-employed. The child is active and healthy and is developing normally.

Noelle is a 35 year old Caucasian mother of two daughters, the first is seven years old, and the second is five years old. She is married and employed as a medical office assistant. Her second daughter was born full term and seemingly healthy at a large metropolitan hospital, except for some initial difficulties breathing immediately after delivery. On the fifth day postpartum the baby had a seizure and was rushed to the hospital. She was diagnosed with kidney failure and put on the transplant list. Over a two year period, she spent approximately 60% of her life in the

hospital, sometimes being admitted for two or three months at a time. She did not ultimately require a kidney transplant. She is currently a healthy, active five years old, and although she is developing normally, there is some concern of slight developmental delay.

Jean is a 43 year old Asian mother of two boys, aged four years and two years. They were both born prematurely, but Jean chose to refer to the first born, who was born eight weeks before term at a large metropolitan hospital. The baby spent six weeks in the hospital, and is currently active and healthy and is developing normally. Jean is married and is employed.

### **Procedures**

#### **Participant Contact**

Participants were recruited for my study via letters to a sampling of General Practitioners and Obstetricians (See Appendix B), known to the researcher, in the Greater Vancouver area. This letter described my area of interest and the format of the study (i.e., interview, guarantee of anonymity, ability to withdraw at any time, etc.). Physicians were asked to consider mothers who are, "articulate, thoughtful, and eager to share" (Thorne et al., 1997, p.174) their experience. Enclosed in this letter were five letters (Appendix C) which I wrote for the doctor, to be sent to patients whom she/he felt would be appropriate for this study. In order to reduce any sense of influence or coercion, this letter advised potential participants that their decision to become involved in the study would not be known to their physician. Also enclosed was a letter from myself to the patient (Appendix D), briefly describing the research topic and interview format, with a number to call should the individual be interested in becoming part of the research.

Upon telephone contact, I 1) restated the intentions, time requirement and format of the research; 2) ensured that they fit the aforementioned criteria by asking questions regarding age of

the baby, condition of the baby, prognosis of the baby; 3) invited any questions; and 4) arranged a mutually convenient time and location for the first interview. As a note of interest, perhaps because one of the physicians contacted did not properly read the material I sent, I received five calls from mothers who had very recently given birth to a baby, in some cases the baby was still admitted to the NICU, willing to speak of their experiences. Right away I informed them that for my study I was only interviewing mothers of older children, but because I sensed the desire and need to "tell their story," I encouraged all of the mothers to relate their experience to me. They all did so, and I sensed that they appreciated the opportunity to do so.

### **Sample Selection**

When initially proposing this study, I intended to recruit eight to ten participants. The first eight appropriate candidates who contacted me were scheduled for interview appointments.

### **The Interview**

The interviews were conducted at a mutually convenient time and place, with attention being given to a quiet, private location. Five of the interviews were conducted at my home, three were conducted at the participants' home. There were no interruptions in the interviews. All of the interviews were audio taped and later transcribed. The first interview, with Alex, resulted in a blank audio tape. This interview had lasted approximately an hour and a half, the interview ending not because the interview was finished, but because Alex needed to leave for another appointment. She was thus happy to be interviewed again, basically picking up where we left off, with attention being given to her sense of transformation resulting from the neonatal experience.

The interviews began with rapport building between myself and the participant followed by attention to the issue of confidentiality. I emphasized the non-judgemental aspect of the

research, reassuring the participant that I was not evaluating the type or quality of mothering, but was only interested in the impact of her experience on her sense of self as a mother. I also made explicit my belief that all mothers have challenges and frustrations in the process of being and becoming a parent, and that this is normal in the building of identity as well as in the act of mothering. Following this, I asked participants to read and sign two copies of the Informed Consent Form (Appendix E), one form to be retained by the participants and one for the researcher. I then made an orienting statement (Appendix F), explaining my interest in the topic, which included my own experience of being the mother of a critically ill baby, and explaining that I was interested in change resulting from difficult life experiences. In most cases, I asked the participants to begin by describing their expectations of motherhood before their baby was born, following which they continued with the story of the peri-natal experience. Two participants requested that I relate my story to them, which I briefly did only from the perspective of the facts of the neo-natal experience. I did not engage in an in-depth description of my emotional experience, nor did I discuss my own process of change. Three other participants, at the end of the interviews, asked that I relate my story. Finally, I asked participants to consider how they "came out of the experience differently as a mother."

I took part in the interview with a conversational tone, providing content and affective empathy throughout, as well as requesting further information via probes such as, "What do you mean by \_\_\_\_\_?" or "Could you tell me more about that?"

### **Data Analysis**

The process of analyzing the data in qualitative research is a continuous exercise, starting from the very beginning of data collection (Ely, Anzul, Friedman & Garner, 1991). It begins with

observations upon initial contact with the participants, and continues through journaling, decisions regarding transcription, and final analysis. All of the above must pass through the subjective lens of the researcher, complete with biases, preconceptions and assumptions, or, "to face oneself as a research instrument" (Ely et al., 1991, p.140).

### **Transcription Process**

Of great importance in the process of making sense of the participants' stories is the accuracy of the transcribed material. Transcription can be seen as a political and interpretive act, in that it is inherently a selective process which is based in the researcher's own subjective frames of reference (Lapadat & Lindsay, 1999). The knowledge, beliefs and interpretations of the researcher are all called into play when the decisions to include contextual information are made.

In an attempt to capture, as closely as possible, the lived experience of the research participants, I added to the typed transcription the participants' and my recalled tone of voice and body language as well as my own internal process as the participants were recollecting and telling their stories. The decision to include my own process in the transcription is in keeping with constructivist theory which would point out that the interview is in fact co-constructed by the researcher and the participant.

Following each interview, the audio-taped interviews were transcribed verbatim, with numbered lines, by a professional transcriber. The verbatim transcription occupied approximately half of the vertical space of the page, leaving the remainder to be divided between notes regarding non-verbal and paralingual behaviour, and researcher notes, or "analytic memos" (Ely et al., 1991). I simultaneously listened to the audio-tape and read the transcript, making notes regarding the participants' and my inflections and tones and recalled non-verbal language. I included those

behaviours which connoted an emotional or reflective process for interviewee or interviewer, such as pauses, changes in tone, laughter or crying.

### **Final Analysis and Interpretation**

Like other qualitative methodologies, Interpretive Description relies on inductive rather than deductive analysis, encouraging the researcher to ask broad-picture questions such as "What is happening here?" throughout the process. By repeatedly immersing oneself in the data prior to the creation of classification and linkages, the researcher develops more coherent, integral conceptualizations that can be applied as universals to each case, without losing the quality of each individual case. Thorne et al. (1997) summarize the data analysis characteristic of Interpretive Description as thus: "researchers come to know individual cases intimately, abstract relevant common themes from within these individual cases, and produce a species of knowledge that will itself be applied back to individual cases" (p.175).

Analytic memos provide the researcher the opportunity to hold self-conversations regarding insights and emerging themes, to record thoughts about what is said, or feelings about the participants themselves. They can also guide the researcher in formulating questions to use in the next interview.

Ely et al. (1991) suggest that researchers may want to begin making sense of the data by establishing categories, assuming that some work had already been done on creating categories during the data collection process, such as via analytic memos. They pose some questions for the researcher to ask herself when analyzing her data for categories, such as, "What is the smallest meaningful chunk of log narrative that I will call a category?" Ely et al. (1991) warn the researcher that, "making categories means reading, thinking, trying out tentative categories,

changing them when others do a better job, checking them until the very last piece of meaningful information is categorized and, even at that point, being open to revising the categories" (p.145). Regarding the coding of emerging themes, Ely et al. (1991) advise the use of brief phrases or terms, or letters, to be changed as the categories evolve. Verbatim narrative is then chosen to link the raw data to the categories.

Categories, according to Ely et al. (1991) then are developed into themes, which can be defined as a, "statement of meaning that 1) runs through all or most of the pertinent data, or 2) one in the minority that carries heavy emotional or factual impact" (Ely, 1984, cited in Ely et al. 1991).

In analysing my data, I would repeatedly ask myself, as recommended by Thorne et al. (1997), "What is happening here?" As I observed repeated concepts, or very evident ones, running through the various transcripts, I would think of a suitably descriptive word and note it in the margin next to the verbatim text. Once I had completed all transcripts in this fashion, I would repeat the process, challenging myself on the previously coined terms. These, once revised and renamed, became the categories. Next, I wrote all the categories out on a blank sheet of paper and attempted to group them in clusters. Then I found words which managed to describe the clusters, these becoming themes. Some of the words chosen to represent the themes were revised, and categories were moved to different themes, throughout the analysis of the findings.

### **Follow-Up Interview**

One of the rigor checks included in the process for Interpretative Description is that of bringing the beginning conceptualizations, representative of the entire sample and not just of an individual case, back to the individual participants. Thorne et al. (1997) point out that, "often,

more important insights about a conceptualization can be formulated from people's perceptions of why it does not quite fit than why it does" (p.175). In this way, emergent theorizing can be challenged and refined in direct relationship to the "grass roots" data, the participants themselves.

Ely et al. (1991) cite Lincoln and Guba (1985) as referring to this process as "member-checking." It is at this point in the analysis process that the researcher checks with the participant regarding use of verbatim quotes. The researcher highlights the quotes which were used to generate the themes, and checks with the participant regarding the "fit" of quote to theme.

Following the initial data analysis, I telephoned the participants, as I had indicated I would, and asked them if they would be willing to participate in a second, follow-up interview. I was unable to contact one of the participants. I booked appointments with the other seven, four taking place in the participants' homes, and three in mine. I indicated to the participants that these would take approximately half of an hour, but in all cases, the follow-up interview lasted between one and one and a half hours.

To this interview I brought two sheets of paper outlining the developing themes and associated categories based on the data as a whole, not simply of the participant's interview. On the paper, I had marked the categories which I felt most applied to them. Participants were invited to speak to any of the categories and encouraged to remark on not only those which applied to them, but to those which they felt were not applicable. I did not audiotape this interview, but took extensive notes on the sheets. For detailed findings from these interviews, see p.107 "Follow-up Interviews" in Chapter Four.

## CHAPTER FOUR

### Results

I initially believed that the interviews for this study would take approximately 60 minutes. Seven of the eight initial interviews in fact continued for 90 minutes each. The research data thus was comprised of approximately 11 hours of audio-taped interviews, and 147 pages (@550 words per page) of transcribed dialogue. The findings here represent predominantly the data which came from the initial interviews. However, data from the second interviews were included, and explicitly so, if the data enhanced what the participant had earlier said in the initial interviews. A section which discusses the findings from the second interviews will be found following that which discusses findings from the initial interviews.

The central question posed of the participants in this study was, "How did the experience of having a critically ill baby change who you are as a mother?" Having experimented with this question with personal acquaintances, two mothers not included in this study, I decided to ask the mothers in the study to approach the question chronologically, beginning by describing their prenatal expectations of being a mother, followed by their peri-natal experience, followed by how they see themselves, as a mother, as having changed. I believed that in order to be able to speak to the issue of change in self-concept due to a specific experience, in this case the birth of a critically ill baby, it would be helpful, perhaps necessary, to discuss the events surrounding the experience.

This, however, is not exactly the sequence of discussion followed by the participants. Even though I invited each participant to describe their expectations of being a mother prior to the birth of their child, two of the mothers told me they had not formulated any expectations of

motherhood prior to the event, and another two began by relating the details of their pregnancy, with no discussion of prior motherhood expectations. Because of the evident intensity in the telling of their story, I chose not to redirect these participants to the first question. Four mothers did address the issue of prior expectations, and this will be discussed below.

It was clear to me that of the three parts to my question, the second part which invited the participants to discuss the event surrounding the birth of their baby was the easiest part for the women to relate. In varying degrees, the mothers spoke of the labour and delivery experience, and of the following neo-natal experience with a fluid pattern of speech. In looking at the transcripts which cover this part of the interview, one sees large passages of uninterrupted text. Comparing this to the transcripts which cover the discussion of change in self, one can see less participant text, and more probes on the part of the interviewer. The verbal description of their peri-natal time was accompanied, in most cases, by an emotional experience. In many cases this was undeniable, evidenced by changes in body language such as marked leaning toward or away from myself, facial expression such as crying, and voice tone such as that raised in anger or hushed in sadness. Many participants used metaphors in their description of this phase of their experience, examples of which will be included in the many quotes contained in the following sections. Perhaps to further indicate to the emotional quality of the experience of describing this aspect of their story, two mothers at the second interview commented on having no conscious memory of making some of the remarks which they had made during the first interview. As well, two other mothers said that they had trouble finding words to describe some aspects of their experience. Noelle, for example, remarked when the interview was over, "It's so hard to describe. It's like there are no words for some feelings. The words we have can be so inadequate."

I noted that when the mothers came to the end of their description of this experience, there was a sense that the story was over; as if this part of their experience, existed in and of itself, somewhat as a separate chapter in the overall story of their life. It was only when I prompted them to speak to their perceptions of how the experience had changed them, that I sensed they began to consciously draw lines from the neo-natal experience to their current life experience. Many paused, as if to collect their thoughts, and to consider the question. Again, their body posture changed, generally to a more upright, "thinking" position, and even the choice of words took on a more cerebral quality. Indeed, in contrast to the emotional quality of the telling of the peri-natal story, the participants began to comment on the impact of that experience in a reflective, cognitive way.

As I was conceptualizing this study, I had planned to 'use' the telling of the neo-natal experience as a way primarily to help the participants access their thoughts about change in self. However, noting such qualitative differences in the way the two aspects of the mothers' stories were told, and with an appreciation of the weight and importance with which the peri-natal experience featured in their memories, I decided to present the findings from the interviews as being divided into two key parts: the story of the event (the "Then"), and the development of self (the "Now"). The stories of the event had a crisis-like character, and were comprised of descriptions of the impact that such a crisis can have on one's sense of self. These stories then informed the next part, which featured, in almost all cases, perceptions of one's self as having changed and/or developed as a result of the experience of the event. Table 1 provides an overview of the themes and categories which emerged from the Data. These are separated into two sections, The Experience - "Then" and Development of Self - "Now."

The following three sections, "Expectations," "The Event," and "The Development of Self" will explore what I heard the participants describe of their experience with having critically ill babies.

### Expectations

#### "Before"

As noted above, only four participants, two of whom had other children, spoke specifically at this time of their prenatal expectations of motherhood. Of the four that did not discuss this aspect of their experience, two began right away to discuss the story of their pre and post natal experience, and two simply said they had not, "given it (their prenatal expectations) much thought." Three of the mothers who did speak about their expectations had not forecast that anything would be wrong with their baby, but instead imagined a happy, normal postnatal experience. One of the mothers did recall worrying from time to time about, "worst case scenarios." All four, however, had positive expectations about motherhood.

Jean, a first time mother, was the participant who articulated to the greatest degree her expectations of what she would be like as a mother. Perhaps this is because she is the oldest of the mothers in this study, and thus had had more time to reflect on what motherhood might be like for her. She herself attributed it, when I remarked upon this at the second interview, to her personality which she implies is very process and detail oriented. She initiated the discussion on expectations by claiming that she had false expectations of what motherhood would be like. She

**Table 1****Impact on Self: Themes and Categories**


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The Experience - "Then"			
Themes	SHOCK	STRUGGLE	EFFORTS TO COPE
Categories	World is Crashing	Grief	External Resources
	Surreal	Guilt	Internal Resources
		Powerlessness	
		Fear	

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Development of Self - "Now"			
Themes	INNER SELF	RELATIONAL SELF	MOTHER SELF
Categories	Higher Consciousness	Relationships with Family	Perception of Child as formed by neo-natal experience
	Personal Benefit	Relationships with Friends	
	Spirituality	Relationships with Unknown Others	Maternal Practices
	Values	Professional Relationships	

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said that she had a "fantasy" that she would have a girl, that her delivery would be normal, that she would be more mature, and that she would feel more care and concern for her children. Jean also suggested that perhaps this fantasy that she related was created by, "stereotyping, that's partly what I heard, what I thought it would be like." Joanna, another first time mother, made several comments throughout the first and second interviews about the meticulous care she took of herself while pregnant, and the consequent belief that she would not have a baby with severe health problems. She does recall, however, worrying from time to time about the baby, and being anxious for the baby to be born, so she could put the worrying behind her. She was otherwise eagerly looking forward to the baby being born, "I was really excited about being a mom and staying home."

The two mothers who already had children also had positive expectations about being a mother again. Noelle recalls her first child being a very calm, content baby, and expected the next to be the same. She was "ecstatic" that they would be having another girl and said that the whole family was looking forward to the new baby with excitement. She thought that as a mother she would be very loving, very caring, very involved, much like she had been to her first daughter. Jasmine, having two older children, aged 17 and 21, believed that this time as a mother would be different than before, due to her improved circumstances. She commented that she saw this time as her "chance to kind of do it again."

### **The Experience**

#### **"Then"**

The stories which the participants told of the event feature the emotional and environmental details which were experienced in the peri-natal period. As was discussed above,

this part of the interview seemed to be that which came most easily to the participants. They "knew" this story. It was clearly a chapter in their autobiography. I sensed from all of the participants that this story had been told before. This is not to say that it sounded rote, or superficial, for I received quite the opposite message. The events which surrounded the experience of having a critically ill baby were and remained of obvious import to the mothers. This was not a story that they felt represented a mere bump or twist in the road. As Joanna told me at the end of our second interview, "I don't want to put this away." In the story of their lives, the part about their sick baby is of great personal significance.

I did not ask the participants to frame their discussion of the neo-natal experience in terms of changes to the self, as I was specifically looking at a how they viewed their self from the perspective some time after the neo-natal experience, thus the decision to speak to mothers of children aged 2 to 6. However, it is evident that the mothers' selves were impacted upon by the neo-natal experience. The narratives tended to be divided into three themes, Shock, Struggle, Efforts to Cope. These themes represent the ways in which the participants' lives took on a new form, and how they struggled to find new meaning in their life. As they relate to the self, shock reflects a time of loss of basic constructs of sense of self, struggle reflects loss of agency of sense of self, and efforts to cope reflect one's effort to maintain a sense of self. The woman's senses of self were evidently threatened in these cases, and seemingly not only who they perceived themselves to be as mothers, but their sense of self in general.

Each theme was further divided into sub-themes, or categories, which were created on the basis of either featuring in many of the participants' stories, or because they were characterized by

a strong quality specific to perhaps only one participant. The categories will be described, and use of quotes will illuminate their meaning.

### **Shock**

In this theme, the participants struggled with the reality of lost and shifting expectations. They experienced the sense of confronting a reality which was dramatically different from that which they had expected. Most of the women seemed to view this time as a crisis or a disaster, and the words of many were indicative of a sense of disbelief and of being removed from the situation, of being an outside observer of their own experience.

#### **World is crashing .**

When describing the first awareness that their baby was critically ill, all but one of the participants referred to the often frightening sense of loss that occurs when previously held expectations do not materialize. A sense of suddenness and confusion characterize these descriptions, as the mothers grappled with facing the juncture of two worlds - the one they expected, and the one which was developing. Noelle remembers this happening as she sat in the car on the way to the hospital following her baby's first seizure:

I remember (my older daughter) sitting in the front seat completely confused, there was panic surrounding her...my heart was pounding, and I was thinking, 'My world is crashing.' This wasn't supposed to happen. I had a daughter already and now another perfect little daughter, and we had the perfect little family, and now everything was different.

Others also referred to the frightening sense of the sudden and completely unexpected change to their world. Joanna spoke to this by saying that, "from then on, our world just

absolutely crashed. It was very scary because we just had no hint that there was anything wrong." Bonnie echoed this by stating that she could not believe that it was actually her daughter that she first saw, completely covered with life-supporting machines, that nothing had prepared her for what she now had to contend with. For these women, it was as if they were frantically searching a foreign landscape for something familiar or recognizable, and finding nothing, were left at a temporary loss as to how to proceed.

Interestingly, neither Jana, the mother of twins, nor Alex, who had 4 days of managed labour before birth, recalled this sense of shattered expectations. Fear for their baby, for their self, and anxiety, in the case of Jana, about how she would manage the care of her two year old son at home, her husband and her household, did feature in their recollections at this time. But they did not refer to the same immense sense of "being at a loss" as described by the other participants. This is likely due to the fact that there was some preparation for premature birth, and awareness of its effects on the baby. Some rehearsal, therefore, had been done to help prepare them for the upcoming reality. Indeed, Joanna, who did feel that her, "world just absolutely crashed," remarked that this feeling may have dominated her initial experience of the event because there was no hint, prenatally nor just after birth, that anything was wrong with the baby's health.

### **Surreal** .

Five of the mothers commented on the incongruous quality of their experience immediately after the baby's admission to the NICU. They were struggling to make sense of what was new, to manage their confusion, to incorporate their new environments and experiences into a consolidated reality. As Joanna remarked, this was a time characterized by the question, "Is this really happening to me?"

For many of the mothers, this incoherent sense was due to the disorienting and other-worldly atmosphere of the NICU environment, as in Bonnie's description:

But that whole ICU (sic) unit - it's just a whole different place. You aren't even part of the world. It was like living your life for two months in suspended animation, in a bubble.

And every time I drive down Oak Street, I remember.

Several of the participants also remember feeling disconnected from their experience, like they were merely actors playing a part, not the true agents of their experience. Noelle articulates this, "We were in this state of panic, we were in a time capsule, and it was this feeling of, 'I can't relate to what's happening, this can't be real'."

Joanna also describes her sense of a sudden and dramatic shift in her take on reality:

Then we arrived (in Medisto, for the baby's heart transplant) and it was very surreal. All of a sudden, you know, the palm trees and everything, just all the ambulances and the people that met us there and then took us to the hospital.

For Jean, this feeling was described as, "just going through the motions." She says that historically she has dealt with trauma by, "putting it over there. It's like being on the outside looking in." The story of her experience was not characterized by the emotional quality which was so evident in that of the other participants (described in the following "Struggle" theme). Instead, she spoke to a sense of numbness and of being removed from the situation.

### **Struggle**

Concomitant with, or immediately following the initial shock at confronting that which was happening to them and their babies, the mothers entered into a phase which was recalled with a largely emotional quality. Feelings such as sadness, fear, guilt and anger dominate the

experiences of the mothers at this time. Commitment to their child was also heard in the stories of several of the mothers. It seemed to be a time of grappling with what was unexpected, feeling the loss of what had been expected, and struggling to make some kind of meaning of their new reality.

### **Grief.**

Most of the mothers recalled feeling intense sorrow and distress during the neo-natal time as well as the time until the baby had reached developmental norms. The memories of these feelings stayed very much alive for the women up to the time of the interviews, and the memories evidently had a largely emotional quality to them. The grief that was felt seemed to, of course, be in response to loss, although perception of what kind of loss seemed to vary.

Seven of the mothers expressed grief for what might have been, they felt a yearning for what they had believed to be "normal." This sense of loss ranged from expectations around labour and delivery, around mother and family experience during childhood, and around child behaviour. So, for most of the participants, although expectations were not clearly articulated at the beginning of the interview, mothers clearly held many well formulated expectations, and experienced a sense of loss when they did not materialize.

Jana echoes many of the participants in grieving the loss of what was expected around labour and delivery. She felt disappointment in her own body, in not being able to produce the "perfect birth experience." Alex recalls, throughout her daughter's infancy, feeling a strong desire to be "normal:"

I remember a real will, a real drive to believe that in time everything will be normal just like everybody else. I really wanted to act like everybody else, to be out in the stroller,

walking down the street with the pram, going to the mom and tots groups, to be exposed to this whole subculture. You see it and you want to connect with it...I remember bringing her to the paediatrician who would be checking her development with what's normal. and I remember being frustrated by that. I actually got very defensive with him about M's development. I felt she had really caught up and I was just so defensive about that.

Noelle also remembers feeling stressed by the challenges of not feeling "normal:"

It had been so long since I felt normal. The specialists, and the emergencies, and the hospital, and the fear, and the panic, it all felt so intense, and so unidimensional.

Justine describes this grief by recalling a strong visual memory:

I had this beautiful nursing gown which I had bled all over and I was washing it by hand, trying to get the blood out. I wanted to look beautiful. Without child. Oh it was such a metaphor for the grief of how you wanted it to be.

Although Joanna did not speak to this at the time of the first interview, she was willing to comment on it during the second interview. She does not recall feeling grief at the time that her son was hospitalized, suggesting herself that the reason for this was due to the critical nature of her baby's situation and being unable to experience anything but concern for her baby's survival. She does, however, now feel grief around the loss of the, "normal mother experience...like going shopping with the baby, doing things out and about with the baby." She explains that for at least the first year of her son's life, at which point he became more resilient to infection, she was unable to pursue this type of activity and realizes now that she missed and continues to miss having that type of experience.

Five of the mothers also reported grief for themselves. They remembered this as a time when their babies' needs were, necessarily, being taken care of. However, these mothers also admitted to feeling that many of their own needs were not taken care of during this time. Justine remembers her husband choosing to sleep on a mat on the floor, instead of with her in her skinny hospital bed, and felt that, "I had a lot of my own nurturing that was really neglected. I needed to be held. I was grieving. I was scared. I didn't know what to do." Jana felt that her expectation of being the primary person in charge of her babies was never realized, leaving her sense of herself as a mother bereft, "you're so ready to be the Number One person, and you don't even know (your babies)." Noelle also spoke to feeling a personal loss at this time, a loss which continues to affect her, that being around her own unfulfilled need for a mother to nurture her during this critical time in her life, "I realized that she wasn't there for me. All of a sudden it hit me. There was something lost forever in that mother-daughter relationship."

### **Guilt.**

Guilt also featured strongly in the mother's stories. They spoke of a sense of having done something wrong. Certainly the enormous sense of responsibility for the health of the baby is felt by mothers in general, leading to a state of heightened grief when the baby is not well. Some of the participants felt they perhaps had not done "the right things" during pregnancy, and then worried that they were not doing enough while the baby was hospitalized. They worried that their pre-natal behaviour may have caused the problems in the post-natal period, that some aspect of who they were as mothers had caused the baby's problems. Noelle articulates this:

One thing about being in the hospital with her, there was too much time to think. I would think, was there anything I did? I got enough rest, I ate the right things, what went wrong? I felt I had done something wrong.

Jana remember this guilt both at the time of the birth, and continuing through her child's illness:

It was devastating to realize why couldn't I have kept them inside somehow or done something. And later, because we lived an hour away, we weren't able to get there absolutely every day and so we felt guilty. You feel like a failure as a mother because you weren't able to provide as a mother the things that your child needed.

In her subsequent pregnancy, Bonnie recalls receiving the news that her unborn child might have Down's Syndrome. In her grief upon receiving this news, she remembers lamenting, "What's wrong with me? First A., and now this. Can't I make a normal baby?"

Jean, however, specifically stated that she felt no guilt, "I don't think I felt a tremendous amount of guilt like it's my fault or any of those things. If anything I remember when he came home for quite a few months I was angry." As earlier mentioned, Jean felt numb during this time, and claims that she was aware of none of these disturbing emotions. She does, however, recall anger as being a predominant feeling shortly after she brought her baby home. She remembers him, "crying all the time" and being difficult to comfort. The frustration which this caused, coupled with the disappointment of the failure of her expectations to materialize, left her feeling resentful and angry.

Joanna also commented that she felt no guilt, but instead something akin to anger directed at the women who did not take care of themselves prenatally and brought an ill baby into the world, citing for example the heroin addicted babies whose mothers rarely visited while they were

in the NICU. She recalls feeling a strong sense of injustice when comparing those situations to her own, in which she took the utmost care in her health while pregnant.

### **Powerlessness**

All of the participants reported feeling powerlessness, or helpless at some point in the experience, particularly in the neo-natal period, and especially with respect to the health-care system. This was one of the most evident themes across all participants. They felt oppressed, not listened to, not heard, at the hands of fate, and out of control. Many referred to a sense of "intuition" or judgment which either was not honoured, or which they were unable to communicate strongly enough to be acknowledged. There seemed to be insufficient validation for them in their roles as mothers, leaving them at a loss, and in many cases, angry.

For Jasmine, this occurred even before the baby was born when she felt that something was wrong during her pregnancy:

The pregnancy was really difficult and nobody believed me. The doctor really didn't believe what I was saying, like, there is really something wrong here.

Joanna also recalls articulating her intuition to others when her baby first showing signs of distress at one week old:

I would say to my husband or my parents, you know doesn't that sound like he's breathing a little bit quicker than he should be? Everyone's comments were, 'Oh, babies breath quickly,' which I had heard too. And you know they just thought I was being a paranoid new mom.

These mothers were relying on their intuitive judgement to pick up signs about their pregnant bodies or their newborn babies, and when attempting to communicate this to others, were not heard.

Jean describes her labour and delivery experience as being coloured by lack of control and fear. She remembers being afraid for herself and for her baby, as the labour and delivery process happening suddenly, continuing quickly, and ending with an unexpected outcome.

Other mothers became aware of this sense of powerlessness throughout their newborn baby's medical care. The emotional quality to this set of recollections was among the strongest offered by the participants throughout the interviews. When reading the quotes, the fear, panic and rage that arose from a sense of helplessness is evident. Jasmine remembers coming up against the power of the hospital and the insurance company after giving birth prematurely while in the United States:

The insurance company wanted to air ambulance the baby home without me. And I said, 'What? I don't know anything about what is going on, I know nothing about my baby, you can't do this!' It's a nightmare because everyone thinks they are looking after you and nobody is listening and nobody is looking after you.

Justine continues to feel a sense of outrage at the system for allowing operative photographs to be taken with improper consultation:

So the student nurse says to me beforehand, 'Can I take photographs of your C-section?' and I say, 'Yes.' No consent signed or nothing. Now somebody has photographs of the inside of my body and my baby, and this woman, this stupid student nurse, she never followed up. I still haven't seen those photographs.

Bonnie felt totally helpless in her inability to actively help her child "feel better." She had a sense of desperation in that, as this child's mother, she was utterly helpless to attend to her child's needs to be nurtured and protected from pain and harm.

Five of the mothers recalled this feeling most acutely when watching their baby undergo medical procedures. Noelle describes the powerlessness she felt watching invasive procedures being performed on her daughter:

I remember the worst part was not knowing, and I wanted answers, but I could do absolutely nothing. And I remember they had to X-ray her, and that was when I lost it. I said, OK, that is enough. She was all of five pounds, and she was going through all these things and I couldn't do anything to comfort her.

Jana also remembers missing the instrumental power which she felt, as a mother, she had the right to:

It's overwhelming because there are teams of people. They make all these decisions and then leave. And they are telling me, 'No, no you can't look after your child like this.' And you can't touch them. You feel like you don't have ownership, or, that's not the right word, entitlement.

Justine speaks to the intense sense of injustice she felt in response to her child undergoing invasive medical procedures shortly after birth:

Somebody has taken a needle and jabbed it into, or poked and squeezed his heels for blood. How dare they without asking me, his mother? What is that little person thinking when he comes into the world for the first time and what are these people doing? It's barbaric.

Although Joanna recalls powerlessness as the most overriding emotion throughout the time when her son was critically ill, she attributes this not to the medical system per se, but to the fact that she had no control over the outcome of her son's situation. She states, in fact, that the medical system, perhaps because it is familiar to her through her career experience as a molecular biologist, was not a source of stress. The reality of not knowing if her son would, for example, receive his heart and then accept his heart and then thrive following surgery, was the source of the excruciating sense of helplessness.

Shock at the baby's appearance in the NICU also seemed to contribute to or cause feelings of helplessness. The most salient aspect of the visual experience seemed to be the technical presence in the NICU in which the baby is hooked up to a series of life-supporting and monitoring machines, and contained by plastic incubators. One of the mothers commented on the relationship between her feelings of helplessness, and her baby's appearance of helplessness. Another keenly recalls the plastic of the isolette as being a shield between her baby and her ability to mother him. Several of the mothers also commented on the existence of the monitors as being an omnipotent and omnipresent alternative caregiver. Many of the mothers clearly retain strong memories of the NICU, and describe it with intense imagery. To communicate the vividness of these images, I will include two of the mother's descriptions here:

I'll never forget the very first time I saw her. Her in the room being wheeled in. Her head was shaved and there was a needle in her head, tape over her nose and tubes in her legs...and the beepers and the sounds, and the heart rhythms on the monitors, it's not just a visual image, there are noises to it and a smell to it. (Alex)

She was covered from head to toe with wires. Needles...both hands, both legs. She had this huge respirator on her mouth which puffs air into the lungs, plus she was paralyzed so she wouldn't rip all the stuff out. Her hair was all plastered back. Her eyes were covered with Vaseline. (Bonnie)

**Fear.**

Related to the mothers' feelings of powerlessness and to those of grief as well, is the experience of fear; fear of the unknown, of the unexpected, and of the possible death of the baby. Five of the mothers, independent of the severity of the babies' illness, explicitly described the fear that their baby would die. Their reaction to this fear varied from acceptance to denial of the reality of death. For example, although Jana made reference to the fear that her baby might not make it, "I remember having S. in there and trying to be encouraging that we would get out, but it's always in the back of your mind that some don't get out," she used her faith in God's presence and support to carry her through her fear to a place of acceptance.

The fear that Noelle experienced through her daughter's virtual death affected her in far-reaching ways. She describes this as:

...experiencing your worst nightmare. When I saw her die, then she came back, it's like you've already begun the preparation for death. And for grief. Your body has to jump back to life again at the same moment that you feel your blood draining,, and you feel like part of you is dying. I remember thinking, 'I can't take this.'

Although Noelle had to look her worst fear in the face, it left her ironically less afraid of her own eventual death.

Even though she understood that his life was not truly at risk, Justine also reported experiencing fear for her son's death:

The whole thing for me was, I knew in my heart I was one of the lucky ones. But to me it might as well have been open heart and that was one of the really standing out things actually that I can tell you, it doesn't make any difference how ill your child is. Because I think that was our fear and I've never said any of that, that this child would die.

When I remarked on this during our second interview, she stopped me to say that she had never stated that she was afraid of this fear. Upon discussion and realization that she had indeed made this statement but had left it in her subconscious, Justine wondered if perhaps an earlier therapeutic abortion, and neglect at dealing with that loss, had enabled her to effectively repress memories of fear of yet another loss of a baby.

Bonnie remembers responding to her baby differently due to her fear of death. It was as if she was going to delay connecting with her baby until she could be assured of her survival:

They said touch her and talk to her so she knows you are there. I still hadn't held her and I said if I get too close to her and she dies...I didn't really want to do that. And every night I went into her little room at home, all set up nice - she hadn't even been there yet, I thought, I wonder if she is ever going to be in here.

During the second interview, she added that she often wondered if her current feelings of not always feeling "close" to her daughter arose from this delay in bonding, her reticence in initially becoming attached to her child. She is not alone in wondering this as two other mothers expressed the same concerns.

Joanna made no explicit mention in our first interview of experiencing any fear for her son's survival despite his critical situation. When I commented on this during the second interview, Joanna hesitated before replying that she feels still too close to the reality of that possibility, and finds she cannot readily consider the thought.

### **Efforts to Cope**

The participants' stories reflected several features of their experience which either helped or hindered them in their attempts to cope with the stress of having a critically ill baby. In general, these experiences and events can be grouped into two categories, External Environment and Internal Environment.

#### **External resources .**

This refers to the mothers' physical environment as well as the behaviour of people, including hospital nursing staff, doctors, family members and clergy, which surrounded the mothers in the post-natal period.

One of the most commonly reported aspects of the external environment considered to be helpful was positive alliances within the health care system, particularly those with nurses and doctors. It is evident from the participants' memories that these people had a terrific impact on the mothers while their babies were in the hospital. Bonnie expressed her gratitude to the staff of the hospital by stating that, "if we ever come into money, a huge chunk of it will go to (a large metropolitan hospital)." These individuals were recalled with fondness, and with great attention being given to the memory of personal characteristics. They were clearly a source of great comfort, the mothers appreciating, perhaps needing, a contact which went beyond the strictly

defined medical role. It was often the details of the human contact which the staff attempted to make which made the most impression and was the most helpful to the participants.

Three of the participants recalled the doctors as being powerful, yet real; wielding the ability to control their situation, yet taking care to acknowledge their fragile reality. For example, Bonnie vividly remembers the physical stature of one of the doctors, "By Sunday morning this doctor came; big huge guy with huge fingers but wonderful feelings." Jana recalls that a classmate of her father, who had died when she was young, remembered her and personally took on her case, "He genuinely took an interest in us. He would talk over with us the decision and just take extra time." Justine also recalls a member of the health care system helping her to cope through personal, human contact:

The anaesthetist...was so wonderful. He got the warming blanket out of the warming cupboard and put it over my breast...it was getting me ready to breast feed! He was stroking my face...doing therapeutic touch which didn't feel, it felt safe and wonderful.

Four of the participants recall members of the nursing staff as helping them to cope. Not only did they perform the important task of "translation," helping the mothers to understand the "medicalese" communicated to them via the doctors, but they were perceived as taking on a nurturing, almost maternal role to the mother. Some of the participants labelled these nurses with supernatural terms such as, "Angel Woman (Justine)" and "Mother Earth (Alex)." Several of the participants mentioned that they continue a relationship with these women.

Joanna found that in almost all cases the alliances she formed within the health care system were helpful to her during the time her son was hospitalized, and continues throughout his follow-up. She remembers closely watching the faces of the medical staff while her son was being

flown down to California for a heart transplant, hoping to find information in the slightest change to their facial expressions. In a similar search for information, she and her husband would spend time researching through the Internet for information on their child's condition. She commented that she appreciated the straight-forward and realistic style of the doctors who would give her updates on her baby's illness, as well as the support offered by nurses, social workers and members of the transplant team.

Another element of the environment which was mentioned by some of the mothers as being helpful was the series of posters which adorned the walls of the NICU depicting a critically ill baby, and then the same baby as a healthy toddler. As well, one participant recalls, posted to the wall of the NICU, letters and photographs of "normal" appearing children which had been sent to the hospital by parent "graduates" of the NICU. These mothers remember feeling encouraged in seeing these images of hope, "You just kind of live through those pictures thinking you do get out of here (Jana)."

Finally, a few of the participants remembered feeling relieved that their child was not among those in the NICU who's future was uncertain, and would find themselves feeling grateful and hopeful to realize that other children were worse off than their own.

Negative interaction with the health care system also took place, hindering participants' coping abilities, in many cases resulting in feelings of anger. These tended to be situations that led the mother to question her own judgement, or to feel that her opinion was not acknowledged or validated. This ties into the powerless category as discussed above under the Chaos theme. Jasmine recalls with some anger this sense of not being listened to, claiming that:

People in a place of authority can really make you question your own judgement; the doctor initially made me question my own judgement.

Alex recalls feeling angry at the doctors for poking and prodding her daughter, who presented with an unusual syndrome, to such an extent that she feared internal damage. Similarly, Justine and Noelle speak of anger and rage when faced with a nurse ( "the nurse from hell" (Justine)) who did not support and in fact challenged their desires to nurse their babies. Bonnie also continues to feel disdain for two of the doctors assigned to her baby's care who were consistently cold, unfriendly, and extremely technical in their communication with her regarding her daughter's state of health.

As well, the technical and impersonal environment of the NICU was challenging to many of the participants. Bonnie recalls, "hating the ICU" and feeling terribly isolated from the outside world. Justine also attributes a delay in bonding with her child to the plastic which encased his isolette.

Paradoxically, however, three of the participants, Joanna, Bonnie and Jana, who on one hand reported disliking the NICU, remembered feeling awkward and alone upon leaving the health care system behind them. These mothers remembered feeling so dependent on the monitors and the nurses and the system in general, that stepping away from that environment was very scary. Jana recalls feeling that her children's lives were totally dominated by the technical world of the NICU, remembering the disappointment that surrounded her inability to care for her children, and the affect of that in terms of her self-image as a mother, "It kind of affects your self esteem as a mother when you can't be the one to mother them." Yet, she came to depend on the system as an omniscient caregiver, from whom she was nervous to separate.

Family and friends were seen by the participants to be, for the most part, a source of support, emotionally and practically, at this time. Participants were grateful to family and friends for simply being with them to share in their pain, as well as for more practical purposes. Jana recalls friends who would take the older sibling for days at a time, and then later a friend who moved into their home, freeing her and her husband up to spend more uninterrupted time at the hospital. She also appreciated the money sent by her parents, who lived far away and thus could not physically help them, which she used to pay for a housekeeper to help with the home and the meals. As well, she mentioned how helpful it was to have a sister who was a paediatrician, to help monitor and interpret the medical situation for them. Joanna was thankful for the car brought down by her sister-in-law while they were staying at the hospital in California. She also felt the presence of her parents and friends in California with her to be helpful to her at that time. And Justine remembers her aunt turning her room at the hospital into a "home" by filling it with food, baby clothes and photographs. Bonnie's story is infused with references to family and friends being at her daughter's bedside, offering her emotional support through their presence.

Many of the mothers referred to the valuable support offered by their husbands. Some referred to the active role that he was able to take with the baby, to the information-seeking role that he assumed, to attending to the mother's needs, or by simply showing his own emotional pain in response to the crisis. This was most evident for Bonnie and Joanna who believe that the experience of their child being critically ill brought them closer to their husbands. Bonnie explained that, regarding her daughter's health, she would consistently take on the negative forecast, whereas her husband would always express positivity regarding her outlook. She

believes that this served to contribute to their sense of their relationship as an integral unit, and deepened their trust in each other.

In contrast to this, however, several of the participants also commented on the awkwardness of others as being an unwanted element. These mothers believed that the well-intentioned sympathy offered by others actually resulted in increasing their sense of isolation.

Joanna explained this by remembering:

The other thing that was hard, was people were very supportive...but they just don't understand unless they have been there. They just don't get it. We heard I don't know how many times we heard, '...and oh, I had a friend and they had a hole in the heart when they were born and they're 30 now.' I mean they are just trying to be helpful and supportive...but it makes you feel that no one really understands.

Bonnie remembers the friends who did not show up to offer their support, explaining that she and her husband eventually "dropped" these individuals from their social group, concluding that perhaps they were not the kind of people they would choose to be in their lives.

### **Internal resources** .

Aspects of the participants' own internal resources, or personal attributes, were also identified as being helpful in their coping abilities. These resources included the participant's system of faith both with God and in their self, past experience with trauma, and sense of humour.

Jana's Christian faith in God was referred to many times throughout her discussion of the events surrounding the premature birth of her twin boys. She recalls having faith in the support she would receive from God if and when she needed it. For example, when she and her husband needed \$300 for a car payment, she believes that God arranged for that money to come to her.

She also recalls believing that God would help carry her through any potential crises, for example if the sicker of the twins did not survive, "even if it hadn't worked out I think God would have helped me heal." Bonnie realizes that it was at this time that she chose to become closer with God, using a memory to communicate this transition:

I remember using the phone in one of the waiting rooms...and seeing something scratched into the wall - 'God, I Need a Miracle.' I needed a miracle then. I was totally out of my element, not knowing anything. What do people do when they have no faith and no religion, they need something more powerful than them. I was always touched when people said, 'We're praying for you,' but wondered what that really meant.

Other participants referred to faith, but in a non-religious way. This faith was more in a sense of their own ability or drive to carry them through their difficulties. For example, Alex remembers a feeling that, "some kind of faith was just carrying me forward," acting as buoy in a situation that was threatening to overwhelm her. Noelle also drew on her own strength to help her through the process, experiencing an intense drive to convince herself that all would end well:

Through that entire time, never once did I feel sorry for myself, never once did I break down, and I would constantly think, 'OK, things are going well,' and I never once let myself think that things weren't going well.

Joanna also figures that it was her perseverance to continue moving ahead, and her ability to focus and use her energy to do what was necessary which helped her to cope with the profound difficulties which her situation presented.

Two of the participants referred to their experience with past trauma as helping to frame what was happening in a constructive way. Jasmine recalls having been through health-related

trauma before with several family members, and believes that those experiences familiarized her with the system, and gave her the courage to assert herself where needed. When faced with trauma, Jean tends to separate herself from any disturbing feelings, instead using her energy to focus on the task at hand. She remembers when her mother died, she reacted in a similar way to her response to her son's preterm birth, she, "put it over there."

Justine is conscious of having drawn on her humour as a strategy to help her through the difficult times in the post-natal period. She remembers renaming her son, "Jack-in-the-Box," because of the amount of time he spent in the isolette.

During the second interview, when I discussed this category with Bonnie, she said that she felt no strength within her at the time. In contrast, she felt intensely weak, pessimistic and without hope which she believes was related to the immense fear which she felt for her child's immediate future.

As earlier noted, most of the participants experienced intense fear at some point during their experience with their critically ill babies, triggering what might be seen as the Fight-or-Flight response. Indeed, some mothers chose to "fight" in a way that was expressed by one as, "an overwhelming sense of responsibility" (Noelle), or an intense urge to protect their "helpless" child. Those mothers who chose the fight response make reference to animal instinct, or "coding," indicating a sense of being taken over by this part of themselves. For example, Noelle commented that:

This instinct came out that said, 'You're mine, and I will do all that's in my power to help you.' It's like there's this coding that has been built in from way far back that caused

me to realize, 'I'm your mother. I'll be here, I'll do what I have to do. This is my job, this will always be my job.'

And Justine remembers defending her choice to dropper feed her colostrum to her baby:

So I said, 'Well what's the policy here? Who's the head nurse? Who's in charge?' Oh, well, the lioness was released.

Choosing different aspects of the fight and the flight response, Alex attempted to protect herself from the world's tragedies by turning a blind eye to negative news accounts, and to become hypervigilant of her child:

I remember I thought, I have this baby and this world is horrible and there are so many tragedies happening and having to do with children, what have I done, how can I ever protect her? We didn't get the newspaper for a while. I was totally protective of her.

Some of the mothers seemed to choose the flight response, and reported feeling numb in response to their baby's plight. Bonnie recalls dissociating from the situation, and having a very cognitive response which seems to her now to be void of emotion:

I sat around with my sister, had coffee and then we went to the hospital, there was no big rush. Now I look back at it and think why weren't we rushing to the hospital? I remember that night, we watched a video. I mean, my daughter was in the hospital, I mean she could have died. I remember driving home and thinking, I'm not pregnant and I don't have a child.

In the very first moment of contact with her child, Justine, although her "lioness" was released at a later point in time, still cannot remember seeing her baby. To this point in time, this memory, or non-memory, causes her great distress. She feels a sense of incompleteness in being unable to recall

the first interaction with her baby. She also chose a similar response to Bonnie initially in that she chose not to stay in the NICU for long while visiting her child, and, again, this memory continues to cause her anxiety.

Jean also tended to distance herself from her situation as a way of coping with the anxiety it caused. She recalls feeling that her experience was:

...kind of way over there somewhere. The drive, we lived in Yaletown at the time, so the commute to (a large metropolitan hospital), Yaletown and Tsawwassen maybe helped me through it all, you know to deal with the whole experience. So it's all a bit of a blur. I wasn't upset.

The issue of the mother's ability to nurse the baby, arose with one of the most frequent rates in an explicit and evident manner throughout most of the participants' stories. Breastfeeding was generally believed by the mothers to be an activity that helped them to cope with the difficulties of having a critically ill baby. It was either stated in a matter of fact way or was imbued with much significance. The lactation consultant was frequently mentioned, and referred to as a saviour. Justine recognized the act of breast feeding as being symbolic of the act of mothering, and felt that the first time her son was able to nurse represented the first true sense of attachment that she felt for her baby. Noelle, counter to her general way of dealing with people, ignored all staff attempts to dissuade her from nursing, and persevered. She felt that she had no choice, that nursing her baby was imperative above all else. Alex also experienced a drive to breastfeed her baby, stating that, "I was so positive that it was the right thing to do."

If the ability to breastfeed was considered as one of the most helpful activities for the mothers, the inability to breastfeed presented extreme challenges. Joanna recalled a time when

her son's condition prevented him from nursing. She emphasized how difficult it was when she had to stop nursing her son, calling it, "one of the biggest issues" which she had to deal with, and describes watching her baby desperate to nurse while she could only look on, unable to do so.

Jana, however, after a valiant attempt at pumping breastmilk via a machine and storing it for the later use of nasal gavage feeding her newborn twins, as well as having a 17 month old child at home, came to the realization after five weeks that she was exhausted and spent from the energy the lactation required. Upon ceasing the pumping, she was reassured that her decision was the right one when her energy and weight returned, allowing her more endurance to deal with her many challenges at the time. Although she is convinced that she made the right decision, she continues to feel some residual guilt when stating that she did not continue to breast feed her babies.

### **Development of Self**

#### **"Now"**

As earlier mentioned, the interviews all emerged with two distinct themes, the "Then" and the "Now." The telling of the neo-natal experience came quite easily to the participants, and some finished their story in an evident way, in a way that might have read "The End." Some trailed off; I could sense the energy behind the telling of the story abating. With others, I felt constrained by time, and had to interject with, "How have you, as a mother, come out of that experience differently?" In all cases, when they began to consider this question, I sensed the participants moving into a more cognitive state. For instance, there often was a long pause during which the mothers were reflecting on the answer to my question, or they would change their body posture; sitting more erect, for example. Examples of the comments made by the participants following

my question are, "Well (long pause), I feel that my world has changed dramatically (Noelle); "Well (pause), I think we definitely have a different perspective on things than the average parent (Joanna);" "Ummm (long pause), far more conscious about my choices (Alex);" "(Long Pause), well, Abby didn't crawl until 11 months (Bonnie);" "I think, (pause), I think I came out feeling humble (Jana)." It is interesting to note the use of words which imply the cognitive process that is taking place.

Some of the mothers explicitly discussed being aware of a sense of evolution, using such terms as "resurrection" (Alex), "rebuilt" (Noelle) and "reborn" (Justine). Others, however, seemed to have difficulty, or to need more time in discussing how they saw their selves as having changed. The story of their and their babies' plight came easily, fluidly, whereas they were more effortful in articulating the impact of the experience on their sense of self. This may have been the first time several of the mothers had consciously considered how they might have changed and the first time that they had attempted to articulate their experience of change. A few of the mothers commented on their frustration at describing how the experience had changed their sense of self, feeling that words were inadequate to fully describe their experience.

Only one of the mothers, Jasmine, although her story of the event was imbued with much emotion and although she recognizes her experience to have been a crisis, claims to not have been changed by the experience:

So that's my story. I don't know if I would necessarily change. I think I was already that person before... You know, I basically don't really trust anyone when it comes to life situations ... If I am different, it's because my life is so much different than when my others kids were born - the first time I had a child was 17 years ago. I've been through

crisis before and I find that afterwards I'm not really sure I changed as a person. I'm sure that during the whole stretch you live your life one way and then when it's over you go back to being the same person.

Jean's story also was unique from most of the other participants in that she explicitly stated that that the event of having a critically ill baby did not change any parts of her Inner or Relational selves. She does believe that her son's neonatal experience had an impact on her mother self different than had he been born full term, as she attributes his current ways to having being formed by his earliest days. She did, however, describe "a new me" that has emerged from the event, in that she has chosen to pursue activities which she had not done before the birth of her first child. These activities include those which do not include her children, for example, jogging and certain artistic endeavors. Perhaps these activities pertain to her Mother self, in that they reflect dimensions of coping in her role as mother. Through these newfound activities, Jean may find the ability to function to the best of her ability when she is with her children.

Furthermore, although I was aiming to hear how they saw their sense of themselves as a *mother* as having changed, the women generally discussed change as occurring within three different facets of their sense of self. Jean and Bonnie were the only participants who answered initially by reflecting on their reactions to their children. The others, however, did not restrict their responses to those parts of them which were specifically "maternal." It seemed to me that this may have been the first time that the women had consciously attempted to pull out from their overall identity that aspect of their selves which was the mother self. These participants tended to begin their discussion of how they had changed with references to their perspective, or point of view of themselves. For example, Noelle, Joanna and Jennifer's first comments in response to the

question was that they had gained a different perspective on their priorities in life. Alex reflected on her sense of becoming further evolved, of having gained a higher consciousness. As our conversations continued, the participants generally spoke of evolution occurring within three separate, but related aspects of self, what I have termed their Inner Self, their Relational Self, and their Mother Self. The first two aspects of self, The Inner Self and the Relational Self, are not direct answers to my question of how the event changed their Mother Self. Yet, these are aspects of their selves which the participants chose to speak of in reply to my question. The mothers seemed to be telling me that having a critically ill child had an impact upon much more than what they would limit to their "mother self". The birth of their child did not only introduce a new facet to their overall sense of self. It cast its light and thus transformed a broader range of their entire sense of self. The participants' descriptions of these three aspects of self will be explored in the following sections.

### **Inner Self**

This term is used to describe those aspects of self which refer to how the women viewed their internal experience; in some cases how they have changed their views on fate and on their own basic personality traits. Categories which fit into this theme of Inner Self include higher consciousness, wisdom, acceptance, strength, spirituality and values. Many of these categories blend into and overlap with each other, but attempts have been made to separate them for the purposes of discussion.

Overall, these categories were the first to be revealed by the participants in response to the question of how they might have emerged from the neo-natal experience differently. The participants perhaps created these categories in an attempt to find meaning in the experience, and

to communicate that something "special" had happened as a result of that experience. Indeed, the vast majority of comments around this theme indicate that the participants felt that positive personal development had taken place in response to the neo-natal crisis which they had experienced.

**Higher consciousness .**

This rather nebulous term describes an increased awareness of one's world, as if the limits to what one heretofore was capable of experiencing were extended to a new frontier. Alex actually used the term to describe how she saw the world differently, which in turn affected her choice of action:

And then there was sort of this higher consciousness stage where I really started to think about life and this life that I had brought into the world. Everything was critiqued and questioned. I couldn't read the newspaper - anything tragic having to do with children just, I fell apart.

This was, for Noelle, one of the most salient aspects of the experience, the belief that her child had died, and the long-lasting repercussions it held for her as the child's mother. On two occasions she had a cardio-respiratory arrest and was completely unresponsive until being successfully resuscitated. She explains that watching her child "die", then come back to life, resulted in a profound bodily experience which forever changed her perspective on life:

You've begun to prepare for her death, and to grieve, and you can feel your blood draining, and then you have to journey back, and I remember thinking, 'I can't take this, my body cannot hold out.' I have gone through something. I have, more than once, thought that I had seen my child dead. And your body just goes through these waves,

these waves of emotion, of knowledge, like where is this coming from? I experienced emotions that I never knew about. I experienced gut-tearing agony, it's very hard to describe.

Noelle has consequently gained an increased and more real awareness of her vulnerability, of being unable to control outcomes, to accept that tragedy may be lying in wait at any time.

Joanna believes that her experience has given her a perspective that she would have had no opportunity otherwise to have had. She feels, "privileged" to see her child in a different way than she might have had he been born and remained healthy.

### **Personal benefit**

This category is an umbrella term for the mothers' sense that somehow they had benefited personally from the experience. It includes the sense of having gained wisdom, acceptance, a higher purpose, and strength from the experience.

For example, Noelle and Joanna both felt that they had acquired wisdom through their experience. They believe that they had gained access to knowledge about themselves and the world which would otherwise have remained beyond their reach. Noelle clarified this comment by emphasizing that all mothers have this knowledge within themselves, but it takes a crisis like the one which she experienced to offer the opportunity of accessing the knowledge. They also both claim to be not as affected by everyday stresses and worries which may previously have affected them much more strongly.

Related to this and frequently mentioned was an increased sense of acceptance of what the future may or may not hold, and acceptance of lost expectations. Noelle realizes that her expectations did not play out as she thought they might, and that part of her challenge has been to

accept what life had offered rather than to forever grieve what might have been. She feels this has changed her in that she is much more realistic in solving problems. For example, she says that:

When people come to me with their problems, they are at the point of being caught up in them and saying, "This is terrible" and I will say, 'OK, nobody died.'

Joanna also feels that having endured one of the most intense crises she can imagine, she has gained an ability to put other problems and lesser crises in perspective.

Noelle articulated what many of the other mothers were perhaps trying to say by relating their lost expectations to who they now are:

I wanted to just slow down and enjoy what life had given me, and I nearly lost it. One day at a time. I believe that, I always will see life that way now. So much of what I thought would happen, hadn't happen and wouldn't happen. It's all about expectations. I remember even growing up thinking everything would always be just fine. And now when people will say, about any problem, 'Things will be just fine,' I say, 'We can only hope so. We can only hope so.'

Jana chose the word "humble" to describe how she has evolved differently due to the neo-natal experience. She believes that the immensity of the event, both its difficulties and gifts, was overwhelming and has left her feeling blessed and at the mercy of greater powers.

Many of the mothers felt surprise at how difficult the neo-natal experience was, as well as at the strength they found in their attempts to cope. Some even commented on their belief that they would be unable to cope if they had to go through the experience again. Many relate how exhausted they were for months, and in some cases, years, after the crisis had resolved. In

general, though, the mothers felt that they had become stronger, "I think that it was a test and was there to learn from. I think that you become stronger because you survive (Justine)."

### Spirituality

Several of the mothers commented on having attained a deeper sense of "spirituality."

This element of Inner Self was most evident in Jana's interview, in which references to God were made frequently. Because she is a committed and practising Christian and married to an Anglican Minister, I took the opportunity during the second interview to ask if the neo-natal experience in any way intensified her belief in Christ, or whether her faith remained unchanged through the experience. She replied by saying that the experience had in fact deepened her faith by giving her the security to know that, "The Christ that I love will stand by me even if things don't work out the way I had hoped they would. At least I have that." Bonnie began going, and continues to go regularly to Church, this transition precipitated in part by the unexpected and frequent visits by her family Church's minister and by noticing an unknown author's scrawl on the wall in the hospital waiting room reading, "I Need a Miracle." This was followed by an awareness of her lack of, and need for faith in her life.

Others referred to their spirituality in a more general way, using the term to describe a sense of the power of fate, or life-after-death existence, an appreciation of the "powers that be" outside of human agency. Noelle found that following her experience of witnessing her child nearly die, she became intensely interested in near-death-experiences, theology and philosophy in an attempt to understand that shift she experienced within herself. She believes that somebody carried her through the experience, and she has a sense of peace in her acceptance of a "larger force." As well, she has come to the realization that that, "God only gives that to those who can

handle." Joanna spoke of her conviction that the "positive energy" which other people sent them was beneficial to their plight.

### Values

Perhaps due to the above described changes to the mothers' perceptions of their inner selves, many of the mothers commented that their values and priorities changed accordingly. Some stated that they became disappointed with the value system held by their social group, even to the point of later rejecting that group. Others felt that members of their social group could not understand their experience, and that this had an isolating effect. Specifically, some said that they became frustrated with the seemingly trivial concerns that others had in comparison to the critical ones with which they were dealing. For example, Noelle recalls noticing the stark contrast between her daily responsibilities and those of the other mothers in her community:

Just looking at my friends at that time, they were all in a very acquisitional stage, the material things were very, very important, and there were complaints that I would hear, like, 'Oh god, it's raining again.' And I'd think, 'Do you not know how lucky you are?'

And I guess that sense of priorities has stayed with me.

The change in values featured strongly in Joanna's account as well. She believes that she now views her role as a mother differently, appreciating everything about her son, particularly the time that she spends with him. She sometimes overhears other mothers complain about issues which seem trivial in comparison to those which she has endured, and at times experiences the urge to stop them and impress upon them their good fortune at having a healthy child.

### **Relational Self**

The Values section, above, points to one of the major changes which the women remarked upon, and that was in their relationships with others. Perhaps because of the shift in their perceptions of their inner selves, and the consequent shift in their values and priorities, the mothers necessarily related to others in a different way. As well, their stories tell of experiences with others which had a profound affect upon them. This will be explored in the following description of the various aspects of the mothers' relational selves.

#### **Relationships with family members .**

Many of the mothers commented on the impact of the experience on their relationships with their family. This was most evident in Noelle's story, in which she told of the impact that the experience of having a critically ill baby had on her relationship with her first-born daughter, her husband, her mother, as well as on others in her life. With respect to the impact on her relationship with her other daughter, Noelle described grief in the sense of abandoning her first child's needs due to the necessity of addressing her sick child's needs. As well, she feels guilt in having to teach her first child that:

Mommy was not always patient, loving, wonderful and calm, because I had this other child who was vomiting her medication and I would have to start all over again, and I didn't always have the choice of calmly explaining to R. what needed to be done.

Regarding her relationship with her husband as well as with others in her life, she felt that the experience and the ways in which she coped with it, framed her, as compared with her husband, as, 'the strong one, the rock.' She feels that this has been one of the costs she has incurred due to the experience, in that:

It is a tough job always being the strong one...what do I do when I'm in need? Who can I go to? I've always been the type of person that people felt they could come to, but this really locked it. It can be very isolating.

The experience also affected her relationship with her mother due her mother's choice not to come to the hospital when Noelle's child was hospitalized. The resultant disappointment which Noelle feels has led her to know, "what not to expect of her in the future" and has in effect lowered her expectations of this relationship.

Joanna and Bonnie also commented on the impact of the experience on their families, specifically on their subsequent pregnancies, by increasing the level of anxiety regarding the health of their unborn babies.

Jana and Bonnie perceive a positive benefit to their relationships with their family, claiming that they are, in a sense, thankful for the difficulty it involved, believing that the events brought their families closer together, rather than sending them apart.

Although two of the participants later became divorced from the fathers of their children, neither claimed that the neonatal experience was a causative factor in the marital strife. In fact, both of the women commented that they appreciated the role the fathers took with respect to their children. Alex articulated this: "...well he was really great and he had a very active role. Actually fathers who have a premature baby can actually take a more active role." However, Justine did say that during the crisis time when she felt the need to be nurtured and supported, her husband distanced himself from her physically and emotionally.

**Relationships with friends .**

Several of the mothers commented on the changes in relationships with friends as a result of their experiences. As mentioned above, Noelle experienced disappointment in the realization that her friends embraced different, less meaningful priorities than she did, resulting in her choice to abandon this social group and, ultimately, move across the country. Bonnie also was disappointed in those friends who did not show support during the difficult weeks when her child was hospitalized. She, too, chose to disconnect from this group of friends, feeling that the relationships had been proven to be superficial. Others, however, such as Jana, felt that their ordeal was a catalyst for friends and family to "circle the wagons," and show their support.

**Relationships with unknown others .**

Several of the mothers commented on significant interactions with unknown others. Noelle recalls approaching an elevator in the hospital where her child was admitted, and the father of a child with leukaemia made an effort to hold the door open for her. She remembers wondering why this total stranger made an effort to be kind, where he had every reason to be bitter and mean. This "act of kindness" by a total stranger, also in distress, deeply touched her, and the memory remains very salient in her memory. She feels that consequently, in her role as a Medical Office Assistant, she is sensitive to others in pain, or who are anxious, and is willing and able to reach out to help the patients that come into her place of work. Joanna also recalls fondly the flood of letters she received in supportive response to her and her family's plight with their critically ill baby. She believes that this has enhanced her faith in humankind. As well as being aware of what she took from others during her difficult time, Jana recognizes the importance of

giving to others who are experiencing similar plights. She realizes that her situation can be used as a resource by others with similar experiences, and can be a blessing to those in need:

Because we are relational beings, people's experience has a lot of weight, so my story may help somebody else, not just the scientific details, but my lived experience.

### **Professional relationships .**

Of the eight women interviewed for this research, six women are currently employed, and of those, four are working in the "helping professions." These four women all commented on the fact that their neo-natal experience has impacted upon their current professional life. As mentioned above, Noelle believes the experience has enabled her to be more sensitive and caring to patients who are anxious. Justine believes that her neo-natal experience has formed her into a much more empathic nurse, as well as a more sensitive medical illustrator. In recalling her own experience with a wonderful nurse, she realizes that she nurses not only the child, but the mother and father too, and that, "The humanness, the authentic caring, the empathy, in a time of utter madness lasts your lifetime." Alex finds passion in her role as health-food distributor in her belief that her daughter's nutritional needs were not met as a premature baby, "I actually think that the work I do now is because i had a premature baby." And, as a minister's wife, Jana feels that she is more compassionate in her ministry with others. As an aside, three other women whom I know, who also had critically ill babies and are employed in the helping professions (two of whom are doctors), also claim that the experience taught them to be more sensitive and more supportive in their interactions with those in need.

## **Mother Self**

The primary initial goal of this research was to explore the impact of having a critically ill baby on one's sense of self as a mother. As remarked upon above, the participants answered this question by implying that more than their sense of self as mother was affected by the birth of their critically ill baby. That is, that in becoming a mother, other significant aspects of their selves were affected. A clear-cut division between their mother selves and other aspects of their selves was seemingly not experienced by most of the participants. In analyzing the data, I became aware of one significant way in which the birth of their critically ill child apparently impacted upon the participants' sense of self as mother, and that was in the way they perceived their child to have been affected, formed, or shaped by the neonatal experience. The mothers also alluded to the way this perception influenced their maternal practices, or the way they acted towards their child. More specifically, the mothers tended to attribute their child's current way of being, for example their social and learning behaviours, and in some cases consequently their relationship with their child, to the events surrounding their birth. The impact upon the mothers' perceptions of their child and resultant maternal practices are the two primary ways in which the experience of having a critically ill child impacted upon their sense of themselves as mothers, and these two will be illustrated in the following section. I have chosen to discuss Perception of Child before Maternal Practices, as the former informs the later; the way one sees another has direct influence on how one acts toward another.

### **Perception of child as being formed by neonatal experience .**

All of the mothers felt that the neo-natal experience impacted upon the way they have perceived and continue to perceive their child. Even Jasmine, who emphasized that the neonatal

experience did not leave her in any way different than she was before, allows that she might have been more "casual" about mothering her son had he been born full-term. The mothers see their child's "personality," "nature," or "behaviour," to have been caused by the neo-natal events which the child experienced. As well, some believe that they see their child in a different light than they might have given more normal, or expected beginnings. For example, some of the mothers view their child as more precious, more special or more vulnerable. Furthermore, some mothers believed that the current state of their relationship with their child was also shaped by the neonatal experience, specifically in that some of the mothers believed that the earliest days of their child's life were such that sufficient opportunities for bonding did not occur. There was much overlap in this category, with many of the mothers mentioning common aspects to their perception of their child.

The most common perception among the mothers of their children was that they were seen as more precious, due to their early beginnings. The mothers referred to this by stating that they do not take their child for granted, or they are more appreciative of their child, that they want to make the most of the time they now have with their child. Joanna and Jana both referred to the neo-natal experience as a gift which has allowed them to see their children differently. Joanna says that, "In many ways I feel almost fortunate that we have been given this perspective so we really appreciate Jack and appreciate every minute with him." When Noelle and I discussed this category during the second interview, she made the point that *all* mothers see their child as precious. She pointed out that no one group of mothers has propriety over the perception of their child as any more or less precious than another group of mothers might. The difference between

mothers of healthy babies, and mothers of sick babies, she said, is that the latter group have had the opportunity to experience the preciousness of their child due to the threat which they faced.

Other mothers feel that their child is special in some way, that he has qualities which mark him as unique. For example, Joanna remarks on not only her family's, but others' recognition of her son's special presence. Joanna sees her son as having a special way with people, as being extremely social and happy and trusting, despite all of the pain and discomfort that's been inflicted upon him. She claims that it is hard to put into words exactly what it is about Jack that makes him special, and says only that, "He has been there. He knows."

Related to this perhaps is the perception of the child as being more vulnerable than children who have not had their neo-natal experience. Five of the mothers referred to this perception by describing their child as less hardy, more needy, more fragile, susceptible to being hurt, susceptible to getting more illnesses, as having, "something finer that could be broken" (Alex). Justine, for example, believes that her son gets more URTI's (upper respiratory tract infections) and that, "his feet are cold because of that first week in the box when he practically froze."

Alex sees her daughter's state of health as being related to her prematurity, "I think that I really am analytical of what is the cause of any particular malady that she has and think, 'Oh, she didn't get that final iron burst that comes through the placenta that is so important'." She also believes that her child cannot handle the kind of stimulation and exposure that other children can. Jana believes that certain aspects of each of her twins' personality stems from their beginning; for one, it's his temper, and for the other, his whining. In the case of the former boy, she believes he has reason to be angry, as his beginnings were so difficult. The latter boy, she believes, tends to

whine due to his insecurity which itself is rooted in his neo-natal experience, when he should have been with his mother, "instead of on a schedule, instead of on machines." She has read research which has indicated to her that much of an individual's disposition is genetic, and wonders whether, because the boys weren't "fully cooked," their early environment had a greater influence on them than their genetic disposition did. As well, Jana believes some of their current school-related struggles are related to difficulty with fine motor skills, these being affected by their neo-natal challenges. Bonnie feels that her daughter's intense sensitivity to her emotional and physical environment, her neediness and wariness is related to her neo-natal experience, "I think it comes from the way she was born. She could have been totally different if she had been born happy. I remember her looking around and thinking, is this life?"

Jean says she has no doubt that the neonatal experience has impacted upon her son's personality, which she describes as sensitive, strong-willed and demanding. She believes that if he had been born full term, he would have been a difficult child. She also asks herself whether the neo-natal experience prevented her from adequately bonding with her child, and questions whether this may have affected him as well as their current relationship with each other. Noelle sees her daughter as being empathic and caring, these qualities perhaps arising from her early experience with pain and discomfort. She also believes that her daughter faces more difficulties in life and wonders if the experience, although her daughter is functioning within developmental norms, has left her in a deficit position with respect to some interpersonal and academic challenges. Justine claims to constantly feel anxiety about the consequences of his neo-natal experience:

I live in fear that Q. developmentally is going to be permanently damaged by that time, whether it's an attachment issue or ADHD. He is not aggressive, he's a gentle boy and I wonder if it's because, when he first came out of me he got hurt...I really know what it is - I think that we build a relationship with our child when he is growing inside of us, and they must have some sense of where they are going to be going as they're being born. Birthing is meant to be a beautiful thing. So when it's traumatic, I would think it would be hell, really.

**Maternal practices .**

It would follow that one's perceptions would affect one's actions, and this seems to be so for the participants. The ways in which the mothers see their children affect the way they treat their children. There were areas in which there was a high degree of consistency in maternal practices with the children.

For example, likely following from their perception of their child as vulnerable, many of the mothers felt themselves to be more protective of their child than they likely would have been having not experienced their neo-natal situations. These mothers felt that they worried a great deal about such calamities as accidents, illnesses, and abduction. Noelle feels that she is compelled to become involved in all aspects of both of her children's life now, as she, "knows that bad things do happen to good people." However, she recognizes that to solve all of her daughter's problems for her would be in fact a disservice to the child, and thus makes an effort to stop herself from doing everything for her:

I am tempted to say, 'You know what, let me do it for you,' and I have to say to myself, 'So what if she can't do something, that's OK.'

Similarly, Justine believes herself to be extremely protective of her child, due to, "this ominous feeling of impending doom revisited, that anything can happen to your child, as it did in the first days of your baby's life." Justine also points at that in an, "odd contrast" to, but perhaps to balance her hypervigilance, she also finds herself to be oddly aloof at times with her child.

Jasmine, who feels that having a critically ill child did not really change her as a mother, or as a person, reflects upon the fact that she did not leave her child with a babysitter for months longer than she expected, summarizing that perhaps she does feel more protective of him. Bonnie tends to protect her daughter from stressful situations due to her perception of her child as extremely sensitive and unable to handle overstimulation.

As noted above, many of the mothers perceive their child as being more precious due to the neo-natal experience, and these mothers report the following maternal practices which may be related to this perception. Joanna, for instance, is not the only mother who feels guilty when she is "cranky" with her son, "because she is just lucky to have him." She also says that she finds it hard to say "no" to him, tending to look at, "the big scheme of things" in which she questions the necessity of drawing the line too firmly. As well, she is hesitant about letting him cry himself to sleep as is Justine, who refuses to allow her son to cry himself to sleep, instead bringing him to her bed or joining him in his bed each night. Noelle makes every effort to be involved in all aspects of her child's life, not wanting to miss any opportunity to, "be there for her." Jana is constantly grateful for her twin's lives and tries consistently to, "give them the benefit of the doubt" when their behaviour falls short of expectations.

Related to this, perhaps, is the comment that many mothers made regarding their views on being an advocate for their child. Six of the mothers remembered feeling paralyzed, when their

child was in the NICU, from speaking out against the medical establishment. This is more fully described in the "Powerlessness" section, above. Drawing from this, the same mothers commented that, given a current situation when their child might be hospitalized and undergoing invasive procedures, they could see themselves as being much more assertive if necessary in their role as the child's advocate.

As well, because the mothers tended to attribute current behavioural patterns to their neo-natal experience, they also tended to tailor their maternal practices to that attribution. Alex, for example, because she views her daughter's health as being compromised due to her earliest days, tends to be "fixated" on her health and her diet, and leans toward alternative medicine for any illnesses her daughter may have. Jana, due to her suspicion that her boys' difficulties stem from their prematurity, strives to give them the benefit of the doubt that they are not deliberately trying to misbehave. She tries first to understand, rather than to react to any provocative behaviour, and to reassure them in a loving manner:

I'm consciously trying to think of the fear (they must have felt as newborns, and still do feel) and say, 'You are loved,' and to give them lots of attention. We are trying to take each of them out on a date, saying, 'What do you want to do for the next hour.'

#### **A Note About Definitions**

It may be recalled that a definition of sense of self as mother as suggested earlier in this paper included cognitive, affective, metaphysical, relational and physical aspects of the self as they pertain to the preservation of their children. That is, the way a mother thinks about, feels about, relates to others regarding, sees the metaphysical world regarding, and experiences her body as it relates to her child and the preservation of her child. In speaking of the way the neonatal

experience affected how the mothers perceive and treat their child, I heard elements of all of the above. More aptly put, I heard evidence of how their child directly impacted upon their cognitive processes (the values they formed, the judgments they made regarding their role as mother), their affective processes (the way they reacted emotionally to their children), the relationships they formed and the way those relationships were managed to further the care of their children, their "spiritual" belief system and the way they experienced their body.

### **Discussion of Change**

The recruitment letter for participants specified that mothers who felt they had changed as a result of their experience with a critically ill newborn would be ideal for this study. Of the eight women who responded, all but one felt that the experience had changed them. The remaining one, referred to me by a friend and perhaps feeling a degree of obligation in her agreement to participate, stressed throughout the interview that she did not believe that the experience had left her as a different person than she was prior to the birth of her critically ill baby. As noted above, she believes that people change while they are in crisis mode, and then go back to being essentially the person they were before the experience took place.

Of those who felt changed by having a critically ill child at birth experience, there was some variance in the way they experienced the change. Jean, for example, was unique in the way she experienced change. She and I talked about this during our second interview, and the following results were what were mentioned in common at both interviews, unless otherwise stated. Jean does believe that she has changed, and refers to herself now as, "The new me." She believes that the experience with her son's prematurity was beneficial for her in terms of encouraging her to revisit her values and priorities in terms of raising children. She also states

that she sees her child as more fragile and emotionally needy than her subsequent child. Her recounting of the labour and delivery of her premature baby features fear, panic, a sense of powerlessness. In these ways her story is similar to that of the other mothers. Her story, however, did not feature the type of perceived beneficial changes to the inner self that was remarked upon by the others. In the second interview, she said that she sees her values and priorities as being affected by parenthood in general; that it has been a life-enriching, humbling experience wherein she has gained appreciation of what others have had to struggle with. She believes that had she had a full-term baby, she would have taken for granted the health of her children and the ease with which she would have experienced breast-feeding, for example. Jean says that the preterm birth of her sons has lent her an appreciation for life, and has opened up a world, the world of a premie, which she otherwise would not have experienced. In these ways she has changed. She emphasized, however, that she has not experienced any spiritual or personal growth as a result of her neonatal experience. And although she feels that she has changed, she claims that, "the new me does not include being with the children." Jean's new self instead has pursued athletic goals, and her creative side through an interest in crafts, both areas being ones in which she earlier had no involvement. She says she pursues these new areas of interest as a source of personal growth and satisfaction, and another place for her ambition. As both interviews, Jean expressed some disappointment, or perhaps shame, when she made these comments, and also stated that she had thought, before she had children, that she would have been different as a mother. In fact, among all the participants, Jean was most able to articulate her expectations of motherhood before having children:

Um, maybe I had this fantasy that I would have a girl and two boys. I would have a normal delivery, instead he was an extra 8 weeks early. I felt that I would have wanted more than I did because I don't think I really bonded with my child or my children. ...I thought that I would be more mature than I am. I guess I thought I would be a better mother than I am basically. As a mother I would care more, I would be more concerned, I just thought I would be more mature ...And maybe that's stereotyping, that's partly what I heard, what I thought it would be like.

Bonnie appraised the way in which she has changed by looking back on who she was three and a half years ago before her eldest daughter was born, and realizing that she is now a completely new person. She believes that much maturing and growth has taken place in her life and necessarily herself as a result of being a mother, and the experience of having a child so ill at birth definitely has created long-lasting changes in who she is, but she finds it difficult to separate out what is a function of the experience with her daughter, and what is simply a function of travelling through life. Bonnie does believe that, "through challenge comes development," so accepts that she is different than who she might have been had her daughter been a healthy baby, but questions the validity of pointing to which parts of herself have specifically changed. The one way in which she is certain that things are different than how they might have been is in her perception of her child as being different had she been born healthy, and recognizes that she thus responds to her differently.

The other five mothers fully accept that long-lasting and definite changes have arisen from their experience in being a mother to a critically ill child. Three of these five spontaneously created their own words to represent their evolution, and these are, "resurrection" (Alex),

"rebirth" (Justine), and "rebuilt" (Noelle). These words all signify a sense of starting over, of renewal, and carry with them positive connotations.

### Follow-Up Interviews

In keeping with the chosen methodology, follow-up interviews were conducted with six of the eight participants. Two of the participants were unavailable for contact. Although I had suggested to the participants that this interview would likely only take half an hour, each follow-up interview lasted from one to one and a half hours. The format I followed was as follows: I began by explaining that the findings represented an amalgamation of all eight interviews, that the participants were encouraged to freely comment on which aspects of the findings fit or did not fit with their own experience. I then showed them a written outline of the themes and categories, and went through it, commenting on the themes which I recalled as having pertained to them. Throughout and following this, all participants did freely comment, and rich discussion would follow. Enhanced and more rich description of the themes and categories were offered, and notes were taken, and verbatim quotes were recorded. Overwhelmingly, the responses by the participants indicated that they felt they had managed to accurately articulate and communicate their experience during the initial interview. Comments which indicated that the findings were generally accurate included, "You seem to have really got what I was trying to say," "I feel like you really heard me," "All of that rings true for me, even the ones which I didn't specifically talk about." A few of the mothers commented that they would like to have had the opportunity to meet the other mothers in a group setting. Perhaps that would have been a rich forum in which to conduct the follow-up interviews. At the end of the discussion, I asked three specific questions of the participants, the rationale of which will follow. These were: 1. Are there

any ways in which you currently feel a cost or a loss from having gone through your experience?

2. How might you appear, to the outside world, to have changed? 3. Did the interview have any later impact on you which you would like to discuss?

### **Costs-Benefits**

As the findings show, much of the changes to the self which were mentioned had positive overtones and were seen by the participants to be largely beneficial in effect. In general, the mothers reported several aspects of inner growth and of confirmed and improved interpersonal relations. This reflects many aspects of my own personal experience of having had a critically ill child - that I feel I learned a great deal about myself as a person in general, and as a mother in particular, and that what I learned has served me well in my experience as a parent. Thus, in order to avoid my own biases from clouding my perception and thus my interpretation of the participants' experience, and in order to circumnavigate the cultural pressure upon the women to only report the beneficial aspects of their experience, it was decided that I ask the participants at the second interview a clarifying question. This was, "Are there any ways in which you currently feel a cost or a loss from having gone through your experience?"

After some deliberation, Bonnie listed three costs to her experience of having had a critically ill baby. The first had to do directly with her mother self, as she claimed that one of the costs which she is most aware of is her decision to have no further children. She said that if Abby had been her second child, and they had wanted three, she never would have tried for the third. It was her "pregnant mother" self, she claimed, that was the most damaged by the experience. The second one also related to her mothering self, and that is the painful memory of her daughter going through her first and second of a series of ten annual X-rays which she will have to undergo

as part of her follow-up program. She recalls those X-ray episodes as extremely difficult to witness, and feels pained that her daughter had to endure such a frightening experience. The third cost mentioned by Bonnie related directly to a cost which she perceives A. as having to deal with, and that is the large and evident scar which traverses her torso. She worries about her daughter's future feelings about this scar, and about any negative body image which she may develop.

Justine believes that the cost involved with her and her child having had their particular neo-natal experience is in her child's current fears and insecurities. She worries that these may continue to affect him in his future. As well, she feels that she is nagged by unfinished business regarding her treatment by the medical system. Although I did not get the chance to directly ask Jana these questions, I believe her interview revealed that any perceived costs which she would consider as having arisen from the experience would be directly related to the current and future consequences which her boys may need to suffer. For instance, one shows a great temper, one shows a whining attitude, there is a possibility that they may suffer from learning disorders, and Jana does question whether these conditions are rooted in their too early beginnings.

Joanna believes that the remaining concern about her son's long term health status is of course a constant worry and source of stress. But in terms of loss to her self, she says that she feels older, "not so much outside, but inside." When I spotted in her home a wedding picture of her and her husband, I questioned whether she feels any resemblance to the woman in the picture, taken four years ago. She replied that she now feels a loss of youthfulness, a loss of innocence, a realization that bad things can happen. Another element of loss which Joanna experienced, earlier described in this paper, is the loss of "the normal mom experience" of having a new baby which she was never able to enjoy with her son.

Noelle feels that she has lost an expectation, never even a reality, of a close, nurturing relationship with her mother. As well, she feels that she has been "put on a pedestal" and effectively isolated by others due to her coping abilities during her daughter's illness. What she sees as her biggest "sacrifice," however, like Joanna, is the loss of innocent time with her daughter as a baby. She explains that she enjoyed the baby and early childhood of her first daughter so intensely, and was never able to experience the same with her second child due to the long-term nature of her illness.

Jean feels that a cost might reside in any developmental or behavioural disadvantages which her son may experience. She was quick to point out, however, that she does not "harp" on this possibility, but does keep it at the back of her mind.

#### **Differences in the Public Self**

Another question which was asked at the second interview was, How might you appear, to the outside world, to have changed? It was decided that this question be asked in order to operationalize, and provide another perspective, of what change to the self means to the individual. The evolution of the "private me" was communicated in the initial interviews, so this question presented the opportunity to access the participants' notion of how their "public me" might have evolved. Noelle answered that, in short, it was, "a maturing experience." She claims that she is more responsible and committed to everything that she does in her life, professionally and personally. She attributes this to the realization that her actions impact upon a large network of people, most specifically, her children. Jana believes that how she is as a mother to her children is probably the aspect of the change in self which is the most evident from an external point of view. She believes that she is better willing and able to accept the variations which each child

demonstrates, and, due to her awareness of the fragility of life, to treat those differences with compassion and acceptance. Additionally, she sees herself as being more willing to "pitch in" and share her knowledge of challenging neonatal experiences as a resource to the community.

Joanna believes that the aspect of herself which is public that may appear to be different than who she might have been is in her willingness and tendency to, "hold Jack just that much longer." She claims that it is mostly in the way she interact with her son which feels the most significant for her in terms of behavioural change. Another way in which she feels she acts differently is in the sheer volume of photo processing she has done at the local photography lab, where they all know her name, her son's name, and the number of copies of each print she will request!

### **Impact of Participation**

One of the participants, Justine, took the initiative following the first interview to call me and discuss how the experience of having taking part in our interview had impacted upon her. This caused me to reflect on the concept of change, and to realize how an interview, indeed any contact between two people, necessarily results in change for both participants of the exchange. And, as this research seeks to study the concept of change to the self, it was decided that a further question about change would be fitting. As the second section of this chapter is titled "Now' A Point in the Evolution", a sub-heading for this present section might be, "Now' A Further Point in the Evolution."

To return to Justine, who initially alerted me to the changes that she witnessed as a result of taking part in the interviews, I will provide an brief overview of her, admittedly dramatic, evolution. As her first career experimentation and pursuit, Justine enrolled at an art college to

study medical illustration. Following this, and motivated by concerns about financial security, she began training as a nurse, and thereafter worked as a nurse in hospital settings. She is currently employed as an adolescent psychiatric nurse. Although she finds much satisfaction and reward in her job, she has never lost her passion for drawing, but has felt constrained by the very real financial demands on her life as a single mother. Following the interview, which did meander around her desire to draw, and which included her presentation to me of a published collection of poetry and drawings of the critically ill newborn, Justine felt like, "a door had opened" and she took the first step in incorporating her love of drawing into her professional life. To date, two months following the interview, she has found the courage and conviction to approach the NICU at the hospital in which she is employed to ask whether she could have permission to draw the newborns there. Consequently, she has been offered the paid opportunity to illustrate a handbook for parents of babies admitted to the NICU, and to sketch any babies whose parents request her to do so. For Justine, this is achievement of a higher calling, and is bringing her invaluable gratification and satisfaction.

Although less profound and dramatic, other participants also commented on the continued impact of having discussed their experience in the initial interview. Alex reflected in the second interview on her awareness of being "out of body" during the first interview as she was describing her experience. She told me that following the first interview, she felt inundated by memories of the neo-natal experience, "Well, really going back, it really opened up the floodgates. You lock all that emotion away; it never really goes away. The experience, even though time goes by, the experience is still within you." Bonnie claims to have suddenly begun dreaming about her daughter's hospital experience. She believes that she continues to block some of her feelings

about the experience, and by discussing it in such depth and detail as the interview allowed for, the emotions have resurfaced to be encountered in her dreams. Noelle, following the initial interview, began to discuss with her daughter her difficult beginnings, and was moved when her daughter expressed concern for her mother, "that must have been so hard, Mommy." She would also go in to her daughter's bedroom at night and stroke her hair, while revisiting the memories of her experience when her daughter was hospitalized. Jana stated that she believes she is, "still on a journey," and frequently considers how the experience will affect her boys' future relationships and separations from loved ones. Joanna believes that because the event is still so recent, that she and her family are still "in it." Thus, she implies that our interview represented a common occurrence in her life which consists almost totally of thoughts, feelings and actions which centre on her son. She did recall discussing with her husband some of the content of our interview, and going back to some of the details around their experience with their child which they had not visited in a while. She states that although painful, this is something she is willing to do, as she never wishes to, "put it away."

#### **Impact of participation on interviewer.**

The interviews impacted upon me, as interviewer, in many valuable ways, in my roles as researcher, as counsellor, and as mother. With each participant whom I interviewed, I was aware, at some or many points in the interview, of a feeling of empathic resonance. In listening to the mothers tell their story, and despite all attempts not to do so, I identified with the participants. Similarly, I became aware of a striking degree of similarity between the mothers in their accounts of having a critically ill child. However, I was also struck by the different inner experiences of each of the mothers. I was profoundly affected and educated by the intensity with which these

women *felt* in recalling their experience and by the awareness they displayed in the way they *conceived* of their experience. My perspective of the experience of having a critically ill baby was widened to include that of eight other women, as well as by the realization that myriad other perspectives exist. This is a valuable realization.

Also valuable is the perspective I gained from the two participants whose stories did not neatly fit into the pattern I expected and which was, in varying forms, presented by the other six participants. These two participants were instructional and informative simply because their experiences were substantially different than the others with respect to the constructs being examined in this study: one was different in that she believes to have been unchanged by the event in any way prescribed, the other was different in that she feels her Inner Self (as here defined) to be unchanged by the event. Because these two accounts diverged from the other participants' accounts as well as from my own, I struggled with how to conceptualize and represent their differences. I had to make a shift in the way I had conceptualized the topic of study. As is true for so much that is "different," depth of learning was offered by these two "outliers." For instance, they strengthened the realization that different perspectives exist outside of the more commonly held ones; that mothering a child impacts upon each of us in different ways, that we make meaning of our crises in different ways, and that we experience ourselves in different ways.

The lessons which I learned through my empathic connection with these mothers have also impacted upon my own mother self. For instance, during the evening following an interview, I would realize how the perspective that one of the mothers had with regard to her child would find its way into my own consciousness, and affect the way I perceived my own child. The effect might last only a few moments, but in some cases, the perspective might "fit" with my own experience

and would be incorporated into my own perceptions, particularly the way in which I recalled the neonatal events.

### Summary

The data which arose from the interviews conducted for this study yielded patterns common to all participants, as well as highlighted unique elements to individual participants. Both the commonalities and the unique elements will be summarized here.

Common to all interviews was their format, that of being divided into two sections, a description of the neonatal experience and a description of perceived changes to self. Paralleling this bisection was a qualitative difference in the way the two "stories" were told, with the first being told in an emotional, fluent way, and the second being told in a reflective, analytical way. Valuable information also arose from the set of second interviews which were held with all but one of the participants. and a summary of this will also be provided here.

Within the first section, all participants reported on the neonatal experience as having a crisis-like character. As well, the women's memories of this time were vivid and intense, imbued with much significance, and for many, remained emotionally evocative. The general pattern of experience was of shock, then chaos, and finally attempts to cope. Shock was experienced by most participants, and was recalled initially as feeling like their, "world had crashed," upon learning of the condition of their baby. This was not true for the two participants who had prenatal forewarning of their baby's condition. Struggle was a stage imbued with much emotion, for example the fear, grief, guilt and anger which were reported by the participants as they grappled with the loss of their formerly held expectations and ideas of what is "normal." Guilt was an emotion which featured strongly in all but two of the participants accounts. The two who

did not report guilt, did report feeling anger at this time, one towards her child, one towards other women who did not care for themselves prenatally, such as in the case of women with substance abuse. A sense of powerlessness, in the face of the system and with respect to the fate of their child, was probably the most common aspect to the experience, being mentioned by all eight of the women.

The participants spoke to various aspects of their environment which either helped or hindered them in their coping abilities at this time. All but one of the mothers commented on the powerful impact that members of the nursing and medical staff had on their attempts to cope. Most of the mothers remembered some of the staff as being supportive, and some as behaving in ways that were perceived as obstructive to their coping attempts, particularly when the mothers felt their intuition or judgment was being questioned. In general, it was the personal, "human touches" which hospital staff communicated to the mothers which had the most helpful effects. As well, information giving was seen as extremely valuable, and many claimed that they did not get enough of this information regarding their child's condition. The other aspect of their environment which affected the mothers' attempts at coping was their network of family and friends, with some mothers claiming that the support showed by their social group brought them closer together, while others claimed to have been acutely aware of and thus isolated from those who did not actively show their support. One of the mothers attributes her current sense of being "alone," to this time, during which her successful coping strategies effectively isolated her as the one, "who can do it on her own." Participants were also able to reflect on their own inner resources which contributed to their coping abilities. One of the participants was unique in her coping strategies in that she put all faith in and drew profound strength from her Christian

spirituality. The act of breastfeeding their baby emerged as a very powerful factor in their state of mind at the time of their baby's illness. All but two of the participants mentioned breastfeeding to be very important to them, and any threats to their ability to breastfeed were perceived as immense challenges.

Within the second section of the interviews, that in which the participants attended to the issue of self change, many commonalities emerged among the participants. Although common themes were evident among the stories of the participants, several experiences which were unique to individual participants were also described. In common was the general arrangement of categories into three major themes, these being changes to the Inner Self, to the Relational Self and to the Mother Self. Not all participants reported changes to these aspects of their selves, however. One of the participants emphasized that although the event represented a "crisis," she feels that she did not endure any long-lasting changes because of it. Another of the participants believes that her child, and thus her treatment of him, was impacted in a far-reaching way by the neonatal events, however she denies that neither her "inner" nor "relational" selves, as described here, were impacted upon specifically by the birth experience. The other six mothers believe that the experience resulted in enduring changes to their sense of their self.

The Inner Self theme refers to such aspects as higher consciousness, wisdom, acceptance, strength, spirituality and values, all generally connoting positive growth and personal benefit. In this theme, many mothers communicated the idea of their child's neonatal experience as a gift, in that they would not have gained access to increased awareness had all have gone "normally." This increased awareness helped them to reorder their priorities, redefine their values, and discover their own sources of personal strength and endurance. Spirituality was also seen by

several of the mothers as being an aspect of their selves which was developed due to their experience, some experiencing increased commitment to orthodox religious practices, and others experiencing enhanced metaphysical awareness.

Relationships with others were commented on frequently as being impacted upon by the events surround the child's birth and hospitalization. The restructuring of relationships likely reflects the shift in priorities and values to which most of the participants referred. Changes in relationships with others included those with family, spouses, other children, friends and even strangers. In many cases, the participants spoke of enhanced intimacy with friends and family. Many others spoke of the long-lasting harm to such relationships in which breaches in trust and expectations resulted. Several of the mothers commented on how their experience resulted in a positive influence on their professional lives, for example enhancing compassion for those in the "helping" industry.

Finally, all but one of the mothers stated that the neonatal experience influenced the way they perceive and treat their child. These mothers attribute current aspects of their child's functioning to the neonatal events. There was some variation in the mothers' specific accounts of how they perceived their child, and how they reacted accordingly. For example, one mother believes that certain challenging aspects of her son's personality, for example his "temper," derive from the opportunity that was lost for normal gestational development due to his premature arrival. Another mother believes that her child is wary and sensitive due to her earliest days during which the child is perceived to have experienced a sensation of questioning and uncertainty. Yet another believes that her child falls ill often due to the substandard nutrition available to prematurely born babies. Given that the mothers perceived aspects of their child's

nature or behaviour to have originated in the neonatal event, this event figured largely in their responses to their children. That is, when considering appropriate maternal practices for their children, the neonatal experience evidently featured significantly in the decision making process for these mothers. For instance, some of the mothers claim to be more "indulgent," or more "protective," or have "lower expectations," of their child than they expected. One of the mothers has higher expectations of her child, and tends to be more demanding on him than she expects she would have been had he been healthy at birth. A descriptive example of this relationship between neonatal experience and later maternal practices is the mother who pauses in the moments immediately following her son's outbursts, to remember his beginnings, make allowances for those, and select an appropriate response. Another would be the mother who chose not to let her child "cry it out at night," remembering how much he had to cry about in his first days of life, and not wishing for him to experience any more distress than is necessary.

The follow-up interviews proved to be very fertile in terms of adding more data to that which had been previously collected. I was able to return to six of the eight participants. The participants responded to the themes and categories which had been developed up to that time, generally agreeing with the conglomerate of findings, and adding more detail to those which applied to them individually. I chose this second set of interviews to add three clarifying questions intended to add validity to the question of change. These were, 1) Was there a cost incurred from the experience?; 2) How might you appear to the outside world to have changed?; 3) Did the interview have any impact upon you?

The participants who were asked this question (five of the eight) did comment on what they perceived to have lost as a result of the neonatal experience. These ranged from loss of an

enjoyable pregnant experience and enjoyable "new baby" experience to loss of certainty around the child's future physical or psychological health. These elements of loss are related to the women's mother selves. Noelle did comment on a loss to her relational self, in that she feels a permanent loss around a hoped-for relationship with her own mother and that the neonatal experience left her in a socially isolated situation. She emphasized that the real sacrifice, however, lies in the loss of her daughter's early years. When asked about any the visible differences in their selves, the mothers reported that these would likely be in their interaction with their children, that is in their mother selves. Regarding the question of ongoing change, the mothers all, to varying degrees, commented that the first set of interviews did impact upon them, in one case motivating one of the participants to commit to a new career direction.

Finally, I believe to have been impacted upon by the interviews held with each of the women. In various ways, I believe that the empathic resonance which I experience with all of the mothers at one or many points in the telling of the stories, led me to expand or shift my perspective on the concept of how the experience of having a critically ill child might impact upon a woman's sense of her self as mother.

## CHAPTER FIVE

### Discussion

The purpose of this study was to explore how a woman's sense of herself as mother might be impacted upon by having a critically ill baby. The findings which represent the stories of the women who took part in this study indicated that the event of having a critically ill baby presented a threat to their perceived sense of self, and seven of the eight women felt that the experience resulted in lasting changes to aspects of their sense of self, including that of their self as mother.

As was discussed in the Findings section, it became evident during analysis of the data that two separate conceptual streams were developing, one being the women's experience around the birth and hospitalization of their baby, and the other being the resultant impact on their sense of self. This chapter will first consider the implications of the findings as they relate to the clinical research literature on women's experience with critically ill babies, following which will be considered implications for the theoretical literature on changes to the sense of self. As well, the implications of the findings as they relate to future research directions and clinical practice will be addressed. Finally, some of the limitations of the research findings will be considered.

### Implications of Research Findings

#### Implications for Clinical Research Literature

As stated earlier, there exists a large body of research which addresses the experience of parents who have had critically ill babies. As mentioned in the Rationale section, above, this literature suffers from the following shortcomings: the limited work with parents of children over one year; the majority of the work does not reflect solely the maternal experience, but often includes in the same construct the paternal experience; and there is a shortage of literature utilizing

methodology which allows the participant to choose to tell the aspects of what she feels is significant in her lived experience.

These limitations were addressed by including, in the criteria for participation, mothers of children two to six years of age, and by the use of a qualitative methodology, Interpretative Description (Thorne et al., 1997), which allowed for the participants to speak of only that which was significant to them in their experience of having critically ill babies, independent of any guidance on the part of the researcher. The following will discuss what arose from these attempts to fill the gaps in the literature.

Because this research reflects work about the change process, I was interested in hearing the stories of women whose children were no longer critically ill and hospitalized and thus had had the benefit of time to allow for reflection on how the experience might have had a transformative effect. For this reason, I chose to speak to women whose experience lay two to six years back in their history. Wereszczak et al. (1997) studied how mothers of prematurely born three-year-old children retrospectively recalled their responses to their infant's hospitalization in the NICU, finding that the mothers reported vivid memories of the stress related to the appearance and behaviour of their infants, the pain and procedures the infants endured, alterations in their role as parents, and stress related to the infant's illness severity and uncertainty about infant outcomes. The authors state that it is not known whether these stressful aspects of the NICU remain salient for parents over longer periods of time.

What I found to be significant in the stories the women told me of the neo-natal experience, is how very salient and emotional their experience remained, in some cases, up to six years following the birth of their baby. The details of their experience were available and were

articulated seemingly with ease. Interestingly, Noelle, whose child is now six, told me that, "this interview would have been much different if you had spoken to me when my baby was 6 months old or so." When I asked her to expand on her comment, she told me that she guesses that the story would not have been so easy to tell, that she would not have been able to articulate her thoughts and feelings in such an organized, lucid way, had she still been "in" her feelings of fear, powerlessness and grief. Perhaps the difficulty which Joanna had in speaking of her fears for her son reflect this process which Noelle spoke of, for not only was Joanna's son the youngest in this study, but she still is grappling, on behalf of her son, with some very real health concerns.

Beyond the finding that indicates that the stressful aspects of the NICU indeed do remain salient for parents over longer periods of time, the findings from Wereszczak et al. (1997) in particular as well as those from the other research studies reviewed, parallel the findings from this section of my research in many ways. This replication of findings is significant in showing that not only do mother's memories remain salient, but the content of the memories seems to be similar to that of mothers telling their story more recently after their experience. Perhaps when we tell a story of immense personal significance, the details of that story do not fade away, but remain clearly visible to us in our recollection. I suspect that these stories had been told and retold, thus engraving them with more clarity on the story teller's page.

An overview of the research reviewed here produced the following list of constructs which were assumed to characterize the mothers' emotional experience when her baby was in the NICU; guilt, sadness for the baby, fear for the baby, shock, grief, anger, anxiety, inability to speak of the events, insomnia, anorexia, concern about baby's health upon discharge, change in maternal role, concern about quality of attachment to baby, child's appearance, NICU environment, staff

behaviours, disturbance in family support and inability to breast feed. All of these were mentioned by the participants in my study except for insomnia, anorexia and hopelessness. As these are symptoms of the stress associated with having a sick baby in the NICU, they likely dissipated with the stress as the baby gained health, and thus were not recounted by the participants in the current study. Of the constructs listed above, guilt, fear, grief, staff behaviours and altered roles were mentioned the most frequently in the research as being elements of the stress response of parents of critically ill babies. In the present study, these also figured prominently across the participants' stories as being significant aspects of the experience. Two constructs mentioned by the participants in my study which were not mentioned in the research were those of surreal and numb. This may be so simply due to different conceptualizations by the authors of these constructs. Or, perhaps they are elements of the experience which were not easily articulated until a period of time had lapsed.

Affleck and Tennen (1991) found in their research that, in addition to the extent of stress emotions experienced while their babies were hospitalized on the NICU, mothers also reported positive feelings about their child. The sections of the interviews in this study which focused specifically on the neonatal experience showed no specific mention of these feelings for the baby. I did hear reference to the mother's intense commitment to her children, and during the discussion on change to sense of self, several mothers spoke of the preciousness of their child, but no remarks were made such as those Affleck et al. (1990) report, for example, love and amazement. No other researchers commented on this finding, either. This surprised me, as I anticipated I would hear such accounts, although I do not doubt that the mothers did experience feelings of love for their child. Perhaps they did not mention these more positive emotions in this and other studies because

they were immersed to such a degree in the telling of their story and in the associated fear, guilt and grief, that they were unable to switch to the 'lighter' feelings of love, as described by Affleck et al. (1990).

Also noted in the research, both past and present, and which I find to be significant, is the finding that even mothers of premature babies who were considered well, that is babies who required hospitalization due to their developmental status, but who did not suffer from any disease per se, suffered severe emotional stress while their baby was hospitalized. This finding was evident in Pederson et al.'s (1987) research, as well as in mine, as three of the mothers had babies who, although they could not survive without sophisticated medical assistance until they had more time to develop, showed no signs of disease and had good prognoses.

It is also significant that the bulk of the research reviewed came out of methodologies which utilized mostly questionnaires and semi-structured interviews, in comparison to this study which used the following question to gather data for the neo-natal segment of the research, "tell me about the birth of your baby." As earlier discussed, this question was intended primarily to bring the participants into a state of mind in which they would be able to discuss the changes to their sense of self as mother, thus explaining the simplicity of the question. However, despite the completely open structure of the interview, the message which the participants felt they wanted or needed to send regarding their experience as mothers of clinically ill babies closely paralleled much of what the mothers reported in other research.

## **Implications for Theory on Self**

### **Neo-natal experience: "Then".**

A review of the literature indicated that the birth of a critically ill baby does constitute a crisis for the mothers (Romney, 1984). The following will discuss how the participants in this study reacted to this experience as it relates to the theory on changes to self.

The four women who spoke of their pre-natal expectations of being a mother indicated that they were looking forward to the event with positive anticipation. They expected the arrival of the baby, and the time beyond that as well, to be a time of happiness and fulfilment for them as mothers. The anticipated birth of a baby represents for many mothers, consciously and unconsciously, the anticipation of hopes and dreams. So, when the baby is born sick and cannot be discharged from the hospital in the expected blue or pink bundle, and instead the mother has to go home alone, the previously cherished expectations are dashed. For Joanna, who claims she is a "worrier" and had considered the possibility of having a baby "with something wrong," she had to face her worst fears and fantasies when her child was diagnosed with severe heart disease.

One of the common elements to the women's experience during this time was that of a feeling of numbness, or of the world having a surreal quality to it. This sensation may have had for the women in this study an adaptive function, helping them to 'shut down' all other cognitive processes other than those required to gathering the energy to do what needed to be done. Post-natally, a woman experiences intense physical exhaustion and rapid fluctuations in hormones, resulting in profound physical and emotional effects. When the stress of having an ill baby is added to their system, the effects can be overwhelming. Additionally, the numb reaction may have been

an attempt at disassociating, helping the mothers to focus on the immediate challenges at hand, without dealing with the immensity of the possibilities regarding their child's outcome.

The women's worlds were turned upside down, and their conceptions of their selves as mothers, indeed as their selves in general, up to the point of birth needed to be rebuilt.

Before the rebuilding could begin, however, there followed for the mothers a time of grieving for what had been lost. Recall from the literature review that Schlossberg (1985) frames this time as one of questioning and regrets, of guilt and grief. Indeed, some of the mothers remembered wondering, "Why Me?," and the guilt that followed, the frantic search for something that they might have done wrong, continues to haunt the memories of their experience. This sense of failure at giving birth to a "less-than-perfect" child marked the evidence of the invasion of culture's prescribed norms into the mothers' psyches. The cultural imperative that a woman, in order to be a 'good' mother, should be able to gestate her baby for the full nine months in order to produce the 'perfect' child had made its way into their conscience leaving some of the women with a sense of shame. This sense of guilt may have been exacerbated by the appearance of the baby, a far cry from an image of the Gerber baby, but instead a tiny, pink, sometimes hirsute, limp figure connected via countless tubes to the omnipotence and omniscience of the NICU machinery. Most of the mothers reacted with guilt, and were motivated perhaps to be more protective, more vigilant, more involved with their babies, almost as a way of working hard to prove their maternal dedication.

Several of the mothers also experienced anger, perhaps as a protective measure against their grief. A few became angry at the medical establishment which was seen as in some way responsible for their child's too early arrival. Another's anger seemed to be directed toward her

child. These women's anger functioned as a way of defending themselves against the sense of powerlessness they experienced when pitted against the unforgiving cultural mandate of producing the perfect baby.

The grief that they felt, on the other hand, may not have been as closely tied to an external frame of reference, as the guilt reaction likely was. My feeling is that the grief which the mothers experienced arose out of a biological imperative, out of an instinctual fear of losing their baby and consequent drive to protect it. While attempting to describe their grief, several of the mothers utilized metaphors which featured instinctive or even primitive words and imagery. For example, Noelle referred to "coding that goes generations back" when describing her silent promise to her daughter to never leave her side. Noelle in particular, although she was not alone in this sense among several of the other mothers, described a feeling which brings to mind a deeply anchored drive and a fierce will to protect her child, *no matter what*.

One of the themes which continued to emerge within and across all of the mothers' stories was that of powerlessness. Almost all of the reviewed research mentioned this as well, conceptualizing it in various ways. Pederson et al. (1987) used the term "alienation" to describe the feelings of helplessness the mothers experienced due to lack of control over the infant's care or well-being, the feeling that the infant did not belong to them, not feeling like a parent, and worry about whether she would be able to feel close to the infant after discharge. Others, (Miles et al., 1992, Wereszczak et al., 1997) use the term "parental role alteration" to describe the parent's perceptions of being unable to take a direct part in caring for the baby, to hold the baby, to protect and nurture the baby, and were forced to endure separation from their baby. I used the term to describe the above sense of generally not feeling entitled, empowered or deserving to be the baby's

mother. I also incorporated Joanna's contribution to the term "powerless" as that of feeling helpless against fate or "the powers that be". It also occurred to me, perhaps in response to hearing the mothers descriptions of how vulnerable and helpless their child appeared to be while in the NICU, that the mothers "took on" or, to borrow a word from psychoanalysis, introjected their child's sense of powerlessness into their own sense of self. This attests to the relational character of a mother's sense of self. The empathic connection between a mother and her child, for instance as hypothesized by Jordan (1984), can be of such a degree and nature that the child's feelings become the mother's feelings.

When an individual feels overwhelmed by powerlessness, they have lost their sense of agency of the self. They feel that they have neither the tools, nor the permission, nor the right to be the self they thought they could be, or should be. Indeed, these mothers when faced with the vast unknowns regarding the fate of their baby, the unfamiliar culture and environment of the NICU, and the loss of their expectations about what it would mean to be a mother, experienced a loss of agency of self.

Next, they told of their efforts, if not to maintain their sense of self, to rebuild their sense of self. One of the things which some of the mothers tried to do was to actively advocate for their child in terms of limiting unnecessary medical intervention or to insist on breast-feeding their babies, as examples. These mothers, having experienced the guilt of feeling they had done something wrong, the grief associated with so many sources of loss, and the feeling of having no power in their role as mother, seemed to begin to regroup their resources, and take an active if not conscious stand on behalf of their child, and perhaps on behalf of their recovering, or nascent sense of self. Two of the mothers clearly remembered watching their child suffer, in their minds

unnecessarily, and feeling the desire to speak out in protest, but could find no words. They had lost their agency to such a degree that they also lost their voice. In reference to this, Justine has made a promise to be more assertive in the future should her child ever be in a similar position again.

One aspect of a woman's sense of herself as a mother seems to be the act of breastfeeding. For many of the participants, this emerged as an act to be staunchly defended. Many refused to let go of their desire and commitment to breastfeed their child. Again, this may have been strongly influenced by the current zeitgeist which dictates that breastfeeding is the best, if not only way, to nourish one's baby. Already feeling that they had not done a 'proper' job of being a mother, perhaps these women felt a powerful determination to do the one thing which they could do, as mothers, in their position. On the other hand, their desire to nurse their infants may have arisen out of a biological urge to establish physical connection. Most of the mothers, excepting Joanna and Noelle who were able to bring their babies home for a short while before complications developed, had experienced their babies being taken from them at birth, without having the chance to hold them in their arms. The opportunity to nurse their babies, in the words of Justine, represented, "the first time I really felt bonded to him." And as earlier noted, Joanna spoke of the sadness she felt when, for a period of time, she was unable to nurse her son even though he was desperate to do so. As she spoke, I sensed that she must have felt like her heart was being torn from her body as she could only sit there and look on.

**A few years later - "Now".**

Following their discussion of the events surrounding the neo-natal experience, I encouraged the participants to speak to the way they perceived the experience as having changed

them. As noted in the Findings section, the women seemed to initially struggle with this, as they made a shift from a primarily affective to a predominantly cognitive state. The women had, for the most part, evidently stored the memory of the neo-natal experience as an emotional experience. In trying to answer the question of how they may have come out of the experience differently, they were required to move into a more reflective state in which they attempted to assess their way of being as a mother and in the world. The following addresses what I learned from the participants about how they perceive themselves as a mother, as well as what they perceived to have changed as a result of the neo-natal experience.

#### **Sense of self as mother .**

One of the first things that I would like to discuss is the information I learned from the participants in terms of developing the definition of a sense of self.

A very strong finding which emerged from the data was that, although I had asked the participants to tell me how they had changed as a mother as a result of their baby being born critically ill, they tended to give responses which addressed a more global concept of self. These narratives yielded rich and insightful data about how the women experienced themselves, but they did not necessarily speak only to their *mother* sense of self. The participants did provide data which described their sense of themselves as a mother, but in answering my question, they provided *more* data about other aspects of their selves.

There are several reasons for why this may be so. One may be because an individual's sense of self is a construct which has been building essentially since the day of one's own birth. Thus, it is an older construct, and therefore perhaps more familiar and available to the individual, than the relatively new construct of sense of self as mother. Another interesting possibility might

be due to the difficulty that women have in separating their mother self from other aspects of self, including the global sense of self. A woman's mother self may be so intricately woven into her general sense of self, that she is unable to isolate it in her mind's eye. It is as if her maternal self, once activated, sheds a light on other facets of her self. Bonnie articulated this well at our second interview. She was looking at the list I had brought which had written upon it in point form the themes and categories which arose from the analysis of the data. As she was running her finger down the words: higher consciousness, wisdom, strength, higher purpose, spirituality, changes in values and priorities, changes in interests and activities, relationships with family members, relationships with unknown others, relationships with friends and relationships with God, she exclaimed, "I have changed in all of these ways! That's what being a mother does to you!" So, although the mother self is only one facet of self, it forever affects one's whole self.

When the participants did speak selectively of their mother self, they spoke of the way they perceived, and consequently mothered their children. The mothers began to respond to the question by describing their child as having been formed by the neonatal experience. They then would address their maternal practices. This indicates that when attempting to describe their sense of self as mother, they "see" their child. How these women see their selves as mothers, is largely comprised of the way in which they perceive their child. Seeing oneself as a mother is intricately entwined with seeing one's child. Their perceptions of their children were heavily coloured by the neonatal experience, as all but one of the participants specifically articulated the belief that their children were formed and shaped by the experiences of their earliest, neonatal days. As such, the mothers attributed their children's current ways of being to their birth experiences. Some mothers felt that their child's essential "worth" was enhanced due to the threats which they faced early on,

saying that they felt their child to be more precious or more special; not more so than other children, but more than they may have felt had the child been born and remained in a healthy state.

The mothers also tended to attribute their children's personality traits, or current ways of functioning, to their neonatal experience. For example, some mothers mentioned their children's physical and psychological sensitivities to the environment as being caused either by the physical or psychological trauma which they endured at and closely following birth.

Regarding their attribution of their child's nature or status to the birth events, it may not be possible to objectively determine whether the physical or psychological issues which the mothers claim characterize their children, do in fact arise from their neonatal experience. However, this is immaterial as long as the mothers believe it is true. This points to the immense power of subjectivity in determining our actions. The mothers make meaning of and act on their children's way of being based on what they see as real. What does seem true, is that, irregardless of whether mothers viewed their child as angry, special, vulnerable, or needy, the neonatal events figured large as they attempted to make meaning of their child's behaviour.

This meaning-making then informs the selection of maternal practices. "If my child is this way due to the neonatal experience," they seemed to be saying, "then what does my child need from me, and how do I best react?" The mothers thus formed their own mothering style based on what they perceived their child as needing in light of the neonatal experience. In other words, the child formed the mother. In traditional parenting literature, the mother is seen as being responsible for forming the child, largely due to the emphasis in the psychoanalytical nature of the mother's influence on the child (Boulton, 1983). Although a child is, of course, impacted by her treatment by and relationship with her mother, other features of the child's psycho-social environment are of

great influence as well. Relatively new to the discussion on motherhood, however, is the concept that the child forms the mother.

I had hoped this research would illuminate what is meant when women speak of their sense of self as a mother. In the above Literature Review, a definition of sense of self as mother was suggested, as including cognitive, affective, metaphysical, physical and relational elements as they pertain to the preservation, protection and growth of the child. While listening to the participants' descriptions of how they viewed themselves as having changed, I heard all of the above, and I would venture that all are essential elements to include when discussing a sense of self - mind, body, heart, and soul, connected with others. Changes to the cognitive aspects of their selves as mothers occurred as evidenced by shifting values and priorities, beliefs and goals. For example, many of the mothers spoke of their priorities about life in general and about their interaction with their child as having been impacted upon by the neonatal experience. As well, the mothers spoke to the affective aspects of their self when referring to the fear they felt for their child's future, the grief they experienced at the time, and which some claim to continue to experience when remembering what has been lost, or the anger that some retain against primarily the medical system. Metaphysical or spiritual changes were reflected upon when some mothers related their enhanced faith as resulting from their experience. The body experience, mentioned by Jordan (1997) as being an element of one's sense of self, was referred to by several participants, most notably by Noelle, who referred to the physical sensation she experienced when watching her child suffer and nearly die, "and your body just goes through these waves, these waves of emotion, of knowledge, like where is this coming from?" A connected, or relational self had a prominent position in that all of the participants spoke of the impact of the neonatal experience on their

relationships with others in their life, including, of course, their child. In these ways, the suggested definition of sense of self as mother seems to have some validity. However, I did not share this definition with the participants prior to the interviews, nor did I ask specifically how they would articulate their own definition of sense of self as a mother. Regarding my decision not to share "my" definition with the participants, I felt that this would have been an imposition onto their own description of self and of change to self. I was curious to see what came out of the data, unhindered by any former concepts of self as mother. The data emerged in such a way as to lead me to conclude that there would be general consent with the suggested definition of sense of self as mother. With respect to eliciting from the participants their own definition of sense of self as mother, I suppose now that this would have been an interesting question in that the resulting discussions would have yielded rich description and perhaps a consensus of the definition. Even so, the question would likely be better asked as a separate study question, given the limitations on available interview time, keeping in mind that the interviews for this study already ran at an average of 90 minutes.

### **The changing self .**

The concept of self change can be unsettling for some people. The realization that we can and often do change in the way we see ourselves throughout the course of our life can be experienced as an existential loss. "If I'm different now than I have been," we might ask ourselves, "If my experience of my self changes in response to changes in my experience, then how can I truly exist?" Despite this potential fear, however, seven of the eight participants in this study believed the experience to have changed them. Bonnie made a point of questioning whether her current "new" self is not simply a product of motherhood in general, despite her difficult neo-natal

experience with her daughter. However, in other aspects of her discussion, she did indicate that she believed the experience to have resulted in lasting changes to how she experienced her self, particularly to how she perceived her daughter's personality as being formed by the neonatal event.

Thus, seven participants felt that the experience had unequivocally changed them, to varying degrees and in various ways. How valid are these findings? The events surrounding the neo-natal experience, as discussed above, posed threats to the mother's previously held notions of self. In the interim between the time of their child's hospitalization and the time of the interviews, or perhaps in response to my question, these mothers were able to articulate the meaning they had made of how they had changed in response to the neonatal experience. It is important to note here that the mothers themselves made the meaning of their personal transformation; they did not conduct their meaning making in any controlled way. Thus, all that had transpired before and since the neo-natal experience would have had an impact on who they see themselves as being. For example, Justine wondered aloud at the impact of her separation and eventual divorce from her child's father, and the additive impact that would have had on her child's experience. I assume that these events would have also had a profound impact on Justine's sense of her self, even as a mother. If the child is affected, the mother is affected. However, the point I am making here is that the results of the personal meaning making process which the mothers used to answer the question of how they had changed are the only results that matter. It happens that the data tended to show similarities and patterns across most of the participants, likely reflecting shared cultural, biological and socio-economic influences. But the responses which the participants articulated regarding alterations in their sense of self are those which they deem to be of significance, and thus

which speak their truth. Collins et al. (1990) address the sceptic who wonders about the use of retrospective data, and state that:

The actual changes these individuals made in their lives may be less important than the perception of positive (or negative) change. The beliefs that one is a stronger person or a more caring partner, for example, may constitute the meaning derived from the experience more than any actual shifts on these attributes (p.283).

Despite the emphasis which Collins et al. (1990) place on the value of the participants' subjective sense of change, it was decided that, in order to gain another perspective on how the participants felt they might have changed as a result of having a critically ill baby, I would take the opportunity at the second interview to ask how others might notice that they are different. The findings indicate that the mothers answered this in a way that I would conceptualize as extending themselves further in their lives, as a mother and in other ways, than they might have previously. For example, Noelle feels that she gives more of her self to all that she does personally and professionally. Jana feels that she goes further in trying to understand her children's behaviour before reacting and by giving more of her self to the community. Joanna, likely reflecting where she is in terms of the remaining concerns about her son's health, feels that she gives more to him, "like holding him just that much longer before putting him in his bed." One could conceptualize these behaviours as reflecting many of the elements of sense of self as earlier defined, that is, a sense of connectedness in values, goals and beliefs. The other elements, those of metaphysical attitudes, body experience and feelings likely were not mentioned as they, by their very nature, reside largely in one's private domain.

The reader may be wondering if those women who had been mothers before they had a child who was critically ill might answer the question, regarding how they had changed, differently than those for whom the child in focus was a first born. Three of the mothers in this study did have older children, and I noted no clear patterns of divergence between them and the other participants, other than the finding that two of these mothers had young children at home, and they both recalled experiencing a great deal of stress regarding their anxiety about finding the time and energy to care for their other child and their household as well as dedicating as much time as they could to their babies in the hospital. Beyond that difference, it appears that these women still carried expectations about motherhood that were challenged and disturbed by the experience of having a critically ill baby. As Jennifer said:

I have four children now. And each time I have a baby, I kind of reinvent myself as a mother. Each baby is different, with different challenges and different personalities, so I end up being different too. It's like I have a four-sided mother self!

As change is, by definition, not a stable state, but a process, I would expect the participants to continue to change beyond the time of our interviews. To what degree and in what ways will depend on the experiences which they will encounter. The findings from the second interviews show that the participants were able to discuss the ways in which the interviews impacted upon them. Of most note is Justine, who felt that the opportunity to articulate her experience six years after her son was born was instrumental in allowing her to see an open door, and enter through it. Her renewed passion in medical illustration has become a professional reality as she finds herself working in the NICU, drawing the sick babies for their parents. Alex commented on how the first interview left her feeling unsettled for some time, as she struggled to make sense, once more, of

the emotions which arose as part of the interview process. I suspect, though, that much of what arose as a result of the participants having the opportunity to tell their story for an hour to somebody who was sincerely interested, may have had more of an impact than the participants were aware of, or able to articulate. This may, of course, be an errant judgement on my part. Yet, as Rosenwald and Ochberg (1992) point out, the very act of relating a story about a particular experience changes the way one sees one's self in that event. They argue that the telling of one's own story may be liberating, in that it may free one from the constraint of psychic and social obstacles, as was the case with Justine when she admitted for the first time her fear of losing another baby. As well, another mother with whom I spoke following the second interviews was relating a story to me about a recent separation with her son and the associated disturbing emotions which she experienced. "Separating from him, and all the stress I feel every time he leaves," she said, "is related to the time spent staring at him in the hospital, when I felt I should do more, but couldn't. I see that now."

I suspect that the crystallization of awareness, posited by Rosenwald et al. (1992), contributed to the fertility of the second interviews in terms of discussion of self change. Following the initial interviews, perhaps the participants were able to peruse the concept of self and of self change. Once they had familiarity with the construct, they may have been more able to speak directly to it.

It was noted in the findings section that the overriding quality of the changes reported by the participants was beneficial. With the suspicion that this may have been due to the effects of social desirability, it was decided that the participants would be asked in the second interview whether they perceived any costs as having been incurred by the experience. In general, the costs

referred to by the participants were related to their relational selves, including their empathic reaction to the consequences their children will experience. I did not hear any accounts of the mothers feeling like they were damaged in anyway. Likely because of the proximity to the event and the feeling that she is still "living" her experience, Joanna answered this question by saying that she feels older, as if she has lost her youthfulness, and her innocence. Both she and Noelle, whose children were the sickest of all the participants, both mentioned that they know now that Bad Things Happen. So, even though, *when asked*, the participants were able to comment on the costs incurred, the bulk of the changes which the participants reported were perceived as being positive. As Saakvitne et al. (1998) point out, in post-traumatic change, the positive coexists with the negative. There is pain at the same time as there is growth. My hunch as to why the participants overwhelmingly reported beneficial aspects to their selves is because their children all survived. Although they went through emotional pain, and although they watched their children suffer physical pain, these mothers got to bring their children home. As Justine said, "I knew I was one of the lucky ones." Perhaps the mothers feel that it would be an act of poor faith, as it were, to report the negative aspects to their sense of self. Perhaps they feel that the most beneficial aspect to the whole experience is that they still have their child in their lives. Their positivity may represent a form of gratitude to their god, whomever that may be. Another factor which likely influences the way these participants perceive their posttraumatic change is that they all are fortunate to be highly functioning, psychologically healthy individuals with substantial support networks. These factors certainly contribute to the way events are assessed. Furthermore, there is always the impact of social desirability on participants in a study, and these women may have been

giving me the "good news" in an effort not to appear as "victims," a role which is certainly celebrated, but not necessarily respected by the society at large.

Western literature is replete with stories of individuals who find meaning in their crises (Collins et al., 1990). Recently, however, there has been a renewed interest and subsequently an increased level of investigation into the ways individuals find meaning and construe benefits from victimizing events ( Saakvitne et al., 1998; Affleck et al., 1990; Collins et al., 1990). Even the lay media are reporting on the phenomena. Note, for example, the newspaper article which reported the finding that surviving a plane crash can bring long-term benefits to one's psychological health (National Post, August 23, 1999). Or, in the barrage of media reports surrounding the current American political campaign between Bush and Gore, one frequently comes across Gore's account of being permanently transformed, personally and otherwise, after watching his six year old son miss death by a narrow margin after being hit by a car.

The findings from this small set of participants who experienced the critical illness of their child indicate that, at the time that they were dealing with the events surrounding their children's illness and hospitalization, their reactions were imbued with stress, guilt, fear and a sense of powerlessness. Over time, however, most managed to construe the event in such a way as to perceive beneficial and positive changes to their sense of self. Of course, every participant's story featured unique struggles and adaptations to their situation. And, one of the participants claims not to have changed, for the worse or for the better, while another characterizes her posttrauma experience as a generally difficult and stressful time.

Jean, although agreeing that the experience had changed her in some ways, denied feeling that she was changed in any spiritual, metaphysical or relational sense. Her sense of having

changed lay almost totally in her maternal self. She believes that her values around child rearing changed, and that the way she perceives, and thus treats her son, is affected by the neonatal experience. For example, she is certain that his behaviour is related to his early birth experience. During our second interview, Jean remarked that she has never asked "Why Me". Nor did she experience the emotions which were typical of the other mothers during the neonatal time. She also emphasized that she does not feel any antipathy toward the people, including friends, relatives and staff, with whom she was involved at the time of her son's hospitalization. Perhaps, because she was not greatly distressed, and because she did not question her experience, she did not feel the need to make meaning, nor construe benefits of the type that many of the other participants did.

Another interesting point which the second interview discussion with Jean engendered is a unique way in which one of culture's imperatives acted upon her. Following her description of the way she dealt with her trauma, and the way she consequently sees herself, she said, "I feel I should apologize, or something. I feel cold, perhaps, in that I did not have the same experience that some of the other moms did. I feel like I should have felt more, but the truth is, that I didn't. I'm just being truthful." What followed was a discussion of the cultural pressure to feel "mushy" about one's child, and the way she feels at times that she "shouldn't" feel the way she does, or that she "should" be feeling otherwise. I suggested to her that another way of looking at this is that she showed courage to be the "different one", and to stay true to her own take on the experience.

#### **Implications for Future Studies**

Because Interpretive Description (Thorne et al., 1997) seeks to explore the experiences which are common and unique to individuals, I feel that this research has succeeded in drawing out

patterns between participants, as well as providing a picture of the individuality of each separate story. Consequently, in my opinion, the present study is rich with detailed descriptions of the experience of mothers who have had clinically ill babies, both at the time of birth and a few years later. The descriptions which the participants contributed to this study provide many opportunities for future researchers. The following suggestions represent only a few examples of future research into the concept of change of self following a crisis.

It would be of interest, for example, to return to this group of participants at a later time to explore their current view of sense of self as mother, more specifically asking them about their maternal perceptions of their child, and maternal practices. Information gathered from women regarding their maternal self concept over time would shed light on the stability of one's sense of self as mother.

As well, I would find it fascinating to ask fathers how they see themselves as having changed as a result of their experience with a critically ill child, both in paternal role as well as in general. Of specific interest with men in such a study would be to listen for evidence of a relational self in their overall sense of self.

Another area of future inquiry would be to focus on the process of change. For example, to draw on Saakvitne et al.'s (1998) theory of posttrauma growth, it would be of interest to explore which changes in self were experienced as abrupt, and which as intentional. Also related to the inquiry into the process of change, it would have been of value to ask the participants if they had given any thought to their change in self before, or whether their articulation of change was for the first time in response to the interview question. Another way of learning more about the

process of change would be through the design of a longitudinal study in which participants would be asked how they have changed at a time close to the event, and then again at a later time.

Another direction for future inquiry into change in sense of self, specifically in that of mother, would be to explore the experience of mothers whose children did not survive their critical illness.

### **Implications for Clinical Practice**

#### **Implications for Hospital Staff**

This research was two-pronged in that it represented the neo-natal experience as well as the concept of change of self. Although I analyzed the data which focused on the neo-natal experience from the perspective of the mother's emotional reaction and sense of self at the time, I did not conduct any investigation into the hospital factors which clearly played an important part in the experience of the participants. I feel therefore that I am not in the position to assess what could be done from the perspective of changes to the systems within the NICU to help alleviate the stress so evidently felt by the mothers during their children's hospitalization.

However, from listening to the mothers tell of their struggles while their babies were hospitalized, I can attest to the profoundly important role played by the doctors and nurses in the mothers attempts to cope. In many cases, mothers felt cowed by the power of the hospital staff, and still are affected by the sense of powerlessness which they experienced. Noelle specified that she would have found it extremely helpful if she could have had regular meetings with the doctors and nurses to give her precise and detailed information regarding her child's status. I believe that doctors, and perhaps especially nurses, as they are the ones in closest and most frequent contact with the parents, need to be constantly reminded of the power which they hold in their position,

and the impact of their behaviour on the coping efforts, short and long term, of the parents of their youngest patients.

Informal discussion with staff in the NICU has made me aware that changes are always being considered to facilitate ideal conditions for mother and child. For example, the system has come a long way from the perspective of mother-child contact in the NICU. Twenty years ago, the mother had very limited access to her child in the NICU. Today, under normal condition, parents and grandparents are allowed unrestricted access to their child. As well, some hospitals encourage "Kangaroo Care" in which the infant is placed skin to skin on a parent's chest, in the well investigated belief that this can be highly beneficial. An example of an attempt on the part of BC Children's Hospital to empower parents is the recent introduction of a video which teaches parents how to become partners in their child's health care. The hospital acknowledges that:

Most families want to be part of the decision-making process, but many need to learn new skills to become competent partners in the process. The program teaches parents how to win respect and play their part in giving and getting information, participating in decisions, and negotiating differences (BC Medical Journal, 2000, p.293).

I commend this effort on the part of the hospital to help guide parents of critically ill newborns through the system in which they have unwittingly found themselves.

### **Implications for Counsellors**

This research has several implications for counsellors. One of the most significant findings was the set of beneficial changes to their self which the participants were able to construe. Because of the renewed interest in this finding, counsellors are likely becoming increasingly aware of posttraumatic growth and this contributes a valuable addition to the literature on how best to help

people through their crises. Growth-related characteristics such as the development of personal strength and wisdom have been found in victims of trauma (Saakvitne et al., 1998) and can guide counsellors in helping other victims perceive how "all has not been lost". In therapy, individuals can be guided to create a sense of personal meaning in their crises, thus helping to transform traumatic events into meaningful, rather than senseless, victimizing experiences in their personal narrative. (I would like to point out that, as evidenced by the women in this study, psychotherapy is not, however, a prerequisite for posttraumatic growth!)

As Noelle indicated, she would not have been able to *see* the changes to her sense of self at the time of her daughter's illness. This introduces another significant point, that time seems to be one of the essential elements in enabling individuals to see the benefits which may have arisen from trauma. So, drawing from the implications for future research in which it was suggested that we learn more about the process that change takes, counsellors should be aware that people may not be able to immediately conceive of the positive aspects to their post-traumatic experience.

Another important implication for counsellors is to be aware that the meaning of the traumatic event is experienced by individuals in their own unique way. Although common coping patterns among survivors of trauma may exist, each individual is affected by the event differently. It is important for counsellors not to apply a recipe for recovery to every individual who is struggling to come to terms with trauma. For example, some of the participants in this study seemed to cope with their crises by compartmentalizing their emotions, "putting their heads down and shoulders out," and focusing only on the next step they needed to take. Others, however, also coped with the situation by freely and intensively experiencing their emotions, and reaching out to others for support.

The findings from this study might also encourage counsellors to integrate the aspect of relational self into a woman's sense of self, thus changing the way self is defined. Of course, feminists have long acknowledged the relational element to a woman's experience. But continued emphasis on this concept can only serve to increase awareness of the importance of others in a woman's sense of self, and thus to help in our attempts to understand women's struggles and growth.

### **Limitations**

The findings from this study must be considered in light of several limitations. One must be careful not to be tempted to generalize the findings from this study to other women who have experienced the birth of a critically ill baby. Although the analyzed data did show patterns between the women, this study was not designed in any controlled way to indicate that these results can be transferred to other women. The group was somewhat homogenous in terms of socioeconomic factors, but many other variations existed which would limit the transferability of the findings. The range of variation will be briefly discussed in the following paragraph.

There were many dimensions on which the participants were variable. The first dimension would be the age of the mother when she had her child. A more mature woman may attribute different meaning to the experience, and handle her emotions differently than would a teenage mother, for example. A second dimension would be the factors which affect memory such as the current age of the child. The closer the mother is to the event, the less time she would have had in the development of meaning as it pertains to the event. As well, her emotional experience may be more available to her in terms of recounting the story. The second factor would include the impact of the child's developmental stage on maternal perceptions and practices. A third factor may be

the number of children the mother has and the sibling placement of the child in focus. A fourth factor would be the quality of support which the mother perceives. The literature indicates that support is one of the most important factors in coping strategies. A fourth dimension would be the ethnic culture of the mother as there is variability in view of death, illness, and maternal role across different cultures. A fifth dimension would be that which affects all studies which depend on recruitment for participants, and that is the character of the individuals who contact the researcher, willing to be a part of their study. I would imagine that women who feel the neonatal experience was not a significant time in their life would not be motivated to share their story and their time as part of a research study. Or, the mother with less support and assistance, and thus perhaps a fundamentally different story, may not feel she has time to volunteer for this study. Finally, even if the participants did not show variability on the above dimensions, the number of participants in this study would be too small to be confident about the commonalities and differences which exist within this phenomenon (Thorne et al., 1997).

Another limitation, which holds for much of qualitative research, is that analysis and interpretation of the data is necessarily a subjective act on the part of the researcher. Another researcher may have conceptualized the findings differently, created different words to reflect different categories, grouped the categories differently, et cetera. Use of quotations to illustrate the categories and themes, as well as checking the findings with the participants were ways in which the validity may have been enhanced, but nevertheless the findings were authored by myself, replete with my subjective point of view.

Additionally, the concept of social desirability might have played into the findings in that participants may have been motivated to not only claim to have changed, but also to have changed

in beneficial ways. I believe that the use of quotes containing explicit references to perceived self change, as well as the opportunity given to the participants to describe any costs which they felt were incurred due to the neonatal experience, add robustness to the data. The desire to please, however, could conceivably have been so pervasive that all comments were influenced by this force.

Another limitation to the findings in this study is the possibility that the participants felt they were changed not specifically by the birth of a critically ill child, but by the birth of a child in general. Although earlier evidence was presented which referred to the differences in experience of mothers of healthy babies and mothers of prematurely born babies, it is possible that the mothers in this study were unable to completely separate the impact of motherhood in general from the impact of mothering a critically ill baby.

### **Conclusions**

The findings from this study, with the above limitations in mind, contribute to an understanding of how a woman's sense of herself might change in response to having a critically ill baby.

Firstly, counsellors can learn from these participants regarding the long-standing and vivid recall of the emotional and environmental details of the neonatal crisis. The recounting of the experience of having a critically ill baby was emotionally evocative and featured significantly in the memories of all eight women. In particular, a sense of powerlessness, as described by feelings of helplessness to care for one's baby either in the face of the medical system or against fate, featured strongly in the accounts of all women, and remained as an upsetting factor for most.

Also important for counsellors to consider when dealing with neonatal crises, is how cultural imperatives, regarding what it means to be a mother in this culture, can impact upon women's feelings about, and interpretations of, their experience. For example, also frequently noted in this research were feelings of guilt and shame on the part of the women for not producing the "perfect" baby, or for not caring for their children in the "right" way. Or, as was evidenced by one of the participants, for not evolving out of crises in an "appropriate" way. These messages, when unchallenged, may result in disabling conclusions and hinder the growth and even the functioning of such women.

Secondly, by seven of the participants own conclusions, the neonatal experience resulted in lasting changes to the way they perceived and treated their children. As well, for the same seven women, other aspects of their selves were impacted upon by the event. For the most part, the changes which these women experienced were perceived to be beneficial in effect. The costs which these women felt they incurred due to the experience of having a critically ill baby, lie largely in the domain of grief, in which they experienced a loss of aspects of their self. For counsellors dealing with post-trauma effects, this might be instructional from two perspectives. One is that benefit can arise from trauma, and growth can be encouraged from the realization and acceptance of such benefits. Secondly, post-trauma gain co-exists with post-trauma pain, and even though growth is possible, the costs incurred and resultant grief must be acknowledged in victims of crises.

Of significance to the theory of self, are the questions raised regarding how we view, or what we know of, the different aspects of ourselves, specifically in this case, of a woman's sense of self as mother. The women in this study, when asked to describe changes to their sense of self

as mother, responded in many cases by describing a more expansive concept of self. For example, they referred to aspects of their inner selves, and to their relational selves, as well as, but not strictly demarcated from, their sense of self as mother. Therefore, just as we cannot view the self in general as a singular monolithic entity, separate and contained unto itself, but must view it in relation to others, so must we view a woman's sense of herself as mother in relation to other aspects of herself.

Another theoretical contribution is found in the results of this study which indicate that, for many women, their sense of themselves includes a sense of connection with other individuals. This finding arose from the repeated references to the significance of others in their concept of themselves. Most notably, when mothers were asked to describe their sense of themselves as mothers, they responded by describing their sense of, or their perception of their children. To coin a phrase, this finding underlines the concept of motherhood as "otherhood."

It is hoped that the findings from this study encourage future researchers to help clinicians in the challenge of helping those who have had critically ill children. Specifically, to aid clinicians in transforming the crisis into a journey of growth. Finally, it is hoped that the results attained here motivate future authors to investigate and contribute to the knowledge of how we perceive ourselves in general, and how we perceive ourselves as changing through life's events.

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**APPENDIX B****Letter to Physicians**

Susan Bartlett  
4012 Maple Crescent  
Vancouver, B.C.  
V6R-4B2

March, 2000

Dear Dr.:

I recently spoke with you about my Master's thesis research, and would like to follow up with you regarding my research plans and my request for your assistance in recruiting participants.

This research, supervised by Dr. Beth Haverkamp, is required for the completion of a Masters of Arts Degree in Counselling Psychology. My thesis research question derives from my interest in changes in the self which result from important life events. Specifically, my question of research participants will be, "How has the the experience of having a critically ill child changed your sense of self as a parent?"

The qualitative research design that I'm using involves two interviews of approximately one hour with each of ten participants. Interviews will take place at a mutually convenient time and location. They will be audio-recorded, but of course there will be no identifying information recorded, to insure anonymity. The patient's decision as to participation will also be kept confidential.

I am asking that you help identify mothers who would be appropriate for my study. Interview participants must reside within the Lower Mainland, be willing and able to speak of their experience regarding the circumstances surrounding the birth of their child, and of their own process of change. Ideally, they shall be thoughtful and eager to share their experiences in a self-reflective way. I am interested in speaking with a wide variety of individuals, so they do not have to be "homogenous" in any way, (i.e.: marital status, socio-economic background, number of children, etc).

For my research, a "critically ill child" shall be defined as one who required admission to the hospital's neonatal intensive care unit shortly following birth. The child should currently have a good prognosis, and be developmentally within norms. The child, at the current time, should be within 30 months to 5 years of age. I have chosen to include only mothers in this study.

**APPENDIX C****Letter from Physician to Patient**

March, 2000

Dear

I have taken the liberty to send to you the enclosed letter from Susan Bartlett, whom I know. Susan is working on a research thesis as part of the requirements for a Master's Degree in Counselling Psychology from UBC.

You will see that she is doing her research on the changes that people experience in their lives due to the birth of a medically compromised baby. Because you have had such an experience, I am sending this letter on to you. I think her research will be helpful to other mothers like yourself. Let me emphasize, however, that you are under no obligation to participate. Susan and I have also agreed that she will not indicate to me whether or not you choose to be a participant in her research study.

If you are interested in helping with her research by discussing your experience, you may contact her at the number on her enclosed letter.

Yours sincerely,

## APPENDIX E

### Informed Consent Form Mothers of Ill Children: Evolution of the Parental Self

**Principal Investigator:** Dr. Beth Haverkamp, Associate Professor,  
Department of Counselling Psychology, 822-5259

**Co-Investigator:** Susan Bartlett, UBC Masters Candidate, Department of  
Counselling Psychology, 224-2219.

**Purpose:**

This research is being conducted as one of the requirements for Susan Bartlett's completion of a Master's Degree in Counselling Psychology. The research will explore how the birth of a critically ill baby changes one's sense of self as a parent. Themes which are common to all volunteer participants, as well as themes which are specific to each individual, will be identified.

**Study Procedures:**

The study involves two interviews of approximately one hour each, and two months apart. At the first interview, the participant will be asked to go back in time to before her baby was born, and try to describe how she saw herself as a parent at that time. Following this description, the participant will be asked to describe herself as she currently sees herself as a parent.

The interviews will be tape-recorded and transcribed, with no identifying information included. The interviews will take place in a location that is convenient to the participant, and offers a private and non-obtrusive environment.

At the second interview, themes which have identified from all of the volunteer participants will be brought back to each participant to determine if they remain appropriate, from the participant's point of view. The participant is encouraged to recommend any changes to these themes.

**Confidentiality:**

Any information resulting from this study will be kept strictly confidential. All documents will be identified only by code number and kept in a locked filing cabinet. Participants will not be identified by name in any reports of the completed study. If the data records are kept on a computer hard disk, the disk and file will be labelled by code as well. All tapes will be erased upon completion. Only Susan Bartlett and the thesis advisor (Principal Investigator, above) will listen to the tapes.

**APPENDIX F****ORIENTING STATEMENT**

I am interested in the changes that we may experience as a result of very important life events. You have indicated that being the mother of an ill child has been an experience that you feel changed how you are as a mother in some way. It is this element of change that I would like to explore. Perhaps you could give some thought to the ways in which you are different in your role as mother than who you imagined yourself to be before the baby was born. Perhaps the changes are in the way you see yourself or the way you see the world in general.

Having small children myself, I am aware of the joy and pride, as well as the challenge and frustration of being a mother. I would like to emphasize that I am not evaluating or assessing how you parent. I am only trying to understand how you experience your sense of self as a mother, and how you may have evolved from the experience of having had a critically ill child.

As I am interested in the process of change in your sense of self as mother, I will ask you to go back in time to before the baby was born, and attempt to describe what your expectations of yourself as a soon-to-be-mother at that time were. Then, I would like to ask you to describe the events surrounding the birth of your baby. Finally, I will ask you to move forward in time, and describe how you might have evolved, or changed as a result of having had a critically ill baby.

**APPENDIX F CONTINUED**

Let's start with before the birth of the baby. You may have rehearsed how you might be as a mother - the kinds of things you thought about, and felt, and imagined. Could you describe what your pre-natal expectations of motherhood would be?