

University of Alberta

Decision Making in the NICU: The Parents' Perspective

by

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Abstract

There are different opinions on who the appropriate decision makers are for extremely premature infants. Some argue the responsibility should fall to the parents, and others argue the neonatal experts should be responsible for decision making. This study explored parental perceptions of their involvement in decision making in the neonatal intensive care (NICU). The NICU operated from the philosophy of Family Centered Care (FCC). FCC situates the parents as central to all aspects of their child's care and as such, the parents should be well informed and actively involved in decision making. An interpretative descriptive approach was used to examine the experiences of seven parents who had infants born at 24-26 weeks gestation who were admitted to the NICU. Thematic analysis revealed that the culture of the NICU along with the relationships developed in the NICU had an impact on the parents' perceptions of decision making.

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CHAPTER ONE

Background

Many difficult decisions follow the birth of an extremely premature infant (24-26 weeks gestation). The initial decision to initiate resuscitation, or choose compassionate care for the infant, will be followed by many more complex and potentially life altering decisions throughout the infant's stay in the neonatal intensive care (NICU) and perhaps throughout his or her entire life. Examples of these decisions include: deciding whether to continue treatment following a diagnosis of complications such as a severe intracranial hemorrhage, or consenting to invasive cardiac surgery to repair a patent ductus arteriosus. These are life-and-death and quality-of-life decisions that exemplify the dilemmas that parents of extremely premature infants may face. The complexity of the decision making process is confounded by the uncertainty that surrounds the outcomes related to infants born at extreme prematurity. It is difficult to predict in the neonatal period, what level of impairment, if any, the child will live within their years to come (Marlow, 2004). The difficulty in determining prognosis arises because the most serious neurological outcomes and sensory disabilities are not likely to be identified before the age of two (Marlow). This cloud of uncertainty leaves the parents and health care providers in a difficult place when it comes to deciding what is best for the child in their first few weeks and months of life.

Debates currently exist regarding who is the most appropriate decision maker for extremely premature infants (Leuthner, 2001; Spence, 2000). Many Neonatal Intensive Care Units (NICUs) operate from a medical paternalism model of decision making (Leuthner) which is based on the belief that the health care professionals have the expertise and objectivity to make the appropriate decisions regarding the infant's care. The principles of best interest are sometimes adopted, in which case the family's and society's opinions are weighted when quality-of-life decisions are being made (Spence). Other NICUs support collaborative or negotiated models of decision making. In this approach, there is an attempt to fully inform the parents of the infant's prognosis and have them become an integral part of the decision making team (Leuthner).

The NICUs within Alberta Health Services - Edmonton operate under the philosophy of Family Centered Care (FCC). The seminal work of Shelton, Jeppson and Johnson (1987) provides the framework for the principles of FCC. They identified nine elements of FCC: recognizing the family as a constant in the child's life, facilitating parent-professional collaboration, honouring the cultural and socio-economic diversity of families, recognizing family strengths, sharing complete and unbiased information with families, encouraging and facilitating family-family support and networking, responding to child and family developmental needs, adopting policies/practices that provide families with emotional and financial support, and designing health care that is flexible, culturally competent and responsive to family needs. Based on this philosophy, the families are viewed as being an integral part of their child's life and must be included in the decision making process.

The Northern Alberta Neonatal Intensive Care Program has a policy regarding implementation of FCC that aims to empower the parents to nurture and support their child through mutually beneficial partnerships between the family and the health care providers (Northern Alberta Neonatal Intensive Care Program (NANICP), 2006). As outlined by the Northern Alberta Neonatal Intensive Care Program the concepts of FCC include: dignity and respect, information sharing, participation and collaboration. Dignity and respect maintain that the family's knowledge, values, beliefs, and cultural backgrounds are incorporated into the planning and delivery of patient care (NANICP). The process of information sharing means health care providers communicate and share complete and unbiased information to families in a timely manner so families are able to participate effectively in care and decision making pertaining to their infant (NANICP). Participation is the way families are encouraged and supported in participating in care and decision making at whatever level they choose (NANICP). Collaboration reflects the way health care leaders collaborate with families in policy and program development, implementation and evaluation (NANICP). The concepts of FCC are taught to all new nursing staff to the NICU

during their orientation program and are to be embodied by the staff already working in the NICU environment.

Purpose of the Study

The purpose of this study was to investigate the parental perceptions of involvement in decision making within a NICU that operates from the principles of FCC. The study aimed to examine the decision making process for parents whose infants were born at 24-26 weeks gestation, as I believed that the decisions these parents faced were different from those of a parent with a prenatal diagnosis of a congenital anomaly that is not compatible with life. The unit where the sample was recruited from consists primarily of premature infants; and the hope was to identify implications for practice that could impact that unit.

Significance of the Study

With respect to parental involvement in NICU decision making, few changes have been reported since 1990. Most of the literature reports that parents are not fully involved in the decisions made regarding their prematurely born infants. These findings are important in relation to a unit whose members pride themselves on practicing from a family-centered care philosophy. Do the applied principles of FCC actually increase the amount of parental involvement in decision making? The results from the review of the literature make me wonder if FCC has influenced parents' perceptions of being involved in the decision-making process. I believe that these issues are important to health care professionals, especially nurses, as we help these parents in their transition from coping in the hospital to coping at home. If quality of life decisions are made, the parents/family may have to cope with these decisions for the rest of the child's life. Ultimately the family will carry the responsibility of the decisions that are made and therefore should be the principle decision makers. To play this role, they need to be well informed of the potential immediate and long term consequences of their decisions, as they will be the primary caregivers and bear the consequences of any decision that is made.

CHAPTER TWO

Review of the Literature

A review of literature pertaining to parental perceptions of decision making in the NICU environment was conducted by searching CINAHL, MEDLINE and socINDEX. Key words searched were family centered care, decision making, parental perspectives, neonatal, neonatal intensive care (NICU) and ethics. Chosen for this review were research studies (quantitative or qualitative) specific to parental involvement in decision making within the NICU environment.

Parental Involvement in Decision Making

Much of the literature reviewed indicated that parents have been oblivious to the ethical component of the pivotal decisions being made for their child's NICU care. In a qualitative longitudinal study completed by Pinch and Spielman (1990, 1993, 1996) a convenience sample ($n=32$ families) of parents of critically ill newborns admitted to a level III NICU were interviewed prior to the infant's discharge. The sample included 32 mothers, two grandmothers and twelve fathers. Parents were invited to participate in the study based on a criteria scale for high risk assessment of their baby. Criteria within the scale included: less than 2500 grams at birth, less than 37 weeks gestation, an Apgar score less than five at five minutes, and/or the presence of surgical interventions or anomalies. The criteria were broad and, while the sample was described, it represented a wide range of infants from a level III NICU. Analysis of data from the first interviews revealed that parents of critically ill infants in a level III NICU initially had no concept that ethical decisions were being made for their child (Pinch & Spielman, 1990). It was evident in parents' accounts that the decisions were made from an expertise model of decision making, and families were not included in those decision making processes.

In the follow-up data collection, at six months post-discharge, these same parents acknowledged that they lacked the appropriate information to participate with the health care professionals in the decision making process. Pinch and Spielman (1993) described this recurring identification of the lack of appropriate

information among the parents as an “emerging ethical consciousness” (p. 427). In the final phase of the study (1996), four years post-discharge, the parents were able to identify, in specific terms, what they needed during their NICU experience. Communication was the theme identified by most parents; they wanted frequent, repetitious information given to them in a simple and easily understandable language. Still, at four years post-discharge, no parent connected ethical or moral issues with decision making for their baby during the NICU experience (Pinch & Spielman, 1996).

Studies completed since the 1990s, along with the work of Pinch and Spielman, have shown little change in the involvement of parents in the decision making process. This further research with parents from different cultures (research from France, Norway, and the United States of America) has indicated that, while parents want to be informed and included in the discussions surrounding the care of their infant, they continue to feel that the health care professionals should be making the critical decisions regarding the care of their infant (Brinchman, Forde & Nortvedt, 2002; Streiner, Sagal, Burrows, Stoskopf & Rosenbaum, 2001; Cuttini et al, 2000).

Parents’ experiences of and attitudes toward their involvement in life-and-death decision making in a NICU was described in a Norwegian study that involved 20 parent participants (Brinchmann, Forde & Nortvedt, 2002). The sample for this investigation was recruited from various parental support associations across Norway, and the majority of interviews were conducted with both parents together (n=15), of the remaining five, four were with the mother alone and one with the father alone. The criterion for inclusion was the indication by the parents that a life-or-death decision was made for their critically ill/premature infant. As the parents were recruited from different associations, the time lapsed since their experiences of the life-or-death decision varied from one to eight years. The majority of these interviews were with parents of premature infants, 24-29 weeks gestation, although the exact number of interviews with parents of premature infants is not indicated. Grounded theory was identified by the researchers as their method of data analysis, although they indicated that

theoretical sampling would not be used; nor was their purpose to develop a conceptual framework based on the topic of the study. Rather, their purpose was, to identify categories and discuss them in relation to theories on ethics. Perhaps, following these realizations, a more appropriate qualitative approach should have been selected.

Despite questioning the methods used to collect and analyse data, the findings were noteworthy. Most of the parents thought that they should be well informed, consulted, listened to, and included, but ultimately the health care professionals carried the responsibility and should have made the final decision. Without actually using the term “relational ethics,” the implications for nursing and health care ethics as identified by the researchers were just that; to judge what was ethically the best action to take in relation to the infant and his/her parents. Considering the more traditional practices that are characteristic of European health care, as stated in this study, would these results differ if the same study was conducted in Canada or the USA?

Attitudes of neonatologists, neonatal nurses, parents of extremely low birth weight infants and parents of normal birth weight infants, about saving infants of borderline viability and about who should be involved in the decision making process were compared in a Canadian study (Streiner, Saigal, Burrows, Stoskopf & Rosenbaum, 2001). The sample consisted of parents [n= 268 of which n=169 parents of extremely low birth weight infants (ELBW) < 1000 grams]. Parents of term infants (n=12) formed the control group. The researchers did not report how the parents of the ELBW infants were selected, although they stated that the control parents were randomly selected from a list of children in the Hamilton Public and Roman Catholic school board when children were eight years of age. The controls were then matched to the index children on the basis of age, sex and social class. The physicians were selected from a national sample of neonatologists working for a level III center in Canada, and all contacted agreed to be in the study (n=130). The nurses were randomly selected from three tertiary care units in Ontario and of the 99 recruited, 81 (82%) participated.

The researchers used a six-item, self-report, Likert questionnaire developed by Lee to collect their data. Reliability and validity data for the measurement tool was not provided by the researchers, nor were the questions in the questionnaire provided.

The majority of respondents felt that decisions should be made on an individual basis and that consideration should be given to the wishes of the family. The results indicated that health care professionals (physicians and nurses) are more ready than parents to withhold life-saving interventions. Limitations of the study were indicated as being completed in Canada where universal health care may have skewed the economic burden felt by parents of ELBW infants; being completed when the children are older (age 12-16 years) the parents were farther removed from caring for an impaired infant. Following the statement of limitation, a brief conclusion was offered with no implications to health care practice or ideas for further research.

In another study, NICU policies concerning parents' visiting, information sharing with parents and parental participation in ethical decisions across eight European countries were compared (Cuttini et al, 2000). Inclusion criteria for the units were outlined and random sampling was achieved by assigning each unit a weight equal to the inverse of the probability of being selected within a given country. A complexity score was created to represent the units' technical abilities (i.e., number of ventilators, high frequency ventilation, etc). Logistic modeling was used to control the differences between countries for the effect of potential confounding variables. A number of variables were identified a priori as potential confounders in the research. Cluster analysis was also used to identify main patterns of care across the countries. Out of 410 units meeting inclusion criteria, 142 were randomly selected to participate in the study and 123 accepted (average response rate of 87%). Outcome measures were defined as parental visiting policy (unrestricted or otherwise); parental presence during medical examinations (regularly allowed or otherwise); and parental involvement in decision making (explicit or otherwise).

Results were presented by country for each of the identified measures. Units with unrestricted visiting tended to have more liberal policies on overall parental participation in their infant's care. In comparison to my experiences in a Canadian, Level III NICU, many of the European countries studied still operated from traditional policies, where exchange of information took place in a hierarchical fashion and when disseminated to the parents, information was given to the fathers first. The researchers noted that, in many instances, ethical decisions were framed as medical decisions and parental agreement was not sought until consensus had been reached among the staff. It was concluded that parental attitudes and requests are markedly different from the organization and existing policies in the NICU, and the researchers suggested that changes to current practice needed to be made, without indicating what were the required changes.

Orfali (2003) attempted a comparison of parental involvement in decision making in the USA and France. Using a comparative, case based approach Orfali (2003) explored the parental role in decision making within two technologically similar, but culturally and institutionally different, contexts. A NICU was selected in France and one in the USA, where the beliefs were that the units operated from a medical paternalism and American autonomy model respectively. The ethnographic study with participant observation of the decision making process at various moments was augmented by in-depths interviews with clinicians and parents to understand the lived experience in the two cultural contexts. The researcher participated in NICU rounds and family meetings to get an in depth picture of how each unit operated from her perspective; close attention was given to critical cases where an ethical dilemma was evident. Data were collected from 85 cases, interviews with 60 clinicians and 71 parents, and chart reviews. Data analysis was based on Dubet's theory on the sociology of experience. The results showed that due to the nature of the legal systems in each country, the French physicians developed their own professional criteria for determining who should be treated and NICU practices remained outside of public scrutiny. Whereas specific rules governed the US physicians in regard to what was and was not legally permissible; it was found that physicians in the US did not offer treatment

limitations even if those limitations were legal. Prognostic determinations were different on the two units and a sociological explanation of prognosis as a social process that can result in an ethical dilemma was advanced. Parental autonomy was limited in relation to how the information was shared with the parents, and it was found that parents tended to agree with information presented by physicians. This meant that if limitations in aggressive treatment are not offered, the parents did not suggest it. French clinicians were found not to ask permission to limit treatment, while American clinicians were found not to ask permission to continue treatment. Implications for further practice as indicated by Orfali (2003) were for further exploration of ethical decision making in regard to areas where treatment limitation is not offered and the reasons for treatment limitations. While Orfali's (2003) results revealed that the neonatal unit in the US had strong feelings for adopting parental autonomy in comparison to their French counterpart, it was recognized that parental autonomy can only exist if the health care team allows it to exist and the parental role was more limited than had initially been expected.

In another American study, Wocial (2000) revealed that parents' perceptions of involvement in the decision making process in NICU were related to the relationships formed with the health care team. A phenomenological qualitative study was conducted to better understand parental perceptions of the decision making process in the NICU (Wocial). Specifically, the meaning parents gave to comments made by healthcare providers was explored. What information was important to parents in reaching a decision about withholding and/or withdrawing treatment? How did parents describe their involvement in the decision making process? (Wocial). There was an underlying assumption that information exchange and communication have a significant impact on parents. The sample consisted of 20 parents whose infants received treatment in a single NICU in a metropolitan area and whose infants died following consideration of withdrawing/withholding treatment. Initial chart reviews identified 31 families who met the outlined inclusion criteria. Of the 31 families, 8 could not be located,

5 declined participation, 5 participated in a pilot to refine the interview tool, and 12 families participated in the interviews for data collection.

Interviews were conducted using five open-ended questions to encourage informants to discover and relate the meaning of their experiences. Questions were developed from relevant literature, and feedback from pilot interviews; no mention was made if these questions had been used in previous research or if the tool was developed specifically for this study. Interview style and technique were developed using feedback from a mental health professional experienced in qualitative research. The decision to close data collection was made in consultation with a panel of expert researchers once saturation was determined. Consideration was given to the sensitivity of the nature of the study and the vulnerability of this population, and the appropriate time frame for contacting the informants was made in consultation with the Institutional Review Board. Although the sensitivity and vulnerability were addressed, no explanation was given of a plan to offer support if the discussion of these topics upset the families.

Data collection and analysis occurred simultaneously, until the researcher was able to articulate the significance and the relevance of the identified themes. Results were reviewed by experienced qualitative researchers and an expert in neonatal nursing to support credibility and objectivity. The results of this study showed that parents wanted to feel as though the health care providers genuinely cared for their infants; which in turn facilitated adequate information exchange about the infant's condition. Parents felt that active involvement in decision making contributed to a feeling of some control over their infant's treatment. Ethics was never a focus in the interviews. The importance of building trusting and supportive nurse-patient relationships with the families of infants in NICU was emphasized. If the exchange of information from the health care team to the parents was clear and understandable, the parents felt involved and part of the process. As indicated by the parents in the Pinch and Spielman studies (1990, 1993, 1996) these parents also focused on the importance of effective communication.

Family Centered Care and the NICU

Ample literature exists regarding the theoretical aspects and clinical applications of FCC including the importance of recognizing that the family has the greatest influence over a child's health and well-being (Griffin, 2006; Malusky, 2005; Franck & Callery, 2004; Shields, Pratt, Flenady, Davis, & Hunter, 2003). Research regarding outcomes or the effect of FCC on parental perceptions of their involvement in decision making is non-existent.

Bruns and Klein (2005) completed a retrospective evaluation of parents' perspectives of the implementation of FCC following discharge from a NICU. One of the themes identified by the families was the importance of straightforward, easy to understand information regarding the care of their infant (Bruns & Klein, 2005). Individualized care with the implementation of effective communication related to the specific family is what the parents wanted out of their NICU experience (Bruns and Klein). Harrison (1993) indentified the principles of FCC that parents of NICU graduates identified as important to them and future families in the NICU. The principle listed first in her discussion was the importance of open and honest communication between parents and professionals on medical and ethical issues. In a clinical article Cone, explained the importance of effective communication in promoting parental involvement in the NICU. Communication between the health care providers and parents needs to extend beyond, what she describes, as the "six C's" (Cone, 2007). In this philosophy, parents are only communicated with for one of the following reasons: convenience, condolence, congratulations, crisis, conflict resolution, and consent (Cone). Health care professionals hold the majority of responsibility when it comes to disseminating the overwhelming information to the parents regarding the care and treatment options available for their infant (Yee & Ross, 2006; Alderson, Hawthorne, & Killen, 2006) therefore it is imperative for effective lines of communication to exist that are appropriate/individualized for each individual family.

An underlying theme of effective communication between parents and health care professionals exists among much of the research reviewed. Authors

have explored the principles of FCC in relation to setting up a unit that is family-friendly in nature (Griffin, 2006; Malusky, 2005), although a lack of the connection between FCC and parental involvement in decision making remains. This gap in the literature directs the researcher to examine the impact that FCC has made on parental involvement in decision making since the foundational work of Pinch and Spielman in the 1990s.

Summary of Literature Review

Review of the literature has indicated that the majority of studies examined parental decision making for all infants admitted to a NICU. Samples were not normally specified to a specific age group, or diagnosis. Inclusion criteria were broad, often including all infants admitted to a level III intensive care unit. The studies discussed above almost always included the mothers in the sample, and only on occasion were the parental dyads interviewed. When looking at the principles of FCC, the views of both parents would be beneficial. Within the reviewed literature, little indication was given to the principles or philosophies that the NICUs operated from. As the neonatal unit from which the sample was derived, espouses the philosophy of FCC, did application of these principles from which the unit operates alter the parent's perspectives of their involvement in the decision making process? Although direct analysis of the unit's effectiveness of implementing FCC was not studied, it was the assumption of the researcher that the underlying principles were in fact enacted by the NICU staff, and thus, influenced the experiences of the parents. The research question that guided this study was: what were parents' perceptions of their involvement in decision making?

CHAPTER THREE

Methodology

An interpretive descriptive qualitative study was conducted to create meaningful description of how parents of extremely premature infants experience decision making within the NICU environment. Interpretive description was the method of choice as the foundation of this method “is the smaller scale qualitative investigation of a clinical phenomenon of interest to the discipline for the purpose of capturing themes and patterns within the subjective perceptions and generating interpretive description capable of informing clinical practice” (Thorne, Reimer, & O’Flynn-Magee, 2004, p. 5). Interpretive description is an approach which identifies patterns and themes as they occur in relation to the phenomenon of interest (Thorne, Con, McGuinness, McPherson, & Harris, 2006) while acknowledging that the existing knowledge provides the grounding and initial stepping stone to begin the qualitative inquiry (Thorne, Kirkham, & MacDonald-Emes, 1997). The existing knowledge for this study was my own experience working in a level three NICU. Having cared for many premature infants and their families I wanted to gain a deeper understanding of how these parents made decisions.

Interpretive description allows for recognition of the contextual and constructed nature of the experience in which “concern for the experience of the aggregate include the individual” (Irwin, Thorne, & Varcoe, 2002, p. 49). In relation to the purpose of this study, this approach recognizes that the parents who have lived through the NICU experience were the best source of expert knowledge regarding those experiences (Thorne, Kirkham, & MacDonald-Emes, 1997). These parents’ perceptions of their involvement in decision making could provide insight into how families are included in the decision making process in the future. The findings from interpretive description research aim to be accessible to the practice of the discipline for the purpose of clinical reasoning, enlightening available insight for practice decisions, and creating explanations for the variability that occurs within the practice setting (Thorne, Reimer, & O’Flynn-Magee, 2004). The challenge comes in the transformation of the parental

experiences (raw data) into interpretive findings (Thorne et al., 2004, Sandelowski & Barroso, 2003).

Sample

A purposeful sample was selected of parents of premature infants born at 24-26 weeks gestation. This gestational age was selected as my clinical experience indicated this group of parents faced numerous treatment decisions during their child's hospital stay in the NICU. Recruitment was done through the Glenrose Rehabilitation Hospital's Neonatal and Infant Follow-up Clinic. The follow up clinic is a place where all premature infants less than 1250 grams are referred to where they are assessed by various members of the interdisciplinary team. Inclusion criteria were infants born between 24-26 weeks gestation and whose parents' lived within the Edmonton area, so they were accessible for face-to-face interviews. Parents were invited to participate in the study during one of their child's follow-up appointments, usually the six month appointment. Contact was initiated by a staff member from the follow-up clinic during that appointment. Those parents interested in participating were presented with preliminary information (See Appendix A) and then given the opportunity to release their phone number (Appendix B) so that I could contact them. I contacted the parents by telephone and further explained the study to them. If they confirmed their interest in study participation I proceeded by setting up an interview time with them. Detailed information about the study (Appendix C) was discussed with the parent prior to the start of the interview as well as signed consent (Appendix D).

Both the mothers and fathers were invited to participate in the interviews, although single parents were not excluded. Interviews were conducted with both parents where possible although three interviews were conducted with only the mother at a time that was convenient for her. The interviews with the couples were informative and it was interesting to hear them retell their experience as a couple. Those interviews that were done with only the mother also provided rich data about their relationship with their significant other as the mothers often referred to the experiences as "their" experiences.

Morse and Field (1995) identified two principles of sampling that are fundamental to ensuring the quality of the qualitative research is not threatened. Sample selection begins with purposeful or theoretical selection that dictates that the researcher knows who is best to invite to participate in the study based on the theoretical needs of the study and the participants' knowledge (Morse & Field, 1995). This principle directed me to include the parents of extremely premature infants to determine what the process of decision making was like for them. The second principle is adequacy, meaning that "enough data is available to develop a full and rich description of the phenomenon" (Morse & Field, 1995, p.80). With the principles of appropriateness and adequacy in mind, a sample size of 6-9 parents was set prior to initiation of data collection.

Data Collection

Data collection and analysis occurred concurrently, and in an inductive manner whereby meaning about what the parents said was identified (Thorne, Kirkham, & MacDonald-Emes, 1997). Interviews were conducted with each participant(s), beginning with the collection of demographic information. The participant's age, sex, level of education, number of children, and occupation were noted (Appendix E). The interviews were conducted within the family's homes, at a time that was convenient for them. Interviews were semi-structured in nature, with the goal of eliciting the participants' experiences. An open-ended, general question asking the participants to take me back to the moment when they realized they were going to have a premature infant began the interview. The participants were encouraged to re-tell their experience as they remember it. Gentle probing questions in relation to the birth of their premature infant, through the potential complications that may have arisen during their child's stay in the NICU and the decision making processes that were involved were used if needed to enrich the parents' description of their experiences (Appendix F).

Data Analysis

Interviews were audio-recorded and transcribed verbatim. Data analysis began immediately following the interview by listening to the recorded interview. Field notes were written by the researcher to attempt to capture emotions and

sentiments that may have been lost through audio-recording. Becoming completely familiar with each interview allowed for a more in-depth/detailed description of the participants' experiences and facilitated reflection on the each parent's/couple's experience in its entirety. Following transcription, I began reading and re-reading the data to fully understand and describe each participant's experience prior to seeking commonalities among the participants (Morse & Field, 1995). Interpretive description requires the researcher to come to know the individual cases intimately before commonalities among the cases are identified (Thorne, Kirkham, & MacDonald-Emes, 1997).

Following each interview I also recorded my thoughts about the interview, the interview process and my initial impressions of the parent's accounts in my reflective journal. The reflective journal was a means to identify my own feelings and my part in data generation and analysis throughout the data collection and analysis process. Open interviews used in qualitative research do not exist without some degree of reflexivity between the researcher and the participant. According to Koch and Harrington (1998) reflexive research is characterized by the ongoing self-critique and self-appraisal that can be captured in a reflective journal. Throughout this process, I myself became a parent. My daughter was born at 40 weeks gestation, healthy, and came home with me 24 hours after she was born. Some of the interviews I had completed while I was pregnant and some in my daughter's first year of life. The experience of becoming a mother impacted me in a way I could have never imagined. I did not have to make any life and death decisions for my daughter, and yet when I listened to these families experiences I could not help but wonder what would I have done? If I was in their shoes with my first child, would my decisions have been any different? From the instant my daughter entered the world an instinct of protecting and keeping her safe consumed me; if these feelings consumed me with a healthy term infant, what did the parents experience when their baby was born so prematurely? The reflexivity between me as a researcher and the parents in this study was impacted by my own experience of motherhood.

Next, the data was analyzed to identify commonalities among the participants' experiences. There were common themes identified among the families: the strain of the culture, the importance of relationships and the impact that these components played on decision making. As well there were unique themes identified that indicated that not everyone experienced decision making in the same manner. Effective interpretive description "distinguishes eccentricities from commonalities" (Thorne, Kirkham, & MacDonald-Emes, 1997, p. 174) within the analyzing process. Thorne and colleagues (1997) identified questions that should be used to guide the analysis process; the researcher should be asking "what is happening here?" and "what am I learning about this?" (p. 174). By asking these generic questions the researcher should be able to produce a coherent framework in which to analyze the data which leaves the contextual nature of the data intact (Thorne, et al., 1997; Thorne, Reimer, & O'Flynn-Magee, 2004). In interpretive description it is imperative to recognize that the researcher is driving the interpretation, and regardless of what constitutes the data, the researcher determines what is generated as findings (Thorne, at al., 2004). By the nature of interpretation, interpretive description yields "constructed truths" as opposed to "facts," in which the researcher structures the aspects of the phenomenon in a new a meaningful way (Thorne, et al., 2004) hopefully with application to the practice discipline.

Following the questioning of the data and identification of commonalities, interpretation of the interrelationships among the themes occurred. Particularly descriptive parent quotes were incorporated into my interpretative writing to provide a realistic portrayal to the reader (Morse & Field, 1995). The interrelationships between themes and parental experiences as well as parents' voices through the chosen quotes serve to enrich the interpretation of data as a whole.

Quality of the Research

Ensuring rigor in a qualitative study requires certain steps be taken during the research process. The early work of Guba and Lincoln, in the 1980s, introduced terminology for the issues of reliability and validity that surround

qualitative inquiry. Since the 1980's many qualitative researchers have developed their own interpretations of ensuring rigor within qualitative studies, and debates exist regarding what constitutes quality criteria (Caelli, Ray & Mill, 2003).

Emden and Sandelowski (1998, 1999) explain that no one set of evaluative criteria can be expected to fit for every qualitative inquiry, and the researcher will be expected to use the means appropriate for his/her research method.

Morse et al. (2002) refer to their techniques as the process of verification. Within this process the "researcher moves back and forth between the design and implementation to ensure congruence among question formulation, literature, recruitment, data collection strategies, and analysis" (Morse et al., p. 10). The first step is to ensure investigator responsiveness; meaning that the researcher must remain open, use sensitivity, creativity and insight, and be willing to relinquish any ideas that are poorly supported regardless of the personal excitement that may have been initially felt about them (Morse et al.). I can attest that the initial biases that lead me to this research project was changed after speaking with these parents. The parents were well informed and able to recount the probabilities and statistics given to them throughout their NICU experience, their decision making was about more than just information. This was where, I as a researcher, had to let go of the notion the parents were not well informed.

The next steps are the verification strategies which include: ensuring methodological coherence, sampling sufficiency, developing a "dynamic" relationship between sampling, data collection and analysis, thinking theoretically and theory development (Morse et al., 2002). Ensuring methodological coherence involves showing the congruence between the research question and the components of the method (Morse et al.). Throughout this study, it was repeatedly apparent that interpretive description was a "good fit" for my clinically based question about parental perceptions of decision making. With guidance from my co-supervisors and two key meetings where we discussed how to move my findings from description to a more interpretive level I learned about the iterative process of data collection and analysis that interpretive description demands (Thorne, Reimer, & O'Flynn-Magee, 2004). The appropriateness of the sample

has already been discussed above, in relation to the researcher purposefully selecting the sample to gain the most insight related to the phenomenon of interest (Morse & Field, 1995; Morse et. al.; Thorne, Reimer, & O'Flynn-Magee, 2004). Morse and colleagues (2002) refer to the third step in their verification process as collecting and analyzing the data concurrently, and ascertain that this interaction is the essence of attaining reliability and validity within qualitative research. While concurrent collection and analysis is occurring, the researcher must be able to think theoretically; meaning, the researcher must be able to take ideas that emerge from the new data and verify those ideas within the data that has already been collected (Morse et al.). These periods of critical reflection allow the researcher to move toward an interpretation that is built upon a solid foundation through a process of continual “checking and re-checking” (Morse et al., p. 13). The last aspect of Morse and colleagues verification strategies is theory development which is developed through two mechanisms: as an outcome of the research process, and as a template for comparison and further development. The definition of “theory development” may be applied loosely to interpretive description, the general concepts of identifying commonalities and meaningful interpretations can be extrapolated. “The product of an interpretive description, or the object of the exercise, is a coherent description that taps thematic patterns and commonalities believed to characterize the phenomenon that is being studied...” (Thorne, et al., 2004, pp. 7).

Ethical Considerations

Ethical Approval

Ethical approval for this study was obtained from the Health Research Ethics Board, Panel B at the University of Alberta prior to the onset of the project. Administrative approval was obtained from the Glenrose Rehabilitation Hospital. The information letter describing the nature of the study, and the consent form was given to the potential participants along with my contact number. I obtained written consent prior to the interview commencing. I addressed the questions or concerns of the parents during the informed consent process and reassured them that the interview could have been stopped at any point, with no need for

explanation. All of the parents were eager to share their experience of having a premature infant, and none wished to stop the interview.

Vulnerability of the Participants

I paid attention to the sensitive nature of the discussion topic and the vulnerability of the participants. The risk versus benefit ratio in discussing sensitive matters was analyzed on a continual basis throughout the interview process. It has been recognized that participating in qualitative interviews can prove to be a therapeutic, healing and an empowering experience (Orb, Eisenhauer, Wynaden, 2001). The interviews gave the parents an opportunity to discuss their experiences in a genuine and safe environment, where they were free to tell their story about how they remembered their NICU experience and their involvement in decision making. I identified the difference between the expression of emotion and emotional distress; when a parent became overwhelmed with emotion I attained consent to continue with the interview and no instances of emotional distress were witnessed.

Anonymity and Confidentiality

In accordance with the ethical research guidelines for Registered Nurses, actions were taken to assure anonymity and confidentiality to the participants (Canadian Nurses Association, 2002). Participants' names were removed from the transcripts and pseudonyms used, and in instances where specific diagnoses may have distinguishing features, these also were altered within the findings. I informed the participants of the possibility of publication of direct quotes from the data collected and assured them that no reference would be made to their identity. Data collected was protected and stored in a secure manner in a locked cabinet or in a password protected computer file. Data collected will be securely stored for a minimum of seven years following completion of the study.

During the final stages of writing with feedback from my thesis committee, I realized that there were certain aspects of the written analysis that could make the families who participated in the research identifiable. The uniqueness of specific family's experiences potentially made their identity known to those who worked within the NICU environment, and cared for their infant(s)

during their NICU stay. The unique nature of each family's experience greatly added to the analysis and interpretation of the data. The manner in which each family's story was unveiled throughout the text contributed to findings that could potentially change clinical practice. Because this type of writing presented a potential threat to anonymity, I contacted the parents involved in the research project to discuss this possibility. Via telephone, I contacted the three families whose stories had unique characteristics. I utilized the contact information I had from their initial recruitment. Consent (Appendix G) was given by the parents contacted to have identifying details written into the findings even if it meant that the health care professionals may recognize their family's story when findings are presented to them.

Researcher Participation

Recruitment of parents as participants was conducted following discharge from the NICU as I was currently working as a Neonatal Transport Nurse on the unit at the time of recruitment. Due to the nature of the transport role, it was feasible to avoid direct patient care with the infants and their families included in this study. None of the parents recognized me from their stay in the NICU. It was my goal to make the parents feel completely candid in re-telling their story during the interview, and not have the realization that I was a nurse on the unit where their child was born a limitation to the quality of their expression of the experience. During most of the interviews it was revealed that I was a nurse on the unit where their infant(s) had been, and in only one interview did I feel that this was a limitation. I felt that these parents did not want to say anything about the care their infant received that might offend me.

Limitations

The parents identified through the follow-up clinic could have been potentially biased by the selection criteria used by the staff in identifying them. To compensate for this potential bias, I asked the staff to approach all parents who had a premature infant between 24-26 weeks gestation, living in the Capital Health region.

I interviewed parents within 12 months of discharge in hopes that their NICU experience was still “fresh” within their minds. The 12 month time frame was chosen in attempt to capture a true reflection of the NICU experience, and not a reflection that may be potentially influenced by the decisions that were made during the NICU experience (i.e. children with developmental delays, brain damage, auditory or visual impairments, etc.).

Acknowledging my own limitations as a researcher, this was the first project that I had participated in. I used experienced researchers to guide me through all of the phases of the research process, from data collection through analysis and interpretation of findings. An experienced researcher, with a background in interpretive inquiry, was utilized throughout the data analysis process.

CHAPTER FOUR

FINDINGS

Introduction of the Families

Five interviews were conducted with a total of seven parents. All parents (and their babies) were assigned pseudonyms which I chose. Two sets of parents were interviewed together; Debbie and John and Anna and Mark. Three mothers were interviewed alone; Saira, Tanya and Kara. Below is a brief description of their experiences.

Debbie and John

Debbie and John conceived twins through in vitro fertilization. At 19 weeks gestation, Debbie and John discovered that one of the twins had died in utero. Debbie's membranes ruptured at 24 weeks gestation and she was placed on bed rest. At 25 weeks, four days, Francis was born weighing 720 grams. Francis' course in the NICU involved repeated intubations, urinary tract infections, and steroids for chronic lung disease to name a few of his complications. Francis, along with relieved parents Debbie and John, was discharged after spending 102 days in the NICU.

Saira

Saira, the mother of three children ages 15, 13 and six years, did not expect to conceive Mikal as she had an intrauterine device (IUD) in place for contraception. Due to the IUD implanting in her placenta, she began to have bleeding early in her pregnancy. She was repeatedly offered therapeutic termination, and due to her religious belief refused this as an option. Saira was placed on bed rest at 23 weeks gestation as her cervix was beginning to dilate. Despite the hospitalized bed rest, Mikal was born at 25 weeks gestation weighing 844 grams. Mikal was faced with repeated intubations, three blood transfusions, and numerous infections. Saira was in constant conflict with herself; wanting to be at the hospital with her son, and needing to tend to her responsibilities as a mother and wife to her children and husband. Mikal was discharged home on oxygen therapy after approximately 90 days in the NICU.

Anna and Mark

Anna and Mark had a long history of infertility when they finally conceived twins with in vitro fertilization. At 19 weeks gestation Anna's cervix began to shorten. A suture was inserted into her cervix and she was placed on bed rest in an attempt to prolong the pregnancy. At 23 weeks gestation Anna's membranes ruptured, and the twins were born seven days later at 24 weeks gestation. Nathan was critically ill during the first few days of his life and the couple was faced with deciding to continue treatment for their son. Following Nathan's recovery, Nicholas became critically ill and required surgery. Nicholas lived in the NICU for four months before he died from necrotizing enterocolitis. Nathan was discharged from the NICU and went home with his parents, 2 weeks later.

Tanya

Tanya was the mother of a toddler when she found out she was pregnant with her second child. She had no pregnancy complications until her membranes ruptured at 24 weeks gestation. She was placed on bed rest in a referring hospital, until labour progressed ten days later. She was immediately transferred via ambulance to the tertiary hospital. Cameron was born at 26 weeks gestation. Cameron was intubated at birth, received a blood transfusion and had a urinary tract infection. He spent 66 days in the NICU before being discharged home.

Kara

Kara was expecting her first child when she learned, at her 18 week ultrasound, that she was pregnant with twins. At 24 weeks gestation, completely unexpectedly, her membranes ruptured. Kara was rushed to the hospital and delivered Ethan the next morning. As the twins were within their own amniotic sacs, Emma was not born for two more days. Ethan and Emma both had their own share of complications throughout their NICU stay. They both required cardiac surgery to close a fetal duct that had remained open after birth. Four months following their arrival into the world, they were discharged home from the NICU.

The following findings are my thematic analysis of the parents' recollection of their experience of having an infant born extremely premature. I

have interpreted the families' experiences and identified three themes: plunged into a strange land: the culture shock of the NICU; enduring in a strange land: will we get through this; and the cart before the horse: information and decision making. The culture of the NICU was the backdrop against which the parents experienced everything; their every relationship, and their every decision. This culture was unknown, foreign and placed a great deal of strain on the parents in this study. Although the themes will be discussed individually, it is my hope to depict how difficult it was to separate the relationships formed from the culture wherein they were formed; the decisions made from the culture wherein they were made. Overlap exists between the identified themes of culture, relationship and decision making.

Plunged into a Strange Land: Culture Shock and the NICU

When the parents in this study arrived in the NICU to see their premature baby, they were plunged into a strange land which they were not prepared to encounter. They knew nothing about the NICU; nothing about the culture, the language, or the norms. The unfamiliar environment and the new language were especially distressing for the parents who were not only plunged into a strange land but also expected to cope with the devastating reality of having a critically ill baby.

Where are we?

To most parents the NICU was a foreign and scary place. Parents described feelings of being overwhelmed and even awestruck by this world, this culture, which they never even knew existed prior to their arrival.

Anna and Mark's twins Nathan and Nicholas were born at 24 weeks gestation. Mark recounted his first experiences in the NICU:

It was chaotic... the red light... and the beeping. At that time that worried me. That really scared me. I didn't know what the red light was meaning... you're worried that something's happening, yet those were all normal sounds. But of course, we learned that a lot through the NICU... what was normal.

Tanya and Kevin's son was born at 26 weeks gestation, and Tanya recalled her first encounter in the NICU. "All I could see were tubes, and needles, and respiratory machines, and things like that... Well, it is... very scary up there. It's like your own little world up there." Debbie and John had a similar recollection of the NICU when their son was born at 25 weeks gestation. "One thing is when that machine go beep... somehow they should explain [to] parents... that this is very common. Everything, everything it beep off, [and I would] jump." (John). The commonalities in the parents' experiences of the NICU environment were remarkable. Despite having different circumstances leading to their baby's admission, their initial reaction to the environment was similar. What was all of the equipment surrounding their child? What were all of the noises and alarms? What did the alarms mean? These parents were plunged into an environment that was completely foreign and strange. The technology, alone, was overwhelming and amazing at the same time; the amount of equipment needed for their child was astonishing. How could their tiny infant require so many machines? These parents soon realized that the life of their baby was dependent on this strange but incredible technology.

Technology, in our society, is glamorized by the media: stories of infants being resuscitated at earlier and earlier gestations, the smallest baby to ever survive, the premature octuplets, and so on. The public is left in awe of what medical technology can now do to save the lives of premature infants. Kara and Jeff felt thankful to have delivered their premature twins in Edmonton. "We have to be so grateful that we were in a large Canadian city where they have the medical resources and the doctors that were trained." They felt fortunate to be living in a city where they believed their twins would get the best medical care possible. At the same time, they were distressed that this technology was needed to keep their twins alive, who were born at 24 weeks gestation.

Given their role as parents of a sick baby, the parents in this study were forced to make a transition into this new and strange environment, which evoked emotions and stresses similar to that of a traveler experiencing culture shock. They were placed into a "culture" that was unfamiliar and they were expected to

adapt to and cope with new situations as they arose. Ineson, Lyons and Branston (2006) identified six aspects of culture shock that a traveler may experience: sense of loss; the strain and effort required to adapt; confusion in personal roles and values; rejection by new culture; anxiety with new situation; and, feelings of powerlessness in the new environment. These aspects of culture shock mirror the parents' accounts of experiencing NICU for the first time.

For Anna and Mark the environment combined with their circumstances lead to feelings of loss: "I was just so alone... you're isolated ...we had nothing normal. There was nothing normal about this pregnancy, about getting pregnant... there was nothing normal about giving birth." For this couple it was a loss of their hopes and dreams for a normal conception as the twins were conceived via in vitro fertilization, loss of the normal pregnancy as Anna was on bed rest for a shortened cervix early in the pregnancy, and then loss of normal, healthy labour and delivery as the twins were delivered by an emergency caesarean section. For Anna and Mark, their childbearing journey was nothing that they had expected and they experienced culture shock.

Tanya felt a disconnection with the NICU environment perhaps caused by the strain and effort required to adapt, or by the confusion she felt related to her new role. Her feelings of not being ready for her son to come into the world, for example not having a car seat, and coming home from the hospital without her child were stressors that made her experience "weird." Having her milk come in and not having a baby to breastfeed, phoning family and friends and not knowing what to tell them, not knowing if their newborn son would survive, were all experiences that left Tanya confused with her role as a mother. "We're new parents again because we have a premature baby. We don't know if he's going to come out of the hospital... I can remember the car ride coming home, going like what's wrong?" Tanya expected the birth of her second child to be familiar and predictable; instead the culture shock of the NICU environment left her feeling confused. The environment and culture did not correlate to anything Tanya or Kevin were used to. Tanya recalled the neonatologist seeing her son for the first time: "I guess he was big for his [age], like his doctor saw him, and said 'Oh, my

God he's huge.' And I'm looking at her, and it's like okay, if he was [eight pounds 11 ounces], so I don't see that." Cameron weighed two pounds four ounces, a good size for a baby born at 26 weeks gestation, but to Tanya and Kevin he was the smallest baby they had ever seen and therefore could not understand how the doctor could think he was "huge." There was a disconnection between themselves and those who were caring for their child. Being able to relate to what was commonplace in this new environment was a challenge for this family to deal with. The staff members in the NICU are conditioned to their environment; the abnormal and strange occurrences for the parents are part of the normal and everyday processes for the staff. To a staff member who cares for the extremely premature infants, a child born at two and a half pounds is "huge" in comparison to a child weighing 450 grams; but to a parent who has never seen a baby weighing 450 grams their child born at two and a half pounds is the smallest human being they have ever seen. The disconnection with the environment was a source of anxiety for this couple.

Are We Speaking the Same Language?

The language of the NICU was unfamiliar to most parents who experienced it and contributed to the parents' anxiety about their new situation. The medical terminology used by the staff in the NICU left the parents, again, feeling as though they were on foreign soil. Despite these feelings of foreignness, the parents in this study, adapted quickly and "learned the lay of the land" in a short period of time. They picked up the "lingo" and began to "talk the talk" of the NICU. They used the medical terms to describe what was happening to their child, or to inquire about their child's wellbeing. Mark and Anna were forced to quickly adjust to their new circumstances and grasp the language that was being used to explain how their twins were doing. Nathan was critically ill during the first few days of his life, and Anna and Mark were forced to make life and death decisions for their son. Listening to Mark retell their experience, he spoke in a manner and with the language of a seasoned staff member.

He was paralyzed at the time, and motionless, and that's the devastating thing to see, when you haven't seen it before... he's not coming off the

oscillator...He was already up in the high 90s on the oxygen requirements, he was on all the maximums of ventilation requirements, there was nothing more that they could do, medically, or, mechanically, I suppose. Anna and Mark spoke in the same language that they had been submerged in. They knew about the oxygen saturations, the ventilator settings, and the ominous outcome of their child being paralysed and ventilated with high frequency oscillation. This couple was charged with the responsibility of deciding whether or not to discontinue aggressive treatment for their newborn son. This example reveals the impact that the culture of the NICU environment can have on decision making. Anna and Mark were not only new parents in a strange environment, but they needed to be responsible decision makers in an area for which they had little understanding of the language.

Kara and Jeff also adapted quickly to the language of the NICU. For Kara, it was important to her to be able to understand and discuss her twins' medical conditions as she wanted those caring for her twins to know that she and Jeff were dedicated, loving and supportive parents. She wanted the staff to see that her infants were more than just another set of 24 week gestation twins; that they were members of a family. Kara became the voice for her twins in a foreign land, submersing herself in the culture and learning the "lingo."

When you [are present for daily rounds and read through the charts] often enough, you really get to know the lingo. And for me too it was also wanting the medical staff to know that Emma and Ethan have family that care about them and parents that are committed to wanting to know what their issues were so that we could do our best to help them with that and I wanted the doctors in particular to know these and other things.

For most of the parents in this study the strange and foreign language quickly became normal place. They adapted to the culture and learned what was necessary to parent their infant(s) in that new environment. After the initial shock to their new environment the parents wondered – will we get through this?

Enduring in a Strange Land: Will We Get Through This?

The overwhelmingly foreign culture of the NICU left some of these parents feeling powerless. They realized that as the parents of a premature infant they were unable to provide everything that their baby needed to survive. In fact, there was little they could do for their infant(s) and they realized that they had to rely on strangers to provide lifesaving care that their child needed to survive. The relationships developed between themselves, as parents, and the staff helped them trust that their infant was in good hands. These relationships either helped them endure their stay in the strange land or made their stay more excruciating both when they first arrived in the NICU and as they settled in for their long stay.

Feeling Powerless: The Importance of Relationships

The early relationships built between the parents and the members of the healthcare team helped the parents manage the feelings of powerlessness they felt regarding the impending delivery of their premature infant. A memory that stood out for Mark was when the neonatal nurse practitioner brought him to where one of his twin sons was immediately after the birth. She had Mark hold his son's hand and cut the umbilical cord. The few minutes this gesture took meant the world to Mark as it was the first "normal" experience he had encountered. In Mark's words:

And then [the nurse practitioner] comes to me and says "do you want to see your son?" Of course, "Yes," so she brought me back, and she had me, she had Nicholas hold my finger, and I cut the umbilical cord and that was, like such a simple moment because up to that point, we had nothing normal.

The nurse practitioner recognized the importance of having a father intimately involved in his child's birth and provided him with some sense of normal. In a situation where Mark lacked control, the nurse practitioner provided him with the opportunity to be able to contribute something to the situation.

The next event that stood out for Mark as he recounted his experiences immediately after his twin sons were born, was an orienting conversation that occurred soon after he arrived to the NICU. Those initial interventions provided

Mark the ability to form relationships with those health care professionals that would be caring for his infants.

I remember sitting on the chair, or I remember somebody bringing me a chair, and sitting me down, and giving me a glass of water. And I have no idea who it was, and talking me through what was going on. I don't even remember what they said, or anything. I just remember that person being there, and taking that effort to be with me was just, I'll never forget that. Being in a foreign place and enduring extreme stress, Mark was grateful to have these strangers make the effort to normalize the experience, by allowing him to cut the umbilical cord, and comfort him by not leaving him alone and isolated during his twins' admission. There was also an experience when a neonatologist took a moment to explain an ultrasound that Nicholas had.

So [the neonatologist] was behind me and she put her hand on my shoulder and she said, "That's a good thing, that's a good thing." And I too, like had tears. I knew it was a good thing, but I mean it was, it's such a personal touch, and that way just really meant a lot. I'll never forget that. The personal, human touch from that neonatologist solidified their relationship and made Mark feel as though he and his twins were important to this physician, and that someone truly cared about them as a family. Not only was the physical touch important for Mark, but to hear the physician calm reassurance "that's a good thing" was important to Mark. This exemplified how quickly relationships with the various members of the health care team developed within the fast-paced culture of the NICU. Within the foreign environment of the NICU, a genuine relationship was developed between Mark and this physician. Relationships such as this, gave the parents some assurance that they would get through this unexpected and devastating experience.

Some of the powerlessness parents experienced was as a result of having to place their infant(s) care into the hands of strangers. The establishment of genuine relationships between the staff and the parents enabled them to develop the trust in those that would be caring for their child; to endure the culture shock. Tanya gained a sense of control from the relationships she developed with various

staff members. “The [staff nurse] would spend, you know, a couple of hours with me, and just kind of sit and talk, and, and then go over a few things, and stuff.” It meant a great deal to Tanya to have this staff nurse take the time to sit and talk about how things were progressing. When the staff members were able to recognize the parents needs and respond in a manner that facilitated their growth as a family, it helped to give them a sense that the strangers who cared for their child really cared about their baby, their family, and them as a person. It helped to reduce the anxiety that these parents felt related to their stressful circumstances. The relationships developed gave the parents what they needed to view the staff as more than the strangers caring for their child.

As parents settled into the NICU, they identified ways to gain a sense of control over their new environment which left them feeling powerless; an aspect of culture shock. Anna and Mark decorated the twins’ bedsides with pictures and items from home in an attempt to render the environment more familiar, more home-like. They even referred to the NICU as their nursery: “You try and make a home; I mean this is our nursery, this is where we live.” Over time they began to refer to the staff on the unit as family: “[our] family is here, us, and the nurses and doctors. We had got to be a family.” Despite knowing little personal information about those staff members caring for their sons, Mark and Anna viewed them as family. These strangers provided for and cared for their children in the ways that they, as parents, could not. These strangers knew their boys almost as well as they did as parents.

Anna and Mark recalled one of their fondest memories, with their new found family, the celebration of the twins’ “zero birthday” (Anna’s due date).

We had a lot of fun. We had the zero birthday party. And it was March 18th, and we made everybody wear a hat, and we brought in a huge cake. It was Happy Zero Birthday, Nicholas and Nathan, and the nurses actually put balloons up in the pod, decorated Nathan’s little spot... It was one of the funniest, most fun days we ever had.

The birthday party with their “family” was a happy and momentous day that stands out to Anna and Mark as a significant memory from their NICU experience.

Immense gratitude was felt for the staff members who cared for their children. Mark was thankful for the staff nurse who had talked him through what to expect just before Nicholas died. Anna and Mark recounted having a staff nurse come in on her day off to be with them in their time of grief. After Nicholas died, the nurse provided Anna and Mark with the opportunity to give Nicholas his first tub bath; this nursing intervention stood out in Mark’s memory. These are memories that Anna and Mark will cherish forever.

Mark: The nurses were beautiful! Again it was [nurse B], and then [nurse F], so she just happened to be there for three of the most critical amazing moments of our experience.

Anna: Yeah. Thank God!

Mark: So then I think back to that discussion that she told me about how things would happen when [Nicholas would die] that this is exactly what was happening. You know, and again, that whole discussion, just came back to my mind. She was so right, you know, and so calming, and the way they took care. And then, [nurse F] came in on her day off, and then, she brought in the tub, and had *us* bathe him. And you know, like he never got a real tub bath.

Forming relationships and feeling like a family with the staff members helped parents, in this study, celebrate momentous happy occasions, and cope with devastating grief.

Another Culture Change

Anna and Mark had a negative experience when Nicholas was transferred to the surgical NICU for a surgical consult followed by abdominal surgery. They had acclimatised to the non-surgical NICU and now they were plunged into another new environment with another new culture. Within the environment of the non-surgical NICU they had become the experts concerning the unique needs of their sons. They knew their boys; what calmed them, what stressed them,

positions they were the most comfortable in. Moving Nicholas to another facility split the family up, and placed a great deal of strain on Anna and Mark. They had high expectations for how they would be treated at the surgical site, and were shocked that the two units did not operate in a similar fashion.

It was just an awful, awful experience, they wouldn't pay attention to what we had to say it was not a team at all, whatsoever. We were certainly not part of that team...the climate there was *horrible* for parents. I mean, the facility itself is no fun at all, so that's part of it... By this time, it had already been three months, or two months into the process, I understood stuff, I wasn't stupid. I certainly wasn't a doctor, but I knew stuff. But I felt like my opinions weren't even listened to, and during rounds... everybody would stand in a circle, in front of me, with their backs to me, instead of making me feel part of the group.

The feelings of being a family with the staff and working together as a team to ensure that their twins had the best care possible were gone. Anna, Mark and Nicholas were not embraced as a family; they were left feeling rejected by the new culture. Mark found the new environment and the new culture distressing.

At the [non-surgical NICU] we felt like we were the most important family. I'm sure every family felt that way. But we felt that, we were the most important family, and that everybody just stopped whatever they were doing for us it seemed. But yet, I could tell that they were doing that with other people. At the [surgical site] we felt like we were in the way... like *literally in the way*.

When transferred to the surgical NICU, they were again immersed into a culture where they had minimal understanding of the language, and were completely unfamiliar with the daily operations. Being seen as "in the way" left Mark feeling as though he did not belong in the new culture, he was on the outside looking in. He was profoundly disappointed that his three months of experience at the non-surgical NICU did not translate into immediate acceptance into the surgical NICU culture.

Kara and Jeff also experienced what it was like to have one of their twins transferred to the surgical NICU. The stress they encountered during their transition was with the new environment initially. Kara felt strongly that the unit was not prepared to care for an infant Ethan's size. It was the first time that she actually questioned whether or not her son was in the "right place."

It was not good. It was not pleasant. We felt that they were totally unprepared for a preemie Ethan's size. The care at the NICU was excellent and it seemed like the facility was well organized and when we were [there], don't get me wrong, the doctors and the nurses were fantastic. They just didn't seem to have the setup for kids as small as Ethan. Like just little things. Like they didn't have a diaper that fit him properly and it was a lot noisier and more open room and he couldn't take any noise or any light or stimulation...He didn't seem to be getting the right kind of respiratory equipment as well. I remember that he had actually self-extubated and they didn't have the right size of tube to put down, so that was, that was pretty stressful while they madly searched and hunted, I think they ended up bringing one in from the NICU. I remember feeling like, for the first time I really doubted whether he was in the right place and I knew that he needed surgery and I knew that there was nowhere else that we could've gone...But I felt like I wanted to go back to NICU so badly and my husband actually, my husband got really angry about it and he actually talked to [the medical director]...they had a really good discussion and in all fairness, when Emma went for her surgery, it was ten days later, I felt like they were a lot more prepared for her.

The environment was so different to Kara. How could she place her trust in those caring for her son when they could not even provide a diaper that fit? Confidence in the competence of those caring for your loved one is essential for family members. Kara also felt the differences between how they, as parents, were treated and she tried to give the benefit of doubt when describing her experience.

I, maybe it was just because I was at the NICU a lot longer...we were present for rounds at the [surgical NICU] but I didn't really get the sort of

inclusionary feel that I got at the NICU, and that might've just been because we were only there for a few days and they didn't really get the chance to know us very well. I found that the nurses [there] were probably our main contact. Like I know that the neonatologist was present during rounds but we didn't really develop much of a relationship with him and again that might have been because we weren't there for very long, right? We were just there for a few days, a couple of times.

There was a lack of relationship development, which Kara attributed to only being at the surgical site for a few days, but this ultimately left her feeling as though she was not an important member of the team caring for her children.

A Familiar Face: Seeing Someone from Home

What does it mean to see a familiar face when parents are in a strange land? Debbie and John recalled what it was like to see a familiar face in the operating room prior to the delivery of their son:

Well, I think it worked out good cause one of mom's good friends, she's the head of the...nursery, so we kind of knew who [she was], so [we] felt a little bit better...I think [she] got off work at I think, at 3:30 or four o'clock and she stayed...so it helped out, a lot.

Having this friend of their mother, who they may have barely even known, provided a sense of comfort in a scary and unfamiliar setting. This was a person who provided a connection to their everyday, normal life. This was a person from their "homeland;" from the life that knew and understood.

Kevin's sister was a nurse working within the NICU, and this dramatically affected his and Tanya's experience. This made their experience even more unique than other families with similar circumstances.

And you know I would have the nurse write something down because I knew [my sister-in-law] would ask me. And I would just look over at [Kevin's sister], and say "okay, what does this mean?" And she said, "oh, it's good, it's good."

Having an “inside” go-to person helped Tanya and Kevin adapt to the NICU environment. Tanya knew she could rely on Kevin’s sister to provide her with the information she would need to make decisions and cope with their circumstances.

For Tanya and Kevin the downside of being related to a staff member was the assumption about what information was provided to them by their sister-in-law. “I had questioned a nurse on this, and she said, ‘Well, [Kevin’s sister] should have done that.’ And I said, ‘No, she shouldn’t have. She wasn’t our nurse.’” This proved to be a source of frustration when it came to day-to-day happenings; the assumptions were that Tanya would have already been told various commonplace things by her insider go-to person. These assumptions seem to exist throughout the health care system; the assumptions that if you are a nurse or related to a nurse, you should understand what the health care professional was talking about. I have had a sick parent and when the physician caring for her learned that I had a nursing background he immediately spoke to me as though I had more knowledge about her condition than I actually did. While I respected the fact that he spoke to me in medical terms, I needed to clarify with him that the world of neonatology is different from adults. I think as health care professionals we do this as a form of respect for each other’s knowledge, forgetting that the person may have no experience in that particular area. Tanya may have heard things from her sister-in-law, but it was still the responsibility of the staff to ensure that she had the knowledge and resources that the staff would provide to any other family.

Enduring Together: Strain on the Marriage

Speaking from my own personal experience, tension exists between my husband and I when we travel. There are inevitable arguments about packing, struggles to make it to the airport on time, misunderstandings about who is in charge of the tickets and passports, all of this for a vacation that we planned and anticipated. I am not meaning to sound disrespectful by comparing the experience of the parents in my study to my own holiday travels, but to provide a frame of reference to understand what it was like for these parents. The anxieties of travelling spills into my relationship with my husband as we both acclimatize to the new environment. During this period of transition there are times when both

my husband and I are different from the people we are in our everyday lives at home; anxiety has a way of changing our personalities. If we experience this tension while vacationing, how do we even begin to grasp the strain placed on these parents' relationships? We were not plunged into our environment. We had the opportunity to research the culture we were going to encounter and prepare ourselves for our trip. The parents in this study were not afforded that luxury. There was no time for them to prepare: to learn a bit of the language, to speak to those who have been there (i.e. other parents) or look up what the climate was like. Tanya recalled what the NICU experience was like for her and Kevin.

We would pass each other in the hallway... it was hard because we didn't see each other a lot, and you know, it was hard for us... The only thing we would talk about was Cameron...there were days that I wanted him, like I would see other fathers there, and realize they were fathers from out of town. You know we were fortunate that we could sleep in our own bed, and be in our own house when this was going on, but it was hard.

Kevin had to return to work shortly after Cameron was born, and as a result he and Tanya would split their time at the hospital. They barely got to spend any time together as a couple, and the time they did have together was devoted to speaking about their son. It was also hard on Tanya and Kevin to divide their time between the hospital and home for the sake of their older child. She felt guilty leaving her one son alone at the hospital and her older son in the care of family and friends:

It was... you'd be scared to leave because you'd come home, and you'd feel guilty leaving. But, I had to go. I had a one and a half year old at home, and you know, I'd call, and he'd be misbehaving or something like that. It just uh, yeah, it was hard.

Following their discharge from the hospital, Tanya acknowledged that it took time for their marriage to mend and heal from their NICU experience:

At first... honestly until Cameron came home from the hospital in March. Honestly, when August rolled around, I felt like our relationship was okay now. It was back on track.

Before the birth of their twins, Mark experienced confusion in defining what his personal roles were in the new and strange hospital environment. This confusion placed strain on his relationship with Anna. While Anna was on bed rest in the hospital, Mark felt as though he was seen as less important, even as a nuisance in comparison to his wife. His role changed from being a husband and a father-to-be, to a caregiver for his wife. Despite all that he was doing for his wife in the hospital, he felt that he was not appreciated or respected by the nursing staff. There was a lack of support for him and the feelings he was experiencing, they were not cared for as a family.

And it was difficult, I mean, Anna is in the hospital, and I think what a real difficult time it was, is the lack of support for the husband or the father-to-be, in that situation... And, at that point I was cleaning the bedpans, I was doing the sponge bath, I was... washing hair, I was doing all the things that they can... I was still just a visitor... the father-to-be is, is second place.

The dynamics of Anna and Mark's relationship changed. In this situation, the father-to-be was not viewed as a patient, as someone requiring care or support as his wife's life and the lives of his unborn children were in jeopardy. The care that he provided to his wife, which lessened the nurse's workload, did not seem to be valued.

Anna and Mark also acknowledged the fear that they had in relation to their marriage during their experience in the NICU.

Anna: But, we were scared, because we said, we have a very good marriage and strong, but we feared if we differed in opinion that our marriage would be at stake...because we were scared, like we could lose everything including the marriage.

Mark: And we did talk about what would happen if I wanted to continue on [with life-saving treatment for our critically ill sons], and you didn't, and what would happen in ten years from now. It would either work one way or the other. Like, the kind of blame and guilt that you would have on each other, without even meaning to.

Not only were Anna and Mark anxious and left to feel hopeless about survival, they were worried about the impact differing opinions could have on their marriage. The parents in this study had their spouse as their travelling companion, but found the strange land easier to endure when they met a fellow traveller.

A Fellow Traveller: Someone Just Like Me

For some of the parents in this study, despite being admitted to a unit where there were 69 infants, they felt alone and isolated. At times, they felt as though they were the only family going through this unique and stressful experience. Anna recalled feeling as though her husband and her experiences were “freakish” and completely abnormal. It was a conversation with her obstetrician that helped to shed some light on her circumstances.

OB: “you’re not the only one.”

Anna: “Really?”

OB: “Oh, yeah. You’re everywhere, you girls are everywhere, you know, dealing with this.”

Anna: “Oh, okay.” Not that it makes my situation better. It just made me feel like I wasn’t the freak.

It was helpful for Anna to hear from a medical professional that there were other families, other women going through similar experiences to hers.

Tanya also found it helpful hearing that there were other families, families that were similar to hers, experiencing the same circumstances. “It made me feel better that there were normal people like me, everyday people that this happened to.” She discovered this information by speaking to the parents around her son’s bedside. She realized that she had a lot more in common with some of the families than what her previous bias had lead her to believe. It was a source of support for her to know that other women; healthy, young women, were also in similar circumstances as hers.

And I found [other families] supportive, too. I was scared. It was nice to talk to people that were going [through] the same thing as you, and it was nice to know that she wasn’t a hooker from underneath the street that was a cocaine addict. I was happy to find out that there were healthy girls just

like me, you know, who had the occasional drink. I didn't smoke; I wasn't hopped up on drugs that this happened to.

It was helpful for Tanya to have another mother that she could relate to, that had circumstances that were similar to her own.

For Saira, she found the other mothers to be a great source of information. She acknowledged that the medical staff provided her with information, but she cherished the information provided from the mothers who were nearby in her absence. She was not able to spend every waking hour at her son's bedside, and she relied on hearing about what happened from someone who was experiencing something similar.

Honestly, I have got a lot of information...the doctors would give information, but you'd use, you would learn more from the other mothers that are already experiencing the same thing...a mom that is from out of town, so they spend 24/7 there. So, you know what's going on, from them. Even the night, my boy got sick I knew, I didn't know exactly, to that extent. I mean, I know he got sick, and this instant she was there, and like I said, she, they would stay there 24/7, beside their child because they have nowhere to go.

Saira had other children and responsibilities at home that she needed to attend to and so she was not able to spend as much time at the hospital as the out-of-town mothers. Saira's relationship with other mothers helped to alleviate her anxiety about what was really happening to her son in the foreign NICU environment when she could not be present. This also helped Saira adapt to the new culture.

Kara and Jeff also valued their relationships with other parents. This couple had a strong, reliable support network of family and friends, but Kara felt that no one could understand what they were experiencing or feeling like other parents in the NICU. Hearing from fellow travellers helped more with her anxiety than the same explanations from the medical staff.

Well I think one of the most important things is to try to establish a relationship, even with just one of the other parents in the NICU. If you can find a support network among the other parents, there's nothing better

because as much as family and friends are supportive, nobody understands what you're going through like the other parents...I met a couple of moms who were close to being discharged when my kids were admitted and so they were really helpful in explaining to me kind of how the process, the process works.

Adapting to the foreign culture of the NICU was challenging for the parents in this study. Learning the lay of the land and the language provided anxiety, strain and effort as the parents adapted. During that process of adaptation, relationships were developed that allowed the parents to cope with the feelings of powerlessness or left them feeling rejected by the new culture. During those experiences of culture shock, these parents were required to process complex and shocking information and make time-sensitive life and death decisions. Throughout my thematic analysis, it became apparent to me, that it was difficult to separate culture and relationships from the decision making process. Information was initially provided to parents by strangers, and decisions were made within the context of the strange land.

The Cart Before the Horse: Information and Decision Making

The old cliché of placing the cart before the horse is a metaphor that may well apply to information and decision making for parents of extremely premature infants. Can decisions be made without having a good grasp of the information relevant to making that decision? Can information and decision making be viewed as separate entities? Can a parent make decisions without being fully informed? What is important to parents when they are making decisions in crisis situations? Do the parents' gut feelings, beliefs, values or convictions trump the information that the members of health care team provide?

The word inform is derived from “to shape,” “to form” or “to give life” (Merriam-Webster, 2009). To form or give life to is an enlightening way to view the relationship between the information parents receive about preterm birth and the inevitability of having an extremely premature infant. When the healthcare team informed these couples that they would become parents much sooner than was anticipated, they were suddenly responsible for making decisions they never

dreamed they would be forced to make. For most of the couples, the reality of having an extremely premature infant was one they had never imagined possible, a reality they never pictured themselves experiencing.

In contrast to the word inform, the root of decide is “to cut” or “cut off,” (Merriam-Webster, 2009) definitions opposing the concepts of forming or giving life. Healthcare providers expended time and effort clarifying, as much as possible, the situation these parents found themselves in. The parents were then forced to decide on a course of action, eliminating or cutting off all other options. The finality of cutting off added to the pressure and stresses these parents experienced in these critical situations. Not only did parents have to decide the fate of their child, they had to make these decisions in a foreign land surrounded by much uncertainty about what the future would be like for their child.

What is information? What does it mean to make a decision? Among healthcare professionals there is the value and expectation that we ensure patients and family members make informed decisions. How is this achieved? Is it the sole responsibility of the healthcare team to inform these families? Most of the families we work with enter the hospital setting in a crisis situation, facing the imminent delivery of their premature infant. They do not have the capability or time to do research on their situation, whether that be accessing the internet, or speaking with other families who have gone through similar experiences. What is the responsibility of the healthcare team? How do we go about providing the information that is pertinent to each family to help them make decisions that are appropriate for their family? How do we determine what is the pertinent information for each family?

For the parents in this study, their experiences of information sharing and decision making were recounted in terms of two time periods – the time before their baby was born and/or immediately after birth and the rest of the time their baby was in the NICU. Every parent in this study had vivid recollections of their first encounter with the NICU team. This was the time when health care professionals presented parents with the statistics and the odds concerning their baby’s survival. As parents, they had to choose life or death for their infant.

Following that initial decision to resuscitate, the parents adapted to the culture of the NICU, and learned how to get the information that they needed to make ongoing decisions for their premature infant.

Perilous Decision Making in a Strange Land: When the Numbers Matter

The first encounter with the NICU team members was usually made in the labour and delivery ward, in an environment foreign and scary to the parents as their worst fears were confirmed. They were informed that their baby would be born prematurely, and they were now responsible to enact their role as parents and decide if their baby should be offered a chance at life. The choice to resuscitate did not come without considerable risk to their infant, both in the short and long term. Throughout my thematic analysis, I learned that the parents' values and beliefs were important influences on their decisions for their infant.

All of the parents in my study vividly remembered the first time the neonatologist spoke to them about their baby's impending delivery. Debbie and John wanted as much information as the physician could provide. They wanted to know the numbers and odds that their baby would have a good quality of life. For them, quality of life was a value that guided them in making the decision to initiate resuscitation of their baby who was to be born prematurely.

It was at 24 weeks, and I was on bed rest for ten days, so Francis was born he was 25 weeks four days. So, at the 24 week mark, the neonatologist gave information as to if you were deliver, what would happen...We asked him the health of the baby, and what were some of the issues, you know, the major issues were, and developmental, all that stuff. So at the time, I can't remember what the percentage was. It was pretty low...at the 24 week mark. It was really low for survival, and the complications really high, so at the time, we decided if he was to be born in the 24 week mark, we wouldn't resuscitate. And then, the week after, and I was still on bed rest, they came back again, because we asked them to come back, and then they gave us more information for that week, if he survived, and 25 weeks he was born, what were some of the issues, and I saw the percentage was way up, so we decided, yes we would resuscitate, if he was born. (Debbie)

It wasn't like a booklet or anything, it was [what] they told us...We asked for odds, we asked for outcomes and things like that, to make our decision. So, for us, I think we were well informed because we asked the questions.

(John)

For Debbie and John, the "percentages," "odds" and "outcomes" were important in trying to determine what the quality of life would be for their extremely premature infant, for this couple the numbers really mattered. They weighed those odds and came to the conclusion that 25 weeks gestation was the right time to take that "chance." "So, and it was a chance, but it was worth taking, the chance. I don't know what it will be like..." Debbie recognized the uncertainty but the numbers now seemed to be more in their favour, and the "chance" at life was worth it.

For another family, religious beliefs were a key factor that guided their decision making. Saira had been offered therapeutic termination early in her pregnancy as she had conceived with an intrauterine device in place and the obstetrician was worried about the complications that the device could cause. For Saira, this was an option she would not consider. "I found out that I was about 6 weeks. She said 'you could terminate the baby,' but that's something we can't, that I can't do." Saira began bleeding at around 16 weeks gestation, she saw her obstetrician, who again offered therapeutic termination. "She said that you could pull your IUD out. 'No! You can't terminate the baby.'" Saira continued to have bleeding and at 24 weeks she was admitted to the hospital. At risk for premature delivery, she spoke with a neonatologist from the NICU. She vividly remembered that initial conversation with the physician, who gave her information about the complications that her baby might experience. A stranger stood before her and spoke to her in a language she did not understand.

And, after that, it just got scary, and then the NICU doctors came in, and your baby's gonna have cerebral palsy, your baby's gonna be handicapped, your baby is gonna be this. This is your decision to make, and I just. I, I couldn't handle it. This is your decision to make, there is compassionate care, well hold your child, and love them, and let them go,

but they pass away then... And because of Muslims, you can't say that. We can help this child as much as we could. There is no way that I was gonna say, "No. You can't do anything."

Saira's deeply held value about the sanctity of life outweighed any of the potential complications that her son might have faced. There was no way that she could not give her child every opportunity for life. Saira's recollection of the neonatologist's interaction included a sense that there was little effort made to get to know her and what she valued. Based on her religious beliefs, Saira would always choose the chance for life over doing nothing. To have the neonatologist tell her she had to make a decision regarding life or death did not fit with her situation in which there was no decision to make; the numbers, to Saira, did not matter.

Specialists admitted Anna to the hospital at 19 weeks gestation with twins conceived by in vitro fertilization. She recounted that her membranes were leaking, she had a stitch inserted into her cervix and was placed on bed rest. The neonatologists presented Anna and Mark with the grim options that were available for the twins at such an early gestation.

They asked us that night, what we wanted to do. At 19 weeks, they said we also had three options. Things come in threes. We'll help you to deliver right now. The boys will die. We can let you deliver, it will probably happen tomorrow. The boys will die. Or, we'll try to do a stitch. We don't think it's possible.

Of interest was that Anna had no recollection of which physician spoke to them at that time. These strangers were the bearers of the worst possible news, informing her that "they" did not think it was possible for her twins to survive. No parent wants to hear that they are likely to lose the pregnancy. Intervention helped Anna and her twins get to 23 weeks gestation at which time her membranes ruptured. At this time, both she and Mark again feared they would lose the pregnancy and their babies. They met the neonatologist during that stressful situation:

23 [weeks], because they told us, basically nothing would happen. The boys would die if they were born that week...They also mentioned if things

progressed, the following week what our choices were at that time.

Whether we were gonna do steroids and what the stats were for babies being born at that time for mortality, and morbidity. And so yeah, all of that was definitely, talked to us about that during that first week...Of course, that first week there, we knew the decision was practically made for us, which we understood. I mean, in our minds too, I mean it's not, we don't deny that was the best decision at that time. But then after we hit week 24, that Saturday, and the steroids were given, and the whole bit, the Monday completely changed. Because that was the next meeting that we had with [the neonatologist], and it was, well, what do we do now? (Mark)

When Anna and Mark reached 24 weeks gestation, the neonatologist informed them that the pregnancy had reached the so-called age of viability, and that they could offer their twins a chance at survival.

He presented us with three options. One was that they wouldn't do anything. And again, re-iterating all the stats of 50/50 and 50/50, and all that. And then, the second option was they wouldn't go to any extra, like compressions or anything like that. They wouldn't do anything extra to save them, but they would just see how it goes. And then, the third option would be just a full resuscitation. And so, then we decided. But we knew that our goal was to get to 24 weeks. So, I think in our mind already, was that once we got the two steroid shots that we were going to proceed... So option one wasn't an option to us, at that point. As soon as that Monday hit, it wasn't an option. So, you know, we thought about option two, and then [the neonatologist] says, "Well, if we're gonna do that, then we might as well...if you're prepare to go ahead, then we will do full resuscitation." And then we felt okay with that... we felt very much at ease with that decision.

The neonatologists presented Anna and Mark with the information needed to make a decision on how to proceed if their twins were to be born prematurely. The discussions with the neonatologist helped Anna and Mark make a decision. Recalling this decision making time, Anna and Mark remembered the particular

neonatologist with whom they started to build a relationship. They respected his expertise and were appreciative of the manner in which he provided them with information. I would highlight that although Anna and Mark indicated that they were the responsible decision makers for their twins; the information was provided in a directive manner, that is, strong recommendations for or against resuscitation. I am not suggesting that this mode of providing information is unacceptable. I am simply wondering what our responsibility is in providing information to parents. In our health region we do not routinely offer aggressive resuscitation to infants born at 23 weeks gestation, however, what would Anna and Mark have decided if this was offered to them? I did not explore this question during the interview, and I wonder if Anna and Mark were aware that if they lived three hours away in Calgary, their twins would have been offered resuscitation at 23 weeks gestation? Do we have a responsibility to inform parents of other centers' practices if those practices are significantly different from our own?

Mark remembered the uncertainty surrounding that initial decision to resuscitate their twins at 24 weeks gestation. He understood that the healthcare team was providing them with all of the information that was available, but that this information was not enough.

It never was enough for us to make any decisions, it really wasn't. It was all the information that they had to give us which we understood, so I understand that there is so much more that you don't know.

As Anna was on bed rest in the hospital, Mark would take the information presented to them as a couple and do his own search. He used the internet to help clarify the information and gain a better understanding of what the future might hold for his twins.

And of course I had the access. I cope by information, research, and whatever, so you know, I had access too. I would leave there, and I would go on the internet, and read whatever I could about everything that I could.

Following the decision to resuscitate the twins, and while Anna was being prepped in the OR for the caesarean section, the couple recalled a sense of ease. The birth of their twins was going to happen and for a brief moment, they felt they

could take a deep breath and relax. The pressure of the previous six weeks had been lifted and their sons were about to be born. "After the decision was made, then it was all very calm, because we had no choice, and it was like, 'Okay, let's accept this, and carry on.'" I think that for Mark the word "choice" refers to the fact that the delivery, at this point, was inevitable and the decision to resuscitate was already made. There was nothing more they could do to buy extra days or weeks for the twins, so there was a sense of peace as they prepared for the imminent delivery; there was nothing more to figure out or decide

Tanya and Kevin had a much different experience leading up to the birth of their son. Tanya was initially admitted to a referring hospital when her membranes ruptured at 24 weeks gestation. She was placed on bed rest on the labour and delivery ward of the referring hospital where her obstetrician was her source of information. After ten days of bed rest Tanya started having contractions, and was emergently transferred to the tertiary center where they would be able to care for her extremely preterm baby if she was to deliver. She arrived at the new hospital via ambulance and was rushed to the labour and delivery ward. Tanya had to cope with being plunged into two foreign and scary environments. After ten days at the referring hospital, she had become familiar with the routine, the staff and that was the hospital her obstetrician worked out of. The transfer to the tertiary hospital left her in unchartered waters, in the face of an imminent crisis. During the interview, I had asked Tanya when she arrived at the tertiary hospital if she remembered speaking with a neonatologist from NICU.

They came in, explained...certain things. That he'd be on a breathing machine right away, and things like that, and kind of what our choices were. And I hardly remember if we signed consent forms or anything. I just remember they were just going over, you know, pretty much what could be wrong with him, and I know Kevin was taking it in more than me. I was just, kind of laid there with my legs crossed, hoping he wasn't going to be born...so honestly, I don't remember...we had a couple of people come down...The respiratory tech, or a doctor came down, and I don't honestly remember who else came down to talk with us.

All Tanya could concentrate on was hoping that her baby would not be born yet, that she would be able to keep him inside her until he could get bigger and stronger and have a better chance at survival. There was minimal processing of information during this crisis situation.

Kara and Jeff had yet a different recollection of their initial consult. Kara's membranes ruptured at 24 weeks gestation with no warning; she was rushed to the hospital where they met with the neonatologist. Kara also recalled the grim prognosis that he gave them.

I remember the neonatologist...he'd come up to talk to us and just basically told us that our chances were not very good and he wanted to know if we wanted life saving measures used when the twins came...there was no time to really talk about it or consider it and they needed to know because the birth was impending and he also gave us a sheet of paper, an information sheet. Basically it's a chart and it lists on one side the number of weeks gestation that babies are born at and the earliest was 24 weeks and then it lists possible complications that can occur. And it also tells you the percentage chance that your child will have those complications everything from death to cerebral palsy and brain damage and all that. My husband and I looked at the piece of paper and for twenty-four weeks it lists every possibility, every chance that they would have these things was like 80% plus and we were, we were just devastated. We're very spiritual and we have the strong faith and so we had basically just decided that we were going to have to let God decide and the babies. The babies were going to become who they were meant to become and that was the thing that we kind of told ourselves all along during our stay in the NICU. You just sort of have to put your faith in something, something else.

Due to the powerlessness the couple felt over their situation, they chose to place their faith in God. They felt that because they were in a city hospital with medical professionals who were trained to resuscitate premature infants and provide them with life-saving technology that could offer them a chance at life, they had to use

these resources to try and save their twins. Kara remembers how she and Jeff came to this decision as a couple:

It's funny; there wasn't a whole lot of discussion. We both just sort of knew that we couldn't stop the labor. We knew that they were going to be born and we had talked about whether or not to use the life saving measures that they had talked about. We thought we have to at least give them a chance...We thought we have to at least, at least try, and give them every chance that we could and we had decided that relatively early on. Like I was having contractions as soon as I, we got to the hospital and I would say it was just like a matter of minutes really after we got the specifics and got the information from the doctor that my husband and I just, we both decided that. So there wasn't really a lot of wondering what to do. It was more like they're coming, we're going to give them every chance that we can and we're going to put our faith in God that things will work out the way they're meant to work out.

Kara and Jeff felt helpless. There was little they could control or influence regarding the fate of their twins. Placing their faith and prayers in God was a way that they had some sense of control in such a stressful situation.

I mean we were very, very scared. But, it's hard to kind of verbalize it but we knew that...there was nothing else that we could do except hope and pray. I mean when you're in that situation you, especially as a mother, you feel helpless. Like you feel like there's something that you should be doing.

Navigating the NICU: Adapting to the Strange Land

The parents in this study found themselves completely immersed in the culture of the NICU, as previously mentioned, this culture was where their decision making took place. What impact did the new environment; the new language; the new relationships have on decision making? Was it possible to make rational, informed decisions when the new culture overwhelms you? What did parents do with the information they receive? Could they process it? How did

parents come to make decisions for their infants throughout their stay in the NICU?

Debbie and John recalled feeling overwhelmed by the amount of information they were receiving. Additionally, they could not relate the information to anything with which they were already familiar. They had little understanding of the medical terminology that the healthcare professionals used, nor of the technology used to keep their son alive. Debbie did not have the knowledge or experience necessary to comprehend what was happening to her son, he was not able to communicate what was wrong she found it difficult to rely on the staff for this information.

There was a lot of information, so, of course it was hard to absorb. We were confident, I guess, with the information, but it was so hard to explain because it's not happening to you. So, at least for me, if I was sick, I would say, "I'm sick" or "I'm cold, I have a stuffy nose," or any of a number of things, but with him it was kind of hard, with him I was told what was happening. I just remember, we were getting a lot of information.

Debbie remembered what it was like for them to make a decision about whether or not to give permission for steroid administration for Francis to help treat his lung disease. She alluded to the fact that there was some time pressure on them as they deliberated whether to proceed with the treatment.

Because we had to make a decision on the steroids for one, because there we had to decide if we wanted to do it, or not, and the window was so small, that it was, no, we had to do it. Otherwise after some point, it's no use, anyways. I can't remember the exact information. We asked them as many questions as possible so that you can know basically know what's going on.

Debbie and John felt that they had to decide in favour of the steroids for Francis and if they missed the window of treatment opportunity, they would not have another opportunity.

We decided on the steroids because that was, one thing that we knew obviously the risk, and then the benefit, on that. I don't think they pressured us into doing one way or another. It was encouraged, obviously because it was a benefit. But I think a lot of the decisions, we made [were] based on what they told us.

Debbie felt as though they made their decision heavily based on the information that the health care professionals provided them, which suggested that the manner in which the information is presented would impact how this family made decisions. If the physician explaining the steroid treatment felt strongly that this treatment was beneficial, this family may have been influenced by his/her beliefs in the treatment. Debbie and John placed a great deal of trust in the information that the neonatologist provided as they respected his expertise.

Saira felt comfortable leaving the decision making in the hands of those caring for her son. Her interpretation of decision making throughout her NICU experience was much different than some of the other parents in this study. She felt overwhelmed and completely out of her comfort zone.

So, most of the decisions are kind of made for you. And you know what? You don't even know what's going on. I mean, you know, I know that they know better than me. So I mean, I would totally leave it up to them, they know what they're doing.

Is it possible that Saira's reaction to decision making was a result of being in an environment she did not understand, and that included a language she did not comprehend? She placed her trust into the hands of the health care team members.

In contrast to her experiences with the health care professionals, Saira found it easy to talk and share information with mothers that were having a similar experience. In fact, she relied on other mothers for information about her son. "I have got a lot of information...the doctors would give information, but you'd use, you would learn more from the other mothers that are already experiencing the same thing." In addition to getting information from other mothers, Saira also found it easier to get information from the nurses as opposed to the doctors caring for her son.

I asked a lot of questions with the nurses. The doctors, in a way, I didn't. I stayed away from most of the doctors. I enjoyed talking to the nurses more because they'd explain it a little bit more, because you...sit with them for a good time, and they're usually on there for three days, right behind each other. So you get to know them, and they explain a little bit more to you what was going on, and how come his machine kept ringing off... another baby's machine's not ringing off. And why is this, and why is that...the nurses did a lot of this... more than the doctors.

Saira did not explain why she "stayed away" from the doctors but as I reflected on her statement, I wondered several things. Did Saira not feel the physicians were approachable? Was she intimidated by them? Was it cultural? Were the mothers and the nurses easier to access than the physicians?

Saira also learned throughout her experience the best way to get a comprehensive understanding of her son's care. She found that by asking different nurses the same question she would get different explanations which she found helpful in deciphering what was happening with her son. "I would honestly ask questions to one nurse, and then to another nurse, and I mean, you would finally get what was going on, because everybody would give you a different kind of [explanation]." To some people this may have been a source of frustration; to Saira it was her way to stay involved in her son's care.

Saira remembered when a nurse practitioner took the time to call her at home to explain that her son needed a blood transfusion. This was his second transfusion. The first time Saira had found out about it after it had been done. The time the nurse practitioner took to explain the process and why he needed another blood transfusion was meaningful to Saira.

The first blood transfusion, actually nobody told me about it, nobody called me and said that he needed blood. They just did it right away. The second one, one of the nurses phoned me the...practitioner, she [called] me up, and she explained to me on the phone, for a good hour, what the blood transfusion did, and because you know I mean we do blood transfusions, right? I know there are a lot of different cultures that don't, but I asked

exactly, "Well, I can't give him that blood?" She says, "You know what? In the long run, if he ever needed, if he ever got leukemia, or he got some kind of disease, and he needed blood from you, or from somebody, he wouldn't be able to, just because he has your blood already." I understood it when she explained it to me.

Not only was this phone call about providing Saira with the information about her son's care, but it was also about building a trusting relationship between her and the staff. The fact that the nurse practitioner took the hour to ensure that Saira understood exactly what was happening fostered the ongoing relationship that she would have with this nurse practitioner.

Anna and Mark had a different experience in regards to the presentation of information and decision making throughout their NICU experience. Anna and Mark encountered repeated situations where they had to make life and death decisions for their twins. Within the first few days of their NICU journey, they had to make a decision about how to proceed with Nicholas' care. The physician explained that the ultrasound of Nicholas' head showed that he had suffered an insult to his brain that would likely affect his movement. Mark explained how he and Anna, as a couple, came to their decisions for the twins.

They had the first ultrasound, and they came around to say that Nicholas has got a spot on his brain, a bright spot, I still have the note that [nurse A] wrote for me, I wanted the exact words written out for me, exactly what it said. And, I still have that note... to explain what it was, and so he says, "It could affect movement on the right side," or whatever side was it. I forget now. And I'm like movement, well does that mean he'll walk with a limp, or be in a wheelchair? "I don't know" was the answer. Oh yeah, I understand he doesn't know. But it could be any range between one and the other, and he's saying, "You know, some people would stop at this point, and withdraw care." I'm thinking... I think what you'll see is that when we made the decisions that we did, we always knew... we always felt comfortable knowing that if we didn't feel comfortable making a decision, there wasn't a decision to be made at that point. So, he came up to us that

day, and said, “Would you consider withdrawing care?” and we didn’t feel right about it, so “No!” You know, at that time we didn’t know that, but eventually we got to be in that pattern, that if we don’t feel right about it then we won’t make that decision because we’re just not, we don’t have all the information that we need, yet. So we said, “No. We’re gonna continue on.” We didn’t know what that meant, and we also had the discussion at that point, I mean, he gave us again all the risks, and all the things that could happen with disabilities, and so on, and I think what we finally decided on in our minds together was would they be able to reciprocate emotion?

Mark described this determinant, the reciprocation of emotion, as the couple’s “so called line in the sand” when it came to making life and death decisions for the twins. This couple also had a relative in the family who was a physician, and helped to give some perspective to the couple about their circumstances.

He’s seen in his line of work, where there’s damage in one part of the brain...He says “the brain has an amazing way of coping.” And then he said, “at the end of the day, are they poopin’, are they peeing, are they eating?” He says, “if they’re doing those things, then that’s it.” And he said, “at the end of the day, you won’t have a decision to make.” And I’ll never forget that, I found that’s the part that affected me most. He says you won’t have a decision to make... That we, it wasn’t our decision to make. It was obvious that, but yet we didn’t have to make it. It was made for us.

From this point on Anna and Mark began to view the twins as the decision makers. Nathan had become critically ill in his initial few days in the NICU, and the medical team had a family conference with Anna and Mark to inform them of Nathan’s status.

There was nothing more that they could do, medically, or, mechanically, I suppose. And so then, it was time to have *that talk*... all the doctors saying that “This is what’s happening, we can’t do anymore, we could give the dexamethasone,” and explained to us the complications with that... so then

they recommended that we stop care, at that time. I mean, that was, it wasn't as simple as that. It was hours of that kind of discussion.

Anna and Mark listened to what the medical team was saying but they felt much anguish with the information. This couple was again faced with a perilous decision; choosing either life or death. They felt that giving the dexamethasone was too risky, yet they were not prepared to discontinue his treatment. They did not feel comfortable with either of those options, so instead of making an active decision, they felt the decision would be left in the hands of their child.

Back to that, not having a decision to make, and yet we were asked to make that decision. Is he going to live, or is he going to die, and when would that happen? Actually, we did not feel right about going with the steroids, we didn't feel right. So then, we're not going to do it. We just didn't feel comfortable with it, but we didn't feel comfortable stopping, either. That didn't feel right, it didn't seem right. There was something that didn't feel right, so then we finally decided that we would let Nathan decide... It wasn't anything external, I don't think it's anything you can explain. There's a feeling that you know that it's, now it doesn't feel right.

The medical team realized that Mark and Anna were not comfortable deciding between the two options that seemed to have equally negative outcomes and so offered them a second opinion of Nathan's condition. A different neonatologist presented similar information but in a way that influenced Anna and Mark in a different way. Although this was the first time that they met this neonatologist, they felt a connection with this physician. His mannerisms were deeply valued as Anna and Mark faced one of the most difficult experiences of their lives.

Mark: And we, we didn't feel right. We didn't want to go ahead, so then we agreed that we would put a DNR order on, so that if things worsened, they wouldn't try to resuscitate him. They wouldn't give him any medications, and just make him as comfortable as they could, but then, we wouldn't withdraw anything. And then, [the neonatologist] asked if we wanted a second opinion, or another opinion. "Well, sure, why not?"... So, yeah, we understand what they were saying, but we just didn't say we

could stop, we couldn't do it. We just didn't feel right about doing that, so then, he brought [another neonatologist] in to talk to us. That's the first time we'd met. I've seen him, I saw him on the unit, [but the] first time we had met, and he had just such a calming way of saying, also recommending that we stop, he would look at us for like 30 seconds, and think, and then would say whatever it was he said, and you could just tell that he was...

Anna: The compassion

Mark: ... yeah, it was like incredible. It was so calming. So then, he says, "Have you held him yet?" "No" "Well then," he said, "We'll let you hold him." And like everybody is well, you know, he's on the oscillator, it just can't happen, but he's like, "You know, you hold him, but you understand that, he will probably die on the way out, or in your arms." And it's like yeah, okay we understand that... So then we agreed.

In the above situation, Anna and Mark had decided that they were going to hold Nathan, knowing that it was likely that he could die while they were holding him. This particular neonatologist presented Anna and Mark with an option that was agreeable to them; an option they could live with. While holding Nathan, Anna and Mark felt as though a miracle happened. Nathan did not die while they were holding him; quite the opposite, his condition proceeded to improve. For this couple, this unexplainable change for the better was Nathan making the choice to live: "So I mean he obviously decided, we let him decide, and he made his decision, so let's not take away that opportunity from him, if this is what [he] wants."

How does an infant consciously make a decision to live or die? Is this a way in which these parents were able to cope with the highly emotional crisis they found themselves in when they thought Nathan was going to die? Mark and Anna were able to reflect on this experience with Nathan, and the manner in which the information regarding his condition was delivered. They appreciated the fact that the way in which he responded when he was held was not the norm, but were saddened by how hopeless the medical team had become.

Anna: Which is just a miracle, like you know, if you see him, there's nothing wrong with him. We went to the [follow up clinic] last week, there's nothing wrong with him.

Mark: You know, and up to that time, how many times were we told just to stop. But again, you go back to the stats, and I understand why they're 25%. I don't begrudge anybody for any of that stuff, that's the job, that's the sad part about that job. They know the outcome.

Anna: But the hope is so, there is none... There's no hope. We don't question that this has to be said, what they have to tell us, we understand, and this is not sugar-coated. Nothing about this is, you know, I understand what they have to do, but just a piece...I think the medical people are fearful to tell you anything good, because you'll hold it against them if things go bad.

For Anna and Mark the aspect that was lacking in their relationships with the various members of the health care team was hope. The hope that there was some small chance that at the end of that terrible experience that they would leave the NICU as a family.

After Nathan's condition stabilized, Nicholas' condition began to deteriorate. He required a transfer to another site for surgery. Anna and Mark respected the matter of fact mannerisms of the surgeon, and appreciated the way he delivered information to them.

You know it was, so matter of fact... he was telling... these are all the things that we could find, and it could be completely dead bowel, and we'd have to take it all out, and it wouldn't sustain life, or it could be this. And I hope it's this, but it could be this, so it was like, kind of like that casual conversation... it was just the way he could talk... it was more us than him, that he could relate to, because it gave us hope again, he gave us hope, right from the beginning, that he gave us hope where we didn't think we had any. And that's all you ask for. So then, the decisions are easier when you have some hope.

Wherever the glimpse of hope came from, they would cling to it and the hope that was presented from the surgeon was the foundation of their relationship with him.

Unfortunately their experience at the surgical NICU was not entirely a positive one. This couple felt strongly that they were not well informed about Nicholas' condition while he was being cared for at the surgical site.

Some of the complaints that I had while we were at the [surgical NICU] were the communication that we had at rounds, or didn't have. The thing that always gets me is that, at the end of the day, us parents have to make the final decision. Whatever that decision is, whether they live or die; sometimes it's as simple, and as difficult as that. But yet, when you have to fight for information, ask repeatedly to see x-rays, to see the documentation, and everything to support that, when at the end of the day, we have to make that final decision what's going on. Again, we cope by getting information. And, at that particular hospital, we *didn't* get that information unless there were certain people that were working that were very flexible in that way. And that was very frustrating, because at that time, we had already spent two months at the, or a month at the [non-surgical NICU], which was completely different. It was, you come within minutes of anything happening, you had everything that you needed, or wanted, without even asking for it. So that, you know, that whole part of it... when we talk about decision-making is that we needed information to make those decisions.

This experience influenced the way in which Anna and Mark made decisions in the future for Nicholas. Nicholas was able to be transferred back to the non-surgical NICU, and the family spent a few weeks together before he got critically ill again. The couple was informed that Nicholas would need to be transferred back to the surgical NICU for another consult and possibly another surgery if he was to survive. Mark and Anna realized that Nicholas was critically ill, but could not bear the thought of being transferred back to the surgical NICU.

He was really sick, he had swelled up, and we weren't sure what was going on. It was a very difficult time... they were doing x-rays... and they

said “well, maybe we need to send him to the [surgical NICU]”... and I said “I don’t want him to go”... I said, “I don’t want him to die there.” I just knew that it was going that direction. I didn’t know that it was going to go that fast, but I didn’t want to take the chance of him going back there, to a place I almost detested because of the experience that we had... I didn’t want him to go, and I didn’t want to have the picture in my mind of him going in the ambulance, and only one of us could go, there was nothing *right* about sending him to the [surgical NICU]. And so they were discussing that in the hallway, and then finally they took us into the room across [the hall]... [A neonatologist] comes in and says, “We should send him there,” and we, thought maybe still at that time that we could... And so, they were like, again going back to the decisions that we never had to make, because I said, “No ,no. We can’t send him there, we have to stop.”

Mark and Anna understood that because of how critical Nicholas’ condition was, there was a good chance that he would not survive the transfer or surgery. If Nicholas was going to die they wanted it to happen in an environment that they had grown to think of as home. Anna and Mark’s decision to not transfer Nicholas to the surgical NICU was based on their previous experience at that site.

Mark and Anna reflected on all of the decisions that they made for their infants throughout their NICU experience. They realized that they had to live with the decisions that were made, and that those decisions impacted how they viewed themselves as parents.

And so we’re very grateful, and then we leave there thinking, you know, we’re good parents. We’re okay parents. We made the right decisions, and there’s not a decision I ever questioned, that we made from day one even before the boys were born. So I think that was, an important closure.

Tanya and Kevin’s NICU experience of information and decision making was different as they had Kevin’s sister to help them process information. Kevin’s sister was a NICU nurse on the unit where Cameron was admitted. Tanya remembered how hard it was for her to absorb any of the information that she was

given. Beside her sister-in-law, there was one nurse practitioner and a few nurses who she relied on for information.

There was the nurse practitioner. She was incredible! She was very helpful, and then there was kind of two nurses that we bonded with really well, besides [Kevin's sister] that helped us out... sat with us... I would see this one nurse... and she would say, "You don't understand that?" And I'm like, "No." It was just so hard to digest anything.

As Cameron's condition stabilized, Tanya felt that they were well informed of what the future might look like for her son. "We were told he would probably need a hernia surgery, and then his eyes. And you know every day, they'd let you know what was kind of on the table." Tanya remembered what it was like for her and Kevin the day that Cameron needed a blood transfusion.

I mean the blood transfusion was a big decision because I said "you know do whatever necessary" and Kevin was kind of the one that said, "You know what? I'm not sure about this".... I think I had left the hospital myself, and I phoned him, and I just said "It needs to be done," and I honestly think [his sister] was, our saving grace because I think she was actually working that day, and like I said we were one of the lucky ones that we had family there, she just said "it's okay, it's okay to do it." So I think she was the tie breaker in a lot of decisions, that we had to make, but we really didn't have too many.

Kevin's sister was a personal source of information; someone with an emotional tie to their son, yet with knowledge and experience of the NICU. Tanya knew that her sister-in-law would not tell them to give the blood if she thought the risks would outweigh the benefits, as she would not want to see any harm come to her own nephew.

Tanya was frustrated with the manner in which the NICU operated. She appreciated being included in morning rounds for Cameron, but felt as though the information was overwhelming. When Kevin would come to see their son after work she was not always able to relay what the plan was for Cameron.

But I think I would have liked maybe even the doctor, they come and they spoke with us in the morning and even if the next set of doctors, whoever comes on, if they had time to speak with you later on during the day, like when Kevin was there, because he would ask me questions, and I said everything was going over my head, and things like that. So if you had time to actually sit, you know?

Tanya also found it frustrating that they were not always able to get information in a timely manner.

If he was getting his blood work done... they would say "oh well his labs will be done at four." And then, we would wait and it would be six o'clock. And I know everybody gets busy, and you know, I mean that's understandable. That's everywhere. But I [wish] I would have been able to just chat with the doctor at that time, instead of waiting for the next morning.

Getting the results of Cameron's blood work in a timely manner was an action that would have fostered the relationships with the various members of the health care team.

The NICU experience for Kara and Jeff began with the birth of their first twin, Ethan. Ethan was born on a Sunday morning while, Emma was not born until the following Tuesday. Following the birth of Ethan, Kara remained on bed rest and was not even permitted to go and visit her son in the NICU. She remembered how scared she was in those initial few days when Ethan's condition remained critical.

It was really hard. We didn't know whether he was even going to make it. I didn't know if I was even going to get to see him. We were so lucky that we have lots of family in town and [they] took tons and tons of photos and video and would bring it to me, which was really helpful. Actually, the nurses in the NICU took the first snapshots and made sure that they brought them to me. I appreciated that so much and they had, little nametags for his monitor and had sent photographs of that to me as well

and they were getting Emma a spot ready for... her beside him, which was nice.

Her family and the members of the health care team were her providers of information. Initially that information was in the form of pictures of her son as she was unable to go to the unit to visit him. Kara cannot remember exactly who was providing her with information during those initial days. "You know the social worker from the NICU came pretty frequently just to check in and I can't remember if there was anybody else from NICU. Quite honestly I don't remember." Early in their NICU stay, Kara remembered a physician telling her that the first week would be difficult.

The first week was so hard because they just had ups and downs all week and I remember the neonatologist telling us that once they make it through the first day, you hope that they make it through the next three days and then once they make it three days, you look for seven days.

When Ethan needed heart surgery, Kara found the manner in which his condition was explained was helpful. Unfortunately, having Ethan and Emma at different hospitals was a source of stress for these parents.

They both had surgery. The PDA ligation they both had it. Ethan had his when he was about 16 days old and that was really hard. Like he was only about 800 grams and hearing that he needed heart surgery it was terrifying but the neonatologists were so good at explaining it to us and why they thought it was necessary: his kidney function was slowing down and the fluid was building up in his lungs but that was very, very difficult on its own because he had to go to the [surgical NICU] for that and Emma, [was still at the non-surgical NICU] so it was hospital ping pong, right? We were back and forth.

It seemed that after coming to grips with the fact that Ethan would require surgery, the fact that the twins would be in different hospitals was devastating.

Kara found that daily rounds and becoming familiar with the medical charts were an important way for her to remain informed on the twins' progress.

My routine was to get up to the hospital by 9 so that I could participate in rounds every day during the week and Jeff would go in on the weekends for rounds and I, we're both the type of people where we want as much information as we can get and I really found it valuable to listen in on the rounds and also I got to know their medical charts very well so that if anybody had been in to see them overnight or whatever, if there were any changes to their orders, I felt comfortable going in and seeing what they were.

Being fully informed and an active member of her children's care was something that was fundamentally important to Kara.

Following analysis of the data, it was clear that it was difficult to separate the NICU culture and relationships from information and decision making. Although culture, relationships, and information and decision making were presented as separate themes, I hope that I have captured the influence culture had over information processing and decision making. The relationships that these parents formed with various members of the health care team, and other parents also impacted the way information and decision making was viewed.

CHAPTER FIVE

Discussion

As a NICU nurse, I had a desire to study parental perceptions of decision making. At the outset of this project, I believed that the parents of extremely premature infants were not well informed about the life and death decisions they were required to make for their baby. I questioned whether we, as the primary information providers, did a good enough job of informing parents of the risks and uncertain outcomes related to life-saving treatment for extremely premature infants. Do the parents of extremely premature infants truly make informed decisions? I now realize that my judgements and opinions came from my experience as a practitioner in an acute clinical setting. I only had experience with these infants and their parents in crisis situations in the NICU hospital setting. Intellectually I knew that many of these extremely preterm babies survived, recovered from their complications and were discharged home, but I did not appreciate what life was like beyond what they experienced in the NICU. This somewhat narrow perspective was also identified in a study examining caregivers' attitudes toward extremely premature infants, where researchers found that nurses' attitudes reflected their personal experiences (Janvier, et al., 2008). These nurses, like myself, worked in a surgical NICU where they typically only saw premature infants with complications requiring surgery, and these experiences negatively impacted their perspective on outcomes for extremely premature infants.

I could feel my perspective on decision making shift as I interviewed parents, and witnessed firsthand what their lives with their babies were like following discharge from the NICU. When starting this research I wanted to discover if parents felt as though they were informed decision makers. I thought implications for practice would be finding a way to provide information in a meaningful manner, one that would facilitate the difficult decision making process. Instead, I began to discover that decision making is so much more than processing information and making a choice in one direction or another. Why was I so closed minded? Why did I think that decision making was solely about

processing information and making a choice? I was not alone in my thinking that parents of extremely premature infants were not well informed. I remember having discussions with fellow nurses, respiratory therapists, and other health care professionals, where we questioned the care we provided to extremely premature infants. We would ask ourselves and each other if the parents understood what we were doing *to* their infant. The parents in this study have given me the opportunity to gain insight on the experience of having an extremely premature infant.

Additionally, the birth of my first child, which occurred during my thesis research, profoundly changed the way I view parental decision making. My thoughts and beliefs about resuscitation of extremely premature infants have changed since becoming a mother. I used to believe that if I was faced with the impending delivering on my own extremely premature infant, I would choose compassionate care. Now, I do not know if I could make that decision for my own daughter. Having experienced the stages of pregnancy and the bond that was formed between a mother and her fetus, would I not want my daughter to be offered every chance at life? I have knowledge about the statistics and odds of morbidity and mortality and I understand what these numbers mean; and yet I have come to understand that there is more to decision making than processing the information.

I recently had the opportunity to join a family as they spent the day in the neonatal follow up clinic. I remembered this family from my practice in the NICU. They had an extremely premature infant who had a difficult course while in the NICU. Their son was now three and half years old and completely full of life; he had no neurosensory, psychomotor, or cognitive delays. It was incredibly fulfilling to see how well this child and parents were doing. I am not so naive as to think that the outcomes for every extremely premature infant will be so positive, but as nurses, we tend to be overly pessimistic about the outcomes for premature infants (Streiner, Saigal, Burrows, Stoskopf, & Rosenbaum, 2001). Throughout the course of this research, my perspective has shifted from a pessimistic and perhaps even a paternalistic view of parental decision making to a more positive and empathic view of the parents' experiences of decision making.

Back to the Literature

Looking back at the literature I reviewed for this research, various opinions were presented on who the appropriate decision makers were in relation to extremely low birth weight infants. Some suggest that decision making should be left entirely in the hands of the experts, while others advocate having parents accept the responsibility for decision making for their premature infant (Leuthner, 2001). The policy statement released by the American Academy of Pediatrics Committee on Fetus and Newborn (2007) indicated that the parents' role is to participate actively in the decision making process. In my study it was apparent that the parents saw themselves as the decision makers, especially in relation to deciding to initiate resuscitation. They appeared to understand the ethical nature of the decisions they were making. All of the parents recounted exactly what this experience was like, and how they came to make a decision to initiate resuscitation. I asked the research question, what are parents' perceptions of their involvement in decision making, to determine if their experiences would be similar to the experiences documented in the literature. In a longitudinal study by Pinch and Spielman (1990, 1993, 1996), parents of extremely low birth weight infants did not even realize that ethical decision making had taken place during their child's experience in the NICU. Pinch and Spielman (1990, 1993) identified ethical decisions as those decisions related to ethical dilemmas including: the use of ventilators, resuscitation, iatrogenic effects of medications, paternalism, and termination of treatment. As time had passed for the parents in their longitudinal study, a realization developed that *perhaps* there was an ethical component to the decision making that happened while their child was in the NICU, but the decisions were mostly made for them. Those parents identified that in order to actively participate in ethical decision making there was a need for knowledge. They felt that the information needed to gain the knowledge had to be provided in an environment conducive to learning and the NICU was not such an environment. Almost every family in my study described what the environment in the NICU was like. The environment was a common thread that I will discuss further in the sections to follow.

In a study similar to my own, Brinchmann, Forde, and Nortvedt (2002) found that when parents were making life and death decisions for their extremely premature infants, they wanted to be well informed, included in the discussion and heard. In contrast to what I discovered, the parents in that study indicated that the responsibility of decision making should be left to the health care professionals. While one mother in my study alluded to the fact that the health care professionals were the experts and “knew better” than her, it was still clear that she felt that she had made the decision to initiate resuscitation. What has made the experiences of the parents in these two studies so different? Is it the family-centred care philosophy of the unit to which the parents in my study were exposed? Or was it the model of decision making from which the health care professionals in Norway operated? Based on the findings of my study the NICU environment, the foreign land, had a great impact on the parents of extremely premature infants. The environment of the NICU is where parents were able to appreciate the impact of their initial decision to resuscitate.

The Strange Land and Its Language

What did it mean for these parents to be “plunged” into a strange land? Partly it meant that the expectations and hopes they had about becoming parents were dramatically changed. The parents in this study were immersed in a land and a culture that was unlike anything they had seen or experienced before. The premature birth of their baby was imminent and they were expected as parents to make a decision that would determine the fate of their unborn child. Should they agree to aggressive life-saving measures to offer their child a “chance” at life? Or should they choose compassionate care? This is ultimately a decision between life and death.

It has been identified in the literature that parents of extremely premature infants are required to make a life and death decision in a state of medical urgency that is time sensitive (Boss, Hutton, Sulpar, West, & Donohue, 2008). This experience was similar to that of some of the parents in my study who had been thrown into their situation with little warning and little time to make their life and death decisions. The strange environment, the strange people, the strange

language, the crisis situation, all impacted how the parents perceived their circumstances.

What impact does the culture and environment have on the parents' perceptions of their decision making? Most of the parents recalled feeling overwhelmed at being in the NICU for the first time, seeing the machines keeping their child alive, and seeing the number of people needed to care for their tiny infant. Much research has been done on parental stress in the NICU. The Parental Stressor Scale: NICU developed by Margaret Miles (1993) has been used as a tool to evaluate parental stress. An entire section of the scale is devoted to assessing the impact of the environment; she refers to this section as the "sights and sounds" (p.150). A Likert scale is used to evaluate each of the following components: the presence of monitors and equipment, the constant noises of monitors and equipment, the sudden noises of monitors and equipment, other sick babies in the room, the large numbers of people working in the unit, and having a machine breathe for their baby (Miles). It is within this stressful environment of the NICU that the parents are expected to make life and death decisions.

Alderson, Hawthorne, and Killen (2005) also identified the NICU environment as influencing the parents' experience. Parents reported being shocked and overwhelmed by the NICU environment. Heermann, Wilson, and Wilhelm (2005) summarized some of the environmental stressors of the NICU to be: the appearance of the infant, the noise in the environment and the communication with the staff. In their study of mother's experiences of the NICU, they found that some mothers had the environment of the NICU in the foreground of their attention. Instead of focusing on their baby, they focused on the technology, the language and the culture of the health care providers. It was apparent in my interview data that technology was a significant focus for the parents: the tubes, the machines, the monitors, were all needed for *their* infant. Over time, the environment became less foreign and even familiar. Several families in my study referred to the NICU as their baby's nursery, as their home even.

For the parents in my study, a transition occurred where they developed a comfort level with the NICU sights and sounds, and an understanding of their surroundings. They learned the language and were able to converse knowledgeably with the staff. The parents' acclimatization to the environment sent me back to the literature to determine how other parents experienced the NICU environment. In the study of mothers' experiences in the NICU, it was noted that as the mothers became more comfortable in the NICU environment, they took on the language and began to speak the "jargon" of the unit (Heermann, Wilson, & Wilhelm, 2005). This is a phenomenon that I also witnessed with the parents in my study. Many of the parents were able to talk about oxygen saturations, ventilation management, and other aspects of their child's condition, which is arguably not normal. A parent should not have to worry about apneas, or be concerned about oxygen saturations, and yet this was a real part of these parents' life while their child was in the NICU. What does it mean that parents speak the foreign language of NICU? When one learns the language in a foreign country, there is increased ability to comprehend but additionally there are experiences of feeling accepted, an increased sense of belonging and relationship. Did the parents feel forced to learn the language so that their baby would be more accepted in the unit? Some parents expressed the importance of having their infant(s) seen as more than another premature infant, and would do whatever necessary to ensure their baby got the care he or she needed. Or is it something much simpler, by physically being present at your child's bedside and hearing this language day in and out, that you inevitably will learn parts of the language?

Language Comprehension

A question that I had as I analyzed the data was what aspects of the language do the parents truly comprehend? Interpreting the language used in the NICU, is much more than being able to pronounce or even define a medical term. For example, knowing the appropriate range for oxygen saturations and being able to recite those numbers does not mean that one understands the implications of high or low oxygenation saturations. Parents are quick to identify that their infant's saturation is too high or too low, but what does this information mean?

Do the parents get to a place, after a certain amount of time, where they can truly comprehend the language? I recently attended a developmental care workshop, where a mother and father came in to speak about their experience in our NICU. They stated that it took them at least two weeks in the NICU environment before they could absorb and digest the information being presented in this new language. They felt as though the anxiety and stress surrounding the birth of their premature infant was all-consuming. What impact does this anxiety and stress have on parents' ability to understand information? Brazy, Anderson, Becker and Becker (2001) examined the manner in which parents gather information throughout their experience of having a premature infant. They found that during the time leading up to and immediately following the birth of the premature infant, parents had a difficult time comprehending information. This study was completed retrospectively, and the parents identified that their capacity to take in information and assimilate the excessive amounts of information was difficult in this period of extreme stress. In an article written by Charchuk and Simpson (2005), Charchuk wrote of her personal experiences of having had her son born prematurely and admitted to the NICU. She found that the neonatologist explained her son's condition, provided her with the information, but the shock of having her child taken to the NICU limited her ability to comprehend any new information. From these examples, it was difficult for parents to *hear* the information when they were trying to cope with their own anxiety. This was a concern of neonatologists when their views of resuscitating extremely premature infants were explored (Payot et al., 2007). What is the responsibility of the health care professional in providing information to parents in a crisis situation? I will come back to this concept that parents need *more* than information to facilitate their decision making.

My experiences as a nurse had often left me wondering if parents understood the "big picture." Are they able to see what life might be like beyond the crisis situation? What is the role of information in helping parents fully comprehend the implications of their decision making? In my study, parents wanted information regarding statistics, odds, and prognosis, but their attention

was not focused solely on this information. When complications were encountered and parents received information about possible deficits and less than favourable outcomes, were they able to grasp what this would mean for the future? How can parents comprehend, early in their infant's life, what it will be like to raise a child with disabilities? For one family, they chose to focus on the positive. They chose to focus on their child's potential abilities rather than disabilities. For another family it was the notion that their twins would become who they were meant to become, they would deal with the disabilities if they were to appear. So even with all of the detailed information that we, as health care professionals, deem necessary to have, the responses of parents are individual and may not match up to what we expected from our professional standpoint. I expected parents to be devastated when they heard of the potential for cerebral palsy, deafness or blindness, but parents in this study were resilient. They discovered ways to see optimism and hope in situations I often viewed as negative and hopeless. As a mother, I now even wonder what the "big picture" is. I would now suggest that it is difficult to comprehend what raising a child, with or without disabilities, is like without having experienced it. As health care professional, we can speculate about burden of care, the "big picture," but the differing viewpoints of parents again exemplifies the importance of individualized family-centered care.

Perilous Decision Making: More than Information

Boss et al. (2008) examined what values parents apply to decision making regarding delivery room resuscitation for high risk newborns. They found that parents were generally not affected by the typically grim predictions regarding their infant's potential for survival or disability. Rather, the parents were influenced by their own sense of the possibility for survival or surviving *without* disability, which uniformly situated them with a positive perspective. In another study, researchers found that parents had a way of reformulating the statistics and odds presented by the health care team to justify to themselves that their decisions were indeed the right ones. For these parents, rather than focusing on the risk for morbidities or mortality, their decision making revolved around the chance of

having a healthy child; for one parent it was choosing “the good side” (Payot, Gendron, Lefebvre, & Doucet, 2007, p.1492). For these parents, as with the parents in my own study, information was far from the only factor guiding decision making.

If parental decision making is not about information or is, in fact, about *more* than information, what is the *more*? What I have learned from the parents in this study is that little of their decision making relied on the information given. All of the parents, except one couple, emphasized that while they needed the information they received, other factors contributed to how they made decisions. It was their values and beliefs that enabled them to make decisions for their premature infants. What were the values or beliefs that guided these parents when making life and death decisions? For one couple hope played a key role in their decision making. It was therefore especially difficult when Anna and Mark encountered health care professionals who did share their optimistic hope for their premature twins. This couple felt that the health care team was hesitant to offer them the hope they needed because of the fear of being wrong. In my experience, Anna and Mark’s perspective strikes a familiar chord with me. As a nurse, I want to be informative and supportive for parents, but I am always careful as to what I say as I do not want to give false hope. Experience can shape your outlook on certain situations. I have seen many premature infants suffer and die, and the heartache that it caused parents is something that always stays with me. Being a nurse, you are all too aware of the fact that medical miracles are not the norm, and you do not want to give a parent an unrealistic hope that their child could be that medical miracle. As with the parents in my study, parents in a study by Payot and colleagues (2007) felt that the catastrophic vision portrayed by the health care team was a lack of encouragement. How then should we interact with parents so we do not come across as hopeless? As a new parent I have a deeper appreciation for these parents’ need to have hope. If my daughter had been in the NICU all I would have wanted to hear from anyone was that “everything would be okay!” How do I as nurse and a mother provide a balance between reality and the need for hope? Do reality and hope need to exist on separate ends of a continuum?

DePalo (2009) writes about hope in the context of post traumatic stress disorder, and explained that hope must be based in reality so that a person can work through their current situation to make life meaningful now and in the future. Hope and hopelessness provide an estimate of the probability of achieving certain goals (DePalo). Parents of extremely premature infants endure a period of time when they do not know if they will have the opportunity to take their child home. During this period of time, whether acknowledged by parents or not, they are hoping for the opportunity to leave the NICU as a family. While some parents in this study accepted the news of disabilities they felt they needed some sense of hope to come from those caring for their premature infant(s). When writing of her personal experience with a premature infant in the NICU, Charchuk (2005) explained that “hope is important and should be attended to in the NICU, as it may help parents find the strength and resilience they need to cope with the challenges they face in dealing with a critically ill newborn” (p.194). For Charchuk, hope was more than hoping her son would live; it was hoping that she was being a good mother, and hoping she was doing everything she could to ensure her son’s health and safety. This mother’s experience provides examples of how health care providers can be hopeful for parents in an environment often characterized by hopelessness.

For some parents, their beliefs were rooted in spirituality which facilitated the decision making process. Spirituality, for some, can be

regarded as the driving force that pervades all aspects of and gives meaning to an individual’s life. It creates a set of beliefs and values that influence the way that people conduct their lives. Spiritual activity involves introspection, reflection, and a sense of connectedness to others or to the universe. For many people, this connectedness focuses ultimately on a supreme being who is sometimes called God (Mowdy, 2009, p.411).

Due to the nature of their circumstances, some couples in this study felt helpless after the birth of their premature infant(s). Due to these feelings, they found comfort in connecting with God. For one couple this connectedness translated into placing their decisions in “God’s hands.” This couple believed that God would

make the major decisions and as a result of His decisions the babies would become who they were meant to become. This was also identified in another study, where parents explained placing perilous decisions in “God’s hands” (Boss et al., 2008, p.585). What does it mean to place a decision in “God’s hands”? The parents, in this situation, had decided to initiate resuscitation of their extremely premature twins, and then the rest would be left up to God. They would be able to accept the fate of their family because they believed that the decisions were being made by a higher being.

How do health care professionals come to understand what beliefs are guiding the parents’ decisions? Part of this understanding begins with forming genuine, caring relationships with parents which is the essence of spiritual care (Carr, 2008). These relationships might provide insight to the beliefs that guide perilous decision making. As I will discuss below, relationships were a critical aspect to the parents’ perspectives of decision making.

The Importance of Relationships

Relationships began the first moment parents met the various members of the health care team. When couples met the NICU team even before the baby was born, they were assaulted with information about the imminent birth of their premature infant. The terms prognosis, mortality, morbidity, sequelae, and disability dominated the information provided by the neonatologist (Payot et al., 2007). Parents viewed this information as grim and bleak. Part of this may have been due to the lack of a relationship with the person providing the information. The parents in the study by Payot and colleagues felt that there was no relationship between the neonatologist providing information and themselves as parents. Several parents felt as though the doctor came in, delivered the information, “laid out his knowledge,” and then left (Payot et al., p.1494). I did not get this feeling from the parents in my study. Although none of them described their relationship with the neonatologist providing their initial consult, there seemed to be a respect for the knowledge and expertise he or she was providing. The parents seemed to feel that after being provided with information from the neonatologist, the decision to initiate resuscitation was up to them. It

would appear that for these couples, the information was mostly presented in an open and matter-of-fact manner. Payot et al. also examined the views of neonatologists involved in consulting parents with threatening preterm labour. Two differing views of information sharing were revealed: the neutral information model, where the autonomy and responsibility of the parents was fundamental, and the assent model, where the neonatologist's preferences were clearly expressed and the parent's choice was limited to accepting or rejecting this decision (Payot et al.). The parents in my study expressed that the role of the neonatologist, during that initial consult, was to provide information to help them make their decision. A model focused on assent was used during times when parents did not have a true decision to make. For example, when Anna was 23 weeks gestation, she and Mark were informed that there was nothing that could be done to save their twins if she was to deliver at that point; she needed to be 24 weeks gestation before resuscitation would be offered to the twins.

Wocial (2000) identified the importance of building trusting relationships with parents in order to facilitate the decision making process. Following the birth of their extremely premature infants, parents wanted to feel as though the health care professional genuinely cared for their infant(s). Several of the families in my study identified the importance of building genuine relationships with the various staff members. For Anna and Mark genuine relationships were fostered by particular nursing actions that profoundly affected them: the nurse practitioner who allowed Mark to cut his son's umbilical cord, or the nurse who came in to be with him and his wife when their son died. Some would frame these meaningful relationships as evidence of providing spiritual nursing care. A Canadian study of nurses' experiences of spiritual nursing care revealed four qualities for providing spiritual care: receptivity, humanity, competency, and positivity (Carr, 2008). Receptivity was the notion of being open to and genuinely present with the client. Taking time out of the busy day to ask the parents how things were going, allowing them to voice their concerns, frustrations or the highlights of their infant's day. Providing an opportunity for parents to have some control in an environment where they are rendered powerless; getting the parents immediately

involved in aspects of their infants' care. Humanity was the aspect of caring for the total person. I would argue that in the NICU setting, humanity would be caring for the entire family. Encourage parents to personalize their infants' space in the NICU, again give them something to have control of. This aspect of caring for the whole family is fundamental to the principles of Family Centered Care. Parents identified the need to have their babies seen as more than *another* premature infant, and the importance of being viewed as loving, devoted parents. Competency meant exactly that, that is, that those caring for the family are competent to do so. The powerlessness that parents felt at not being able to provide for their infant left them needing the reassurance that those caring for their infant were competent to do so. Positivity or a positive energy is often missing in the care of the families in the NICU. As noted, the discussions surrounding outcomes were often dismal and the relationships with the staff failed to convey hopefulness. Consistent application of these four qualities would help provide the parents with a more balanced approach to care.

Lemermyer (2007) explored the moral relevance of relationships between parents of critically ill newborns and their health care providers. Throughout my research I have also discovered the significance of relationships between parents and health care providers. Parents in her study described how relationships with the health care practitioners shaped their NICU experience. While it was not my initial intention to study relationships, the data revealed that relationships were indeed part of the parents' perceptions of decision making.

While Lemermyer and I set out to study relationships and decision making respectively, we both discovered the impact the environment of the NICU had on parents. "Walking into an alien world" was the metaphor she used to explain how the parents viewed the NICU. Similar to my study, her parents also showed a progression from their initial feelings of being overwhelmed, to learning the language and becoming comfortable in the NICU environment. A theme identified through her data was the parents' discovery that "home is where the baby is." The NICU became home for these parents.

Family Centered Care

When beginning this research I felt that the parents from the NICU where I worked would have different perceptions of their involvement in decision making because of the applied principles of Family Centered Care (FCC). Most of the articles reviewed for this research did not mention if their NICUs operated from the philosophical standpoint of FCC. Although it was not the primary goal to evaluate how effectively our unit implemented FCC, it was easy enough to extract this information as I read through the transcripts. For two of the families who had experienced being at both the surgical NICU and the non-surgical NICU, they were able to eloquently explain the difference in the involvement of them as a family. Mark recalled feeling that while they were at the non-surgical NICU they were the “most important family” and he was able to observe that other families around them likely felt the same way. This was an incredible feeling for them. By feeling as though they were the most important family, the principles of FCC must have been applied: dignity and respect, information sharing, participation and collaboration (Northern Alberta Neonatal Intensive Care Program, 2006). Another family also reported not getting the “inclusionary feel” while at the surgical NICU, which made decision making difficult in an environment where they were not viewed as active members of the team caring for their infant(s).

Having the principles of FCC implemented allowed the families to be actively involved in decision making. The families were included in all aspects of their infants’ care, which in turn, kept them informed and enabled them to make decisions as they arose. When two of the families had their infants transferred for surgery, the lack of parental involvement made decision making difficult. One family felt that if they were not informed and included in discussions with the health care team, then it was difficult to be responsible for the decisions they needed to make.

Implications for Practice

I choose interpretive description as my methodology as its foundation is the smaller scale qualitative investigation of a clinical phenomenon for the purpose of generating a description that could inform clinical practice (Thorne,

Reimer, Kirkham & O'Flynn-Magee, 2004). Interpretive description can provide "contextual understanding to guide future decisions that will apply evidence to the lives of real people" (Thorne, 2008, p.36). It is not my intent, nor the goal of qualitative research, to make broad generalizations based on the findings of this research. I simply hope that I have captured what was important to these families in a way that can inform clinical understanding and practice in the NICU.

As health care providers, we need to be genuinely present for the parents we encounter; to be approachable and available for every family; to recognize the need to individualize their care. We need to recognize that the environment and culture that we, as health care providers, take for granted is foreign and incredibly intimidating to parents. As a staff nurse, this recognition might mean taking a few extra minutes to explain the mundane, the aspects of our environment that we deem unimportant or ordinary. For example, a father was incredibly worried about the large, red flashing light and alarm that was sounding from his infant's isolette. As nurses, we knew that this alarm did not need an immediate response as it was not indicating that the infant was in any form of distress. As a parent, with no knowledge of what the alarm and light meant, it was literally "alarming" to see that no one was running to check on his infant. We also need to recognise that parents will need explanations repeated, that anxiety and stress will limit their ability to retain and process information.

Parents identified the importance of knowing what to expect. For one family, this was learning from other families experiencing similar circumstances. For another family, it was the explanations received before the circumstances happened. If neonatologists and nurse practitioners have the opportunity to provide these explanations (i.e. before the birth of the parents' premature infant) this might ease the transition to the foreign NICU environment. I do not personally know how each individual neonatologist or nurse practitioner provides an antenatal consult, but for my own practice I will make the effort to prepare the parents for what they might expect in the NICU environment.

Each parent came to make decisions for their infant(s) in a different way, and while the information being provided was important, there needed to be more

than information given. We, as the health care providers, need to make a connection with these parents and foster a relationship built on trust. It becomes our responsibility to empower parents to be involved in their infants' care. It is our responsibility to give parents individualized resources which will enable them to make the decisions they will need to make as parents. The nature of the nurse practitioner (NP) role in the NICU, allows for a genuine, long term relationship to be developed with the parents of an extremely premature infant. I am in no way implying that this relationship is more important than that of the bedside nurse or the neonatologist, but I am suggesting that the NP may quickly become a consistent face in the family's care. There are many staff nurses, and unless assigned to be a primary nurse for a family, they rotate assignments throughout the sixty bed unit of our NICU. They may admit a family to the NICU and then not be assigned to look after them again for a number of weeks. The neonatologist may only be on service for one week, and then another neonatologist will be responsible for the infant's and family's care. The size of the NP group at our site is relatively small, which gives us the opportunity to build a rapport with the parents on our unit (Bowen, 2007).

Further Research

Where do we go from here? I think that it would be interesting to interview these particular families in the future, and re-examine their perceptions of decision making. Would the parents' experiences and perceptions of decision making remain unchanged, or as their child ages and potentially faces disabilities, would they have a different view on their NICU experience?

While I chose not to include families who decided not to initiate resuscitation of their extremely premature infant, research is needed to examine these parents' perceptions of decision making. What were the deciding or influential factors that lead these parents to choose compassionate care? What differences exist between the families that chose to resuscitate and those that did not?

I feel as though I have raised more questions than I have provided answers for in this research. Some of the questions raised in this chapter warrant further

research. For example, what does it mean to make an informed decision? I have indicated that decision making is about more than information, but further research is warranted in this area. Research could include further investigation of the values and beliefs that parents in this study identified as important; hope, and spirituality.

As my perspective of decision making changed throughout this research project, I think it would be important to identify the differences in defining informed decision making between the health care professionals and parents. By identifying the differences we, as the health care professionals, may gain insight into what it means for a parent to make an informed decision. What are the health care professionals' perceptions of parental involvement in decision making? Are health care professionals aware of the impact the culture and relationships can have on decision making? How much comprehension is required to make informed decisions? How do health care professionals begin to understand the parental beliefs that guide and influence decision making? Addressing these issues would help us, as health care providers, to understand the experience of parenting and making decisions in the NICU.

Conclusions

This research project began as an inquiry of parents' perceptions of their involvement in decision making in the NICU. I chose to focus on those parents whose infants were born between 24 and 26 weeks gestation, as these parents are forced to make life and death decisions commencing at the time of their infant's birth. At the outset, I believed that these parents were required to make informed decisions for their infants and I wanted to understand what this experience entailed. Through the descriptions provided by the parents, and my own experience of becoming a mother, I now realize that these decisions are about more than being informed. Decision making was not only a matter of processing the statistics, or understanding the long term risks, it was a personal and highly emotional process. I thought the implications for practice would be developing a better way of providing information to parents of extremely premature infants to facilitate their decision making. Instead, I discovered the importance of

acknowledging the strange and new culture, and the influence genuine relationships can have on parents' experiences in the NICU.

The environment and the new culture were the context where life and death decisions were made, and this strange world was overwhelming. Additionally, the language that was used to describe the care that their child required was foreign and made comprehension difficult. An adaptation occurred over time whereby the parents gained comfort in their new surroundings. They learned the new language, and were able to converse with the health care professionals caring for their infant. Some parents began to look at the NICU as their home, their infant's nursery and a transition took place that allowed them to be a family in the strange place that was the NICU.

Relationships formed between parents and health care professionals were capable of providing the parents with a sense of control in an environment where they felt powerless. Parents wanted to feel a genuine connection with the health care professionals caring for their infant(s). They wanted their infant(s) to be seen as more than another extremely premature baby, and that they were more than just the parents of that extremely premature baby. The application of the principles of FCC enabled families to feel important and respected. In instances when these principles were not utilized families were left feeling confused, frustrated and not involved in their infant(s) care. The principles of FCC demand that health care professionals facilitate relationships that empower parents to nurture and support their child and in turn help them make decisions.

Having an appreciation of the environment and the importance of our relationships with parents will help us, as health care professionals, interact with parents in the future. I hope that I have captured what it was like for these parents to make decisions for extremely premature infants. Further study is needed to gain insight on all aspects of parents' and health care professionals' perceptions of decision making.

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Appendix A

Recruitment Information

PROJECT TITLE: Decision Making in the NICU: The Parent's Perspective

INVESTIGATOR: Dawn Pepper RNC BScN, MN Student

Email address: jdpepper@shaw.ca

SUPERVISORS: Dr. Gwen Rempel, Faculty of Nursing (780) 492-8167

Dr. Wendy Austin, Faculty of Nursing (780) 492-5250

Thank you for agreeing to contact potential parent participants for this study. All mothers and fathers whose child was born between 24 and 26 weeks gestation, and live within the Capital Health region and speak and understand English are eligible for study participation.

When talking to the parents please feel free to refer to the following "script" that highlights the purpose of the study and how the parents could be involved.

"Dawn Szigety, a Registered Nurse and graduate student within the Faculty of Nursing, is interested in gaining an understanding of what it was like to have a premature infant in the NICU. Specifically, she is interested in the decision making processes, that the parents of premature infants, were involved in. She is interested in talking with both mothers and fathers. If you join her in her research, she would meet with you for an interview at a location that the two of you would agree upon. Whether or not you decide to participate in the study, the care that you or your child will receive at this clinic will not change.

If you are interested in hearing more about Dawn's study I will give her your name and number so she can contact you. Or you can sign this form and she will contact you."

Thanks again.

Appendix B
Consent to Release Information

PROJECT TITLE: Decision Making in the NICU: The Parent's Perspective

INVESTIGATOR: Dawn Pepper RNC BScN, MN Student

SUPERVISORS: Dr. Gwen Rempel, Faculty of Nursing (780) 492-8167

Dr. Wendy Austin, Faculty of Nursing (780) 492-5250

I have heard about the study and give _____ permission to provide Dawn Pepper with my name, telephone number and/or email address so that she can contact me and provide me with more information about the study. I understand that Dawn Pepper is a Registered Nurse, and a graduate student in the Faculty of Nursing, and is interested in talking with parents about what it was like for them and their child in the NICU.

By signing this form I am not saying that I will participate in the study. I am only indicating that I want more information about the study so I can decide if I want to take part in the study.

I understand that Dawn Pepper will contact me within the next few weeks and that if I decide that I do not want to hear more about the study that I can say that when she calls.

Signature:_____

Printed Name:_____

Phone number:_____

Email address:_____ Date:_____

Appendix C
Information Letter

PROJECT TITLE: Decision Making in the NICU: The Parent's Perspective

INVESTIGATOR: Dawn Pepper RNC, BScN, MN Student

SUPERVISORS: Dr. Gwen Rempel, Faculty of Nursing (780) 492-8167

University of Alberta, Edmonton, AB

Dr. Wendy Austin, Faculty of Nursing (780) 492-5250

University of Alberta, Edmonton, AB

Purpose of this Study:

The purpose of this project is to find out, from parents, what it is like to make decisions when their baby is born early. What we learn from parents will help nurses and doctors and others they work with parents whose babies are in a neonatal intensive care unit (NICU).

Details of the Study:

I want to talk with mothers and fathers. I would like to meet with you separately. I will tape-record our conversations, which will be 1 to 2 hours long. I will be glad to come to your home for the interview or we will arrange a location that is most convenient for you. I want to hear what it was like for you when your baby was born early and had to spent time in NICU.

Everything that is recorded will be typed out and kept confidential. Any identifying information will be removed from the typed-out interviews. The interviews will be discussed with my research committee only. , The audio-recordings and typed-out interviews will be stored in a locked file cabinet separate from the consent forms. I will keep the information you provide for at least seven years after I finish the study. The final report may contain your actual words, but nothing will identify you personally.

Benefits/Risks of Participation:

There is probably no direct benefit to you of being in this study. This study will give you the opportunity to discuss your NICU experience. I hope that health care professionals and other parents will be able to benefit from what we learn

from you. The only risk to you is being uncomfortable with what you tell me. You can stop the interview at any time, and if there is anything that you would like erased from the tape I would be glad to do that. You are free to withdraw from the study at any time, with no need to provide an explanation. I would also like to stress, that your decision to participate or not in the study will in no way influence the care that you receive from the staff at the Follow-up clinic. I would be happy to provide you with a report of my findings from the finished study.

If you have any concerns about any aspect of this study, you may contact Dr. Christine Newburn-Cook, Associate Dean Research, Faculty of Nursing at 492-6764.

Appendix D
Consent Form

PROJECT TITLE: Decision Making in the NICU: The Parent's Perspective

INVESTIGATOR: Dawn Pepper RNC, BScN, MN Student

SUPERVISORS: Dr. Gwen Rempel, Faculty of Nursing (780) 492-8167

Dr. Wendy Austin, Faculty of Nursing (780) 492-5250

Do you understand that you have been
asked to be in a research study? Yes No

Have you read and received a copy of the
attached Information Letter? Yes No

Do you understand the benefits and risks involved
in taking part in this research study? Yes No

Do you understand that you are free to refuse to
participate or withdraw from the study at any time?
You do not have to give a reason. Yes No

Has the issue of confidentiality been explained to you? Yes No

Have you has an opportunity to ask questions
and discuss the study? Yes No

Would you like a report of the research
findings when the study is done? Yes No
This study was explained to me by: _____
Date: _____

I agree to take part in this study.

Signature of Research Participant

Witness (if available)

Printed Name

Printed Name

I believe that the person signing this form understands what is involved in this
study and voluntarily agrees to participate.

Signature of Researcher

Printed Name

Appendix E
Demographic Information

Parent Information:

	Mother	Father
Age	_____	_____
Occupation	_____	_____

Education:

University/College Graduate	_____	_____
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Some university/college courses	_____	_____
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High School Graduate	_____	_____
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Some High School education	_____	_____
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Gestational Age of Infant at birth:	_____
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Weight of Infant at birth:	_____
----------------------------	-------

Length of Stay in NICU:	_____
-------------------------	-------

Siblings:	Age	Gender
_____	_____	_____
_____	_____	_____
_____	_____	_____

Appendix F

Guiding Questions

- 1) Take me back to the moment when you realized that your baby might be born prematurely.
- 2) What was this time like for you?
- 3) Do you recall having conversations with health care professionals during this time, before your baby was born? If so, what was discussed?
- 4) Can you tell me what happened following the delivery of your baby?
- 5) What were the health care professionals telling you at this point?
- 6) Did your baby experience any complications during their stay in to the NICU? If so, what were they?
- 7) Who was explaining the complications to you as they arose? What were they telling you at those times?
- 8) What were you thinking about when your baby experienced complications?
- 9) Can you tell me about any of the decisions that were made during your child's stay in the NICU?
- 10) Did you feel involved in making these decisions? What was that like for you?
- 11) Were there times that you were not involved in decisions regarding your baby? What was that like for you?
- 12) How did you come to make decisions regarding your child's care? (i.e., discussed things with your spouse, family influences, religious beliefs, medical advice, etc)
- 13) Who at the hospital was the most helpful in talking to you about your child's treatment and condition in the hospital?
- 14) How satisfied were you with the communication about the care that your child received?
- 15) Any suggestions for change?

Appendix G

Consent Form for Release of Identifying Information

PROJECT TITLE: Decision Making in the NICU: The Parent's Perspective

INVESTIGATOR: Dawn Pepper RNC, BScN, MN Student

SUPERVISORS: Dr. Gwen Rempel, Faculty of Nursing (780) 492-8167

Dr. Wendy Austin, Faculty of Nursing (780) 492-5250

I am near completion of my written thesis. My committee is pleased with how I have written my findings. But they are wondering if NICU staff will recognize details about your family. It was hard to write my thesis without describing your unique experiences. With your consent, I would like to leave these aspects of your story in my thesis. I believe they are valuable. They will help nurses and doctors understand more about the kind of care parents are hoping to receive. Should you prefer to have your experience remain completely anonymous, I will change the written text and remove any identifying information.

I am aware that there may be aspects within the written text which make me or my family identifiable by those who cared for us during our NICU stay. I consent to release this information.

Signature of Research Participant

Witness (if available)

Printed Name

Printed Name

I believe that the person signing this form understands what is involved in releasing this information and voluntarily agrees to participate.

Signature of Researcher

Printed Name