

Stories of Early Experiences of Nursing Care in the Neonatal Intensive Care Unit from
Parents' Whose Infants are born with Congenital Diaphragmatic Hernia

by

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Bachelor of Nursing Science, Queen's University, 2003

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Supervisory Committee

A Narrative Inquiry Study: Stories of Early Experiences of Nursing Care in the Neonatal Intensive Care Unit from Parents' Whose Infants are born with Congenital Diaphragmatic Hernia

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Abstract

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The birth of a child diagnosed with congenital diaphragmatic hernia (CDH) involves significant intensive care at the beginning of life and the need for surgery. Parents' experiences during the acute phase of hospitalization for a critically ill infant not born premature is currently limited in the literature; in particular, there is no literature describing parents' experiences of nursing care for having a infant with CDH in the Neonatal Intensive Care Unit (NICU). Using narrative inquiry this study explores stories of parents' early experiences of nursing care in the NICU for an infant born with CDH. A thematic analysis revealed a main overarching theme of "not knowing" with three interrelated subthemes related to parents' need for information and open communication; participation, power and partnership; and nursing presence to transition from not knowing to knowing their infant. The findings from this study suggest that parents want to be recognized as key members within the multidisciplinary team and that the nurse has the ability to facilitate aspects of care to impact parents positively or negatively. Implications for practice focus on supporting parents through evolving empowerment and participation in the care of their infant.

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Dedication

This thesis is dedicated to my family for the immeasurable support, kindness, patience and love they provide on a daily basis and who have shaped me into the person I am and the nurse I am. Words cannot describe how much you mean to me and how lucky I feel to have you each in my life.

Chapter 1 – Introduction & Background

Becoming a parent is often viewed as a pivotal transition in life for a person, family or a partnership. Working with parents who are thrust into the complex healthcare system during this time raises questions about how best to support them. Understanding how transitions intersect with health and well being is pertinent to nursing practice and the profession as a whole (Hattar-Pollara, 2010). For instance, the experience within the Neonatal Intensive Care Unit (NICU) can encompass the transitions to parenthood, to having a critically ill infant, to dealing with death or the threat of death and occasionally to having an infant born with a congenital anomaly. The NICU parental experience is described as a stressful time dependent process filled with emotions of anxiety and exclusion from the infant (Aagaard & Hall, 2008; Obeidat, Bond & Callister, 2008; Shin & White-Traut, 2008). Parents' of infants born with a congenital diaphragmatic hernia (CDH) may have a more complex experience due to the unpredictable nature of the diagnosis and their experience of multiple transitions.

CDH is a congenital defect that occurs when abdominal contents are herniated into the chest cavity early in gestation, which is accompanied by varying degrees of lung hypoplasia¹ and pulmonary hypertension² (Rollins, 2012). The presence of the intestines and/or liver above the diaphragm compresses the developing lungs and stunts growth. For example, if an infant presents with the liver above the diaphragm then the defect is considered large and to have occurred earlier in gestation; thus, the disruption of pulmonary growth is significant and the prognosis is often poor (Rollins, 2012). In a

¹ Hypoplasia in congenital diaphragmatic hernia infants refers to underdevelopment of the lungs.

² Hypertension is elevated blood pressure.

recent meta-analysis, Mullassery, Ba'ath, Jesudason and Losty (2010) identified infants born with their liver herniated upwards to have a 45.4% survival rate, while those infants born with liver down had a 73.9% survival rate. The Canadian Pediatric Surgery Network's 2012 annual Canadian report documented 381 infants born with CDH in 2011, with a survival rate of 80.7%. Thus, the trajectory of an infant born with CDH is complex and multi-faceted.

Congenital anomalies, such as CDH, are often diagnosed prenatally today. Askelsdottir, Conroy and Rempel (2008) describe parents' experience of a congenital antenatal diagnosis as varying parental moods to prepare for the birth and subsequent admission into the NICU with emphasis on relationships with healthcare professionals. Congenital anomalies usually mean a high degree of uncertainty of prognosis, which can contribute to parents' fears of the unknown and uncontrollable (Askelsdottir et al., 2008). Delivery of a critically ill infant has been shown to trigger a cascade of psychosocial crises for parents; however, parents of CDH infants' experiences are also compounded by the anticipatory diagnosis of a congenital anomaly, the degree of uncertainty with the diagnosis and the impending surgery and care goals within the first few weeks (Bass, 1991). The first few weeks of life for CDH infants consist of stabilization with ventilation measures, numerous medications and tests in preparation for surgical repair. Surgical repair, most often achieved in one surgery, is a necessary treatment for all of these infants' care plans. The most common long term implications involve the pulmonary, musculoskeletal, gastro-intestinal and neurodevelopment systems (Rollins, 2012). In particular, neurodevelopmental delays include delays in fine and gross motor skills, speech and language, cognition and behavioural skills and visuo-spatial skills (Rollins,

2012). These infants undergo a lengthy NICU stay and are followed after discharge for these long-term health implications.

The Neonatal Follow-Up Clinic at British Columbia's Women's hospital (BCWH) follow infants discharged from the BCWH NICU that fit high-risk criteria. Infants with congenital anomalies followed by the clinic include congenital heart disease and CDH infants. Infants with congenital heart anomalies are admitted to the paediatric intensive care at BC Children's hospital; thus, parents' experiences of nursing care in the NICU environment may not be the same as parents' experiences of the paediatric intensive care. Infants born with CDH, however, are admitted and treated in the NICU for the duration of their hospitalization.

According to the BCWH NICU database and the Canadian Neonatal Network³, there were seven infants admitted with a diagnosis of CDH in 2009, nine admissions in 2010, six admissions in 2011 and seven admissions in 2012. Although these are small numbers in comparison to the number of infants admitted to the unit, the health issues associated with this developmental defect are considered neither small nor short-term. Currently, BCWH is second only to the Hospital for Sick Children in Toronto for admissions of infants born with CDH in Canada. Furthermore, these infants have detailed medical care plans for their NICU care, but have no care plans that focus on nursing care of the family in BCWH. Infants born with CDH are eligible for the Neonatal Follow-Up (NFU) program due to a high risk for developmental issues after transition home. Therefore, families of these infants face uncertainty in their illness trajectory and long-

³ The Canadian Neonatal Network refers to a group of Canadian researchers who collaborate on neonatal research and maintain a neonatal database aimed at improving efficacy and efficiency of neonatal care.

term outcomes, which could contribute significantly to difficulties during their stay in the NICU.

Statement of the Problem

The birth of a child diagnosed with CDH involves significant intensive care at the beginning of life. Parents of these infants are thrust into the complex world of the NICU. Nurses are in a position to positively impact parents by providing supportive care during these complex transitions (Meleis, Sawyer, Im, Hilfinger Messias & Schumacher, 2010). There is currently little published research about the experiences of NICU parents of critically ill infants who are not born premature; in particular, no literature was located that describes parents' experiences of nursing care for having a infant with CDH in the NICU setting.

The birth of an infant requiring hospitalization has been shown to adversely affect the parental role by altering attachment, stress and transition (Jackson, Ternstedt & Schollin, 2003; Lundqvist & Jakobsson, 2003; Mackley, Locke, Spear & Joseph, 2010; Pinelli, J., 2000; Shin & White-Traut, 2006). Some studies have described early parental experiences in the NICU as feelings of alienation accompanied by the need to be a parent (Agaard & Hall, 2008; Jackson et al., 2003; Heermann, Wilson & Wilhem, 2005; Lundqvist, Hellstrom & Hallstrom, 2007; Lupton & Fenwick, 2001). Understanding the complexities, vulnerabilities and diversities associated with specific transitions is relevant to the care nurses provide (Meleis et al., 2010). Furthermore, Doane (2005) acknowledges the need to understand conditions of complex uncertainty to provide family nursing. Thus, understanding the transition of becoming a parent in the NICU and how nursing care is experienced for a critically ill infant born with CDH may identify the

unique challenges and obstacles these parents face and how family-nursing care can be improved.

Purpose of Proposed Research

The purpose of the study was to explore stories of parents' early experiences of a NICU hospitalization with a particular focus on the nursing care experienced during this transitional time of becoming parents to an infant born with CDH. The practice-oriented purpose sought "understanding to illuminate specific problems or improve specific practices" (Haverkamp & Young, 2007, pg. 274). The primary audience for this research was neonatal nurses since they provide direct care to both the infant and the parents during this transition. Secondary audiences include other health care professionals and families that comprise the neonatal team. The focus was on the parent's story as the primary data source for the research. The accounts are first person through the eyes of parents with infants diagnosed with CDH. Methods of narrative inquiry recognize the individuality and uniqueness of our participants, which can contribute to evidence-informed practice and patient-centred care (LoBiondo-Wood & Haber, 2013). Thus, it was my hope that this study contributes to knowledge of how parents experience early nursing care in the NICU for infants diagnosed with CDH; ultimately to increase NICU nurses' sensitivity to the needs and concerns of this population. Narrative inquiry was used for the power of storytelling as a data source to understand another's world and for the ability to illustrate the experiences of those in transition (Riessman, 2008).

Research Questions

The research questions addressed in this study included the following:

1. What do parents' stories about nursing care of a critically ill infant born with a congenital anomaly in the NICU tell us (nurses) about their early experiences of parenting?
2. What do parents identify in stories as the most and least supportive neonatal nursing practices during this time?

Significance of the Topic

As technology advances and our picture of viability changes, so must our practices as nurses to reflect the needs and concerns of all those we care for. In British Columbia there are three levels of NICUs. A level three NICU is a dynamic environment that provides the highest level of NICU care, which includes surgical capabilities and extracorporeal membrane oxygenation⁴. In addition, the NICU at BCWH admits infants from all over the province; thus, nurses work with a variety of families from diverse backgrounds with different needs. Narratives of parents' experiences in the NICU within the Canadian context are scarce in the literature. Although Canada shares similarities with other countries, it is important to conduct research that is specific to our population and context. The stress of parents during this early "acute" stage of transition is documented as being high – in one study, some parents had indicators for post-traumatic stress disorder (Lefkowitz, Baxt & Evans, 2010). More importantly, admission to the NICU can cause a delay in attachment and parental transition, which needs to be further explored (Shin & White-Traut, 2006).

⁴ ECMO is a heart-lung bypass machine.

Qualitative research reports focused on parents' experiences of having an infant diagnosed with CDH in the NICU were not located in my initial literature search. Parents of infants born with CDH are faced with a degree of uncertainty associated with the defect, along with the unfamiliar NICU environment, which could compound parental stress and delay parenting. In particular, neurodevelopment delays are common implications of CDH, which could affect the family long term. The importance of focusing on this small population was identified in the literature due to the acknowledged ongoing multidisciplinary long-term follow-up needed to identify and manage CDH-associated morbidities (Rollins, 2012). The initial relationship that was generated between parents and a neonatal team could be influential to the ongoing care of the infant beyond the confines of the NICU. I used a narrative inquiry approach to gain an understanding of parents' experiences of having an infant born with CDH in the NICU, which contributes to knowledge about the NICU experience and identifies facilitative nursing practices pertinent to the ongoing care of the family and infant living with CDH-associated health challenges.

Chapter 2 – Literature Review

Introduction

Currently there is no qualitative literature addressing the phenomenon of parents' experience of having an infant born with CDH in the NICU. Five areas of literature related to my topic of interest were explored: parents' transition experiences in the NICU, parents' experience with a sick infant, parents' experience with an infant with a congenital anomaly, parents' experience of infants requiring surgical care and lastly facilitative NICU nursing practices.

Transition Experience in the NICU Context

Firstly, transitions are relevant to the nursing profession because of the influence transition experiences have on health consequences. Similar to change, transitions can be abrupt or occur over time. Role transitions refer to, "a change in role relationships, expectations, or abilities," which result in "the person needing to incorporate new knowledge, alter his behaviour, and thus change his definition of himself in his social context" (Meleis, 2010, pg. 15). Meleis (2010) highlights that role loss or difficulty in role acquisition can lead to feelings of depression, grief, mourning and powerlessness. Present within the literature are themes such as struggling to parent, vacillating emotions, and delay in parenting, which could be related to issues with role sufficiency (Aagaard & Hall, 2008; Jackson et al., 2003; Lundqvist & Jakobsson, 2003; Shin & White-Traut, 2006). According to Hattar-Pollara (2010), developmental transitions can involve predictable or unpredictable events, which can positively or negatively influence health and well-being for those in transition. Thus, the transition to parenthood in the NICU

could be compounded by an array of emotions and barriers related to the environment and context.

Shin and White-Traut's (2006) report of a concept analysis of transition to motherhood in Korea identified three critical attributes that result in delayed motherhood and developing a sense of meaning concerning family and life. Ten Korean mothers of infants with varying health concerns in an NICU were interviewed about the definition, meanings and impact of transition to motherhood. The critical attributes identified were motherhood as a time dependent process, psycho-emotional swirling and hovering around the edge of motherhood (Shin & White-Traut, 2006). Shin and White-Traut (2006) highlighted that mothers of hospitalized infants start their transition to motherhood in confusion with mixed feelings, such as "sorrow and shock, which progress to ambivalence and conflict near the time of infants' discharge" (pg. 94). Antecedents to the process of transition experiences to motherhood are identified as unexpected outcome of pregnancy, awareness of the situation and mother-infant separation.

Jackson et al.'s (2003) phenomenological study focused on parental experiences of having a preterm infant in a Swedish NICU as a transition affected by the role of healthcare workers. No infants were identified as having any congenital anomalies. Jackson et al. (2003) described the time dependent process as moving from alienation to responsibility to confidence and finally to familiarity. Mothers described alienation as ambivalence about the baby and parenthood, concern for the infant and need for participation and control of care; fathers experienced alienation as an unreality or outsider, concern for the infant and expressed difficulty attaching to the infant, preferring delegation to the staff (Jackson et al., 2003). Several interviews took place with both

parents together over the course of hospitalization, including post discharge interviews. Within the sample of seven sets of parents of premature infants in a level III NICU, parents felt confidence when their infant reached six months of age, and familiarity within parenthood came when the infant reached 18 months of age (Jackson et al., 2003). Implications for practice were identified as a need for individualized support of mothers and fathers, as it affects the long-term outcome of relationships within the family. There was also emphasis on awareness of gender when engaging and interacting with parents.

Lundqvist et al.'s (2007) hermeneutic phenomenological study focusing on fathers' lived experience of caring for their preterm infant was also described as a transition. Transition from feelings of distance to proximity was disrupted by several situations, such as "deterioration in their partner's medical condition, her way of handling the situation, the infant's medical condition, and how they experienced the teamwork with the professionals in the NICU" (Lundqvist et al., 2007, pg. 495). Feelings of distance were related to subthemes of living outside reality, becoming an outsider and living with worry (Lundqvist et al., 2007). No infants were identified as critically ill in the study; however, there were infants with gestational ages of 25 weeks, which is often accompanied by varying health problems. This study was conducted in Sweden with mostly Caucasian participants. Lundqvist et al. (2007) stressed that fathers often focus on the needs of their partner instead of their infant during the acute stage of hospitalization, which may contribute to their feeling of distance from fatherhood. The idea of distance may also be related to the time it takes to get to know an infant due to the constraints of the environment as highlighted in the maternal literature.

Lastly, Lutz, Anderson, Riesch, Pridham and Becker's (2009) integrative review sought to further understand the parent-child relationship via a discovery approach. The studies examined were from Australia, Canada, Europe and the United States. Common themes involving the perceptions and experiences of parents of preterm and high-risk infants included parent-child relationship as a process, vacillating emotions, the NICU as a stressful environment and influences of interpersonal relationships and interactions (Lutz et al., 2009). The process of relationship building was deemed individualized and constantly evolving. Further barriers that promoted feelings of disconnection included the health status of the infant or mother, the inability to hold, touch or care for the infant, the infant's overall appearance, concerns about outcome, medical interventions and treatments, as well as poor quality interaction and communication with health care professionals (Lutz et al., 2009).

Thus, current literature on parents' experience of transition to parenthood in the NICU consists of a myriad of emotions regarding the environment, circumstance and care practices that place barriers to bonding. The context and environment surrounding the birth of an infant born with CDH includes recommendations to limit movement and stimulation, which may pose as a further barrier to parenting. Studies identified were focused on parents' experience with the premature population in the NICU, but no studies were conducted in a Canadian context directed specifically at the population of parents' of infants born with congenital anomalies.

Parental Experience with a Sick Infant in the NICU

Moreover, early parental experience of a critically ill infant in the NICU provides background to compounding factors of parents' experience. Present within the literature

are themes such as feeling like an ‘outsider’, feelings of distance, periods of uncertainty, desire to be close to the infant, turbulent environment and loss of control (Aagaard & Hall, 2008; Arockisamy, Holsti & Albersheim, 2008; Lundqvist & Jakobsson, 2003; Watson, 2010). Therefore, exploring these experiences contributes to the understanding of parents’ experiences of having an infant born with CDH in the NICU.

Infants are admitted to the NICU for a myriad of diagnoses and reasons; similar to the parental transition literature, most literature of parents’ experiences in the NICU of a sick infant involve the birth of a premature infant (Aagaard & Hall, 2008; Cervantes, Feeley & Lairviere, 2012; Erlandsson & Fagerberg, 2005; Hurst, 2001; Jackson et al., 2003; Lindberg, Axelsson & Ohrling, 2008; Lundqvist et al., 2007; Pohlman, 2005; Reid, 2000; Schenk & Kelly, 2010; Wakely, Rae & Cooper, 2010; Watson, 2010).

Undoubtedly, having an infant admitted to an NICU for any reason can cause a cascade of emotions for parents.

Heerman et al.’s (2005) qualitative study of fifteen mothers of premature infants in the Midwestern United States also generated themes surrounding the mother’s development from outsider to engaged parent through four domains: focus, ownership, care giving and voice. Mothers’ early experiences in the unit involved being “totally overwhelmed by the technology of the unit and the expertise of the nurses” (Heerman et al., 2005, pg. 177). The subtheme of ownership illustrated how health care professionals provide primary care during the admission and acute phase, due to the critical illness of the child, which resulted in mothers’ feeling that their infants belonged to health professionals (Heerman et al., 2005). Mothers felt they were ‘borrowing’ their child from the nurses, which further gave rise to feelings of exclusion or non-involvement. Barriers

that prevent a sense of ownership were the environment, state of the infant and care of the infant during this initial period. Therefore, it is apparent in the literature that overwhelming feelings of being an outsider are present during early maternal experiences.

Similarly, using a Husserlian phenomenological approach, Erlandsson and Fagerberg (2005) describe the essence of six Swedish mothers' experience of a preterm or sick full-term infant as a strong desire to be close, bond and care for the infant. Mothers identified the desire to be close as a result of a prolonged separation due to staff, environment and organization. Other identified needs included the need to be seen and to be part of a functional team. Hence, the environment of the NICU served as a barrier to mothers being close to their infants.

Moreover, Hurst's (2001) critical ethnographic study of 12 mothers of premature infants in Northern California with varying ethnicities in a level three nursery found mothers' actions focused on concern for their infants' safety. As mothers became familiar with the environment, actions surrounding safeguarding occurred to promote safety. The study noted that healthcare professionals were in a position of authority due to their "expert knowledge of the technology, policies and procedures" relative to mothers (Hurst, 2001, pg. 43). Environmental barriers and nursing resource distribution was identified as preventing empowering information, which was desired by mothers. No infants in the study were born with any congenital anomalies. The study findings emphasized the need to partner with families during this complex time.

Fathers of NICU infants are often the primary contact in the immediate postpartum period, being the first to meet the medical team while the mother is still in the

delivery area. Fathers' early experience in the NICU are important to explore due to their unique position during this transition, as well they are a prominent support system for the mother and often the first to make contact with the infant. Furthermore, differences have been noted as to how fathers and mothers cope with the NICU experience (Arockiasamy et al., 2008). Only one qualitative Canadian study involving fathers' experiences in the NICU was found (Arockiasamy et al., 2008). The study sample consisted primarily of Caucasian male subjects with a small number of participants from other cultures. The sample was 16 fathers' of infants of varying complex health needs, including some born with congenital anomalies. The study was not focused on early paternal experiences, but on the overall experience of fathers. The central theme of feeling out of control was interrelated to subthemes of worldview, information, communication, roles and external activities (Arockiasamy et al., 2008). Consistency of information was related to how much control fathers felt they had over the situation. Fathers in this context commented on a preference for support from healthcare professionals and personal support networks with a particular focus placed on how and when information was shared.

Furthermore, Watson (2010) focused on the early experiences of parents of a premature infant in relation to liminality – a state of limbo. Watson's (2010) study included parents of premature infants, neonatal nurses and senior nurses from two study sites in the United Kingdom. The early experience was conceptualized as a period of uncertainty in regards to the future, and an inability to care for the infant due to the health state (Watson, 2010). These two concepts could be related to parents' experiences of having an infant born with CDH in the NICU due to the uncertainty of their illness trajectory and the extensive respiratory, metabolic, nutritional and hemodynamic support

they can require during the initial period in the NICU. Watson (2010) argues that the context of early preterm birth is not conducive to secure attachment and parental sensitivity. Themes generated through Watson's (2010) interpretive interactionism study were crisis, uncertainty and powerlessness, which were all related to the position of liminality.

Pepper, Rempel and Austin's (2012) descriptive interpretative study within a tertiary level⁵ Western Canadian NICU generated three themes surrounding decision making, before and in the NICU, culture shock in the NICU and relationships in the NICU. The initial impression and early experience of the NICU is as a strange land, which emphasizes the unfamiliarity of the environment and situation (Pepper et al., 2012). Only two of the five families interviewed had both parents present, which resulted in an underrepresentation of fathers. Implications for practice focused on the need for nurses to be genuinely present, to be available and approachable and to recognize the ongoing need to individualize care for families (Pepper et al., 2012).

In a literature review Obeidat et al. (2009) explored literature of parents' experiences in the NICU from 1998-2008. The identified overarching themes were feelings of stress, strain, separation, depression, despair, disappointment, ambivalence and lack of control over the situation, as well as vacillating between inclusion and exclusion. Studies showed that when mothers were involved in providing care they transitioned from a passive to an active role and from exclusion to participation. Caucasian parents were over-represented in the studies reviewed and only one Canadian study was present. Recommendations included facilitating the parental role within the

⁵ Highest level of NICU care in Canada.

NICU by promoting more time and proximity between the infant and the parents. The study identified the need for further research surrounding parents' experiences of developmentally supportive care provided by neonatal nurses.

Aagaard and Hall's (2008) meta-synthesis of mothers' experiences of having a preterm infant in the NICU generated metaphors centered around reciprocal relationships, which illustrate the evolution of a mother's experience over the course of a hospitalization. For example, the five metaphors consisted of mother-baby relationship (from their baby to my baby), maternal development (striving to be a real normal mother), a turbulent neonatal environment (from foreground to background), maternal care giving and role reclaiming strategies (from silent vigilance to advocacy) and mother-nurse relationship (from continuously answering questions through chatting to sharing of knowledge) (Aagaard & Hall, 2008). The first metaphor illustrates well the feelings of being an outsider by describing the infant as not her own. Studies reviewed were from Australia, the United States, the United Kingdom, Sweden and Denmark; no Canadian studies were included in Aagaard and Hall's (2008) meta-synthesis.

Identified in the literature was parents' desire to be close to the infant, but environmental or staff barriers prevent proximity. The NICU environment was seen as a 'strange land' with healthcare professionals holding authority. Studies focused on the parental experience often under represent the fathers (Cleveland, 2008; Wakely et al., 2010). Most studies were conducted with White, middle-class families in the United States, United Kingdom, Australia or Scandinavian countries (Cleveland, 2008; De Rouck & Leys, 2009; Jackson et al., 2003; Heerman et al., 2005; Obeidat et al., 2009; Smith, SteelFisher, Salhi & Shen, 2012; Wakely et al., 2010). Further research is needed

to identify facilitative nursing practices. Thus, there remains a need for research within the Canadian context including both diversity of families and the presence of the father in regards to experience and nursing practices.

Parental Experience with an Infant Born with a Congenital Anomaly

In addition to the environment within the NICU, the parental experience of having an infant born with a congenital anomaly often impacts the parents in a variety of ways. Visits to the physician or midwife could be seen as momentous occasions highlighting hallmark moments in development. The antenatal diagnosis of a problem, such as a congenital anomaly, could shatter parents' plans for a 'normal' pregnancy and child. Expectations of parent-infant interactions can be disrupted by hospitalization and accompanying revelations about the infant's condition. Some literature was found regarding parents' experience with antenatal diagnosis of congenital anomalies, while other literature focused primarily on parents' experiences of infants diagnosed with congenital heart disease.

Using a grounded theory methodology, Miquel-Verges, Lee Woods, Aucott, Coss, Sulpar and Donohue (2009) aimed to describe parental expectations of a prenatal consultation with a neonatologist after diagnosis of a fetal congenital anomaly. Interviews with 22 mothers in the United States occurred one week after consultation and the first week after delivery. Five main themes were generated including preparation, knowledgeable physician, caring providers and allowing hope and time. Mothers valued the preparation that prenatal consultation provided them with; in particular, mothers identified a NICU tour as essential and that consultation helped decrease their anxiety. Care providers equipped with compassion and sensitivity was critical to consultation.

Askelsdottir, Conroy and Rempel (2008) highlighted the experiences, concerns and healthcare needs of parents who receive a prenatal diagnosis of a congenital anomaly during routine ultrasounds. Three parents, two mothers and one father, from rural Alberta whose infants were diagnosed with gastroschisis⁶ were interviewed in a pilot study. Parents struggled with the uncertainty and fear that came with the initial diagnosis. The diagnosis brought awareness of the problem, but the reality of the problem was “that no one could predict how big or complicated the defect was or how the baby was going to fare after delivery” (Askelsdottir et al., 2008, pg. 350). Similar to a diagnosis of CDH, a medical team is unable to predict the precise extent of the defect and course of the infant, which creates a situation of uncertainty. As parents gained more information, fear of the unknown switched to fear of the uncontrollable. Parents’ identified in interviews that consistency and interaction with health care workers made a big difference. Overall, a lack of communication and coordination from time of diagnosis to birth was highlighted. A nursing presence was recommended for an earlier multidisciplinary approach to attend to parental moods and concerns. Further research is needed to understand how parents face the diagnosis of a congenital anomaly and how nurses can attend to this. Overall, the presence of the nurse is seen as important in the care of these parents.

Aite, Trucchi, Nahom, Casaccia, Zaccara, Giorlandino and Bagolan (2004) conducted a quantitative survey designed to assess parents’ emotional and cognitive reactions to the prenatal diagnosis of CDH. The questionnaire focused on three specific categories: learning and information giving, pre-diagnostic knowledge of the anomaly and acquisition of the information at the first antenatal counselling, and emotional

⁶ A congenital defect resulting in the infant being born with the intestine protruding out of the body.

reactions during and after the first antenatal consultation. The study was conducted in Italy with 37 participating couples. Fear was recognized as the most frequent emotion experienced at the first consultation and intense emotion was noted to complicate understanding. Recommendations included multiple antenatal visits and continued interactions with health care professionals to provide opportunities for multiple ways of understanding the implications of the diagnosis as evidenced by the intense emotional distress that affects parents' ability to assimilate information (Aite et al., 2004).

Similar to CDH, diagnosis of congenital heart disease can be life altering for families. Rempel and Harrison (2007) conducted a grounded theory study to describe the parenting experience of mothers and fathers whose child was born with hypoplastic left heart syndrome (HLHS). Repair of HLHS requires a series of high-risk surgeries; as well the syndrome remains the leading cause of death of infants born with congenital heart disease (Rempel & Harrison, 2007). The study was conducted in a Western Canadian tertiary referral center with 16 parents of nine infants. Extraordinary parenting was exemplified throughout the findings, which included the need to safeguard their child, themselves, and their couple relationship (Rempel & Harrison, 2007). Extraordinary parenting was described as, "extensive assessment and problem-solving knowledge that parents applied as they took charge of complex nursing skills" (Rempel & Harrison, 2007). Safeguarding the child included themes of taking charge, struggling for balance and involving others. Parenting challenges identified included: ensuring weight gain and shielding from infection. There was a constant concern from parents of whether they were being overprotective and unquestionably overextending themselves to achieve safeguarding. Parents looked after themselves individually and as a couple through

strategies including: directing their minds, normalizing, trusting, buffering severity and staying on the same page.

Rempel & Harrison (2007) compared their findings with Ray's (2002) Canadian study of parents of children with chronic health conditions highlighting "parenting plus". Each study highlighted the extra effort taken to care for these infants and recognized the importance of safeguarding both the child and themselves. Rempel and Harrison (2007) suggested future research that replicated this study with parents of children with CDH at different stages of their diagnosis and treatment would "provide valuable comparisons to further understanding of parenting children who receive technologically advanced life-saving interventions" (pg. 836).

Furthermore, Lee and Rempel (2011) conducted a secondary analysis of data from Rempel and Harrison's (2007) grounded theory study to describe the relationship between the parental processes of perceiving their child as vulnerable and normalizing their child's outcomes. Parents of children surviving HLHS shared their perceptions of child vulnerability, normalization and optimistic appraisal. The theme of parental perception of child vulnerability focused on fear and distrust, precariousness of survival, vulnerability to illness and discipline. Nurses were highlighted as key players to balance normalization with awareness of child vulnerability.

Finally, Nelson, Glenny, Kirk and Caress (2011) conducted a literature review of parents' experiences of caring for a child with a cleft palate/lip. The 57 articles reviewed contributed knowledge of the emotional, social, and service related experiences of parents caring for a child with a cleft. Early emotional experiences were noted as feelings of shock, anger, grief and worry. Rewarding aspects of caring for a child with a cleft

were noted to be “recognition of own personal strengths, stronger relationships, appreciation of diversity and others’ good intentions, tolerance, a sense of community and hope for the future” (Nelson et al., 2011, pg. 13). The majority of articles were from the United States and United Kingdom with only three Canadian studies. The reviewers found limited qualitative literature available on the topic, limited studies that included fathers’ responses and variable quality of research methodologies. .

Thus, literature surrounding parents’ experiences of infants born with congenital anomalies highlights the extraordinary actions that parents embark on to care for their infant’s health and maintain their own well being. The role, presence and actions of the nurse are noted to impact parents. The need for information and partnering with health care professionals is recurrent within this literature. Relevant Canadian research surrounding parents’ experiences of having an infant born with congenital heart disease is present within the literature; however, Rempel and Harrison (2007) highlighted in particular the need for research with the parents of children with CDH.

Parental Experience of Infants Requiring Surgical Care

Admission to an NICU can be a confusing, intimidating experience for those who are unfamiliar with hospitals. Compounding this admission is the need for surgery. Parents’ may have experience with surgery that could facilitate or complicate their experiences with their own infant going for surgery. Adjusting to the environment of the NICU, the birth of a new infant and the information surrounding surgical intervention undoubtedly could impact parents.

Reis Teixeira and Santos da Silva (2011) sought to understand the feelings experienced by mothers of infants born with congenital malformations requiring surgery.

Using narrative inquiry and thematic analysis, 18 mothers of infants undergoing surgical procedures in the neonatal period were interviewed in Brazil. The most prevalent congenital malformation was concerning the gastrointestinal tract. Three themes were revealed from the interviews: the search for “normalization” of the child, the need for hospitalization for surgery, and an experience of multiple fears. Mothers view surgery as the solution to the child’s health problems; however the need for hospitalization provoked feelings of sadness, anxiety, depression and abandonment of personal life. Prior experience with hospitalization was shown to reduce or exacerbate fear of death depending on the nature of these prior experiences. Multiple fears were identified within the narratives, including fear of death, surgery, anaesthesia, chronicity and social prejudice against their child. Reis Teixeira and Santos da Silva (2011) observed that surgical procedures and the environment interfere with maternal functions. The study identified a need for healthcare professionals to practice with greater sensitivity towards these mothers.

Joseph, Mackley, Davis, Locke and Spear (2007) completed a quantitative study of 22 fathers in the United States aimed at surveying stress factors in fathers of “surgical infants”. The Parent Stressor Scale: Infant Hospitalization was used to assess perceived stress. Fathers reported elevated levels of stress, with seeing the infant in pain as a large stressor. Parental stress was highest in the domains of “Parental Role Attainment” and “Infant Appearance and Behaviour”. This study highlights that fathers require the support of staff during the tumultuous time of hospitalization and surgery.

Lastly, Diffen, Shields, Cruise and Johnston (2013) completed a literature review focusing on parents’ experiences of caring for their infant following surgery in the

neonatal period. Only four studies, all self-report studies conducted outside Canada, were identified that related to parents of infants that required surgical intervention. Diffen et al. (2013) concluded from the studies that infants who require surgery are at risk for experiencing longer-term complex health needs, which highlight the importance to assess the short and long-term impacts on this population. Stress levels were seen to be high in this group as indicated by the reviewed studies (Diffen et al., 2013). One particular study focused on the longer-term impact on the family of caring for an infant born with CDH in the United States (Chen, Jeruss, Terrin, Tighiouart, Wilson & Parsons, 2007). Chen et al.'s (2007) retrospective study of 53 parents suggests that there is large emotional strain impact on these families. Moreover, there was a greater emotional impact on families with children with current clinical health problems. These findings were self-reported, so there are always questions regarding accuracy and memory recall; however, the study highlights the potential issues this group could be at risk for.

Thus, parents of infants requiring surgical intervention experience stress, emotional strain and multiple fears. The environment and care required poses barriers to parenting actions. Care directed towards these families needs to include the sensitization to these needs. Supporting Canadian literature was scarce.

Facilitative Nursing Practices

Lastly, reviewing the state of current literature on facilitative nursing practices in the NICU from the perspective of the parents can shed light on what parents currently identify as helpful and whether there are any similarities with what is generated from this proposed study. Transitions can also be affected by specific pre-conditions, which can either result in an inhibition or facilitation of transitions. Schumacher and Meleis (1994)

identify transition conditions as meanings, expectations, level of knowledge/skills, environment and level of planning. These conditions are not exhaustive of conditions present, but further research is needed to identify other contributing factors. Review of current literature could identify facilitative nursing practices to meet the needs of parents in the NICU.

Smith et al. (2012) focused their research on how parents cope with the complex NICU environment. Interviews with 24 families in Israel generated five primary coping strategies parents enacted in the NICU: participating in care, getting away from the NICU, gathering information, involving friends and family and engaging with other NICU parents. Parents appreciated nursing staff who provided formal and informal training to enable parents to provide baby care, and created a welcoming and encouraging environment. It was also noted that parents appreciated the availability of staff for answering questions, as well as tailoring answers to parents' current state. Primary nurses were seen as key confidants. The study highlighted the need for further research to refine the ways for staff to support parents.

Fenwick, Barclay and Schmied (2001a) identified chatting as an important clinical tool for facilitating mothering in the NICU. The study utilized previous interview data from a grounded theory study of 28 Australian women with infants in a level two nursery. No infants were identified as requiring invasive respiratory support beyond oxygen. Mothers' experience within the nursery was in relation to the interactions that were shared with nurses. The study emphasized the important role nurses plays in engaging mothers in a supportive relationship and fostering communication. Nurses' communication either hindered or facilitated mothering depending on the type of social

chat implemented. Fenwick, Barclay and Schmied (2001b) used the same interview data for the purpose of describing and explaining the experience of mothering in the NICU. The major category generated was “struggling to mother”, which resulted in a cascade to disenfranchised mother when inhibiting nursing practices was present. Inhibitive nursing actions were described as, “authoritarian style of clinical practice that was primarily focused on protecting the infant”, which maintained the nurse as the expert and the mother as an outsider (Fenwick et al., 2001b, pg. 52). Fenwick et al. (2001b) participants described facilitative nurses as those that “acknowledged the unique, interdependent nature of the maternal-infant relationship” and enabled opportunities for mothers to be with their infants in a “meaningful way” (pg.52). Thus, nurses were portrayed as inhibitors or enablers in this study.

DeRouck and Leys (2009) initially reviewed the literature about the information needs of parent whose children were admitted to the NICU. DeRouck and Leys (2011) later updated the literature review and explored parental information needs in semi-structured interviews to develop a conceptual framework for understanding those needs. A total of 78 studies were reviewed and only six of those studies were Canadian. De Rouck and Leys (2009) acknowledge that the high tech environment that is the NICU, along with the fragile appearance of an infant and the loss of expected parental role, contribute to parents’ stress. Information and communication were identified as the most important need for parents, which could be related to feelings of shock, anticipation and uncertainty (DeRouck & Leys, 2009). Information provided during the acute phase either focused on information regarding equipment or parent-infant bonding as determined by preference of the nurse (DeRouck & Leys, 2009). Neonatal nurses and neonatologists are

identified as the primary sources of information. The provision of information during this time is identified as an ongoing process of repetition and clarification (DeRouck & Leys, 2009). During the acute phase of hospitalization parents were noted to be passive recipients of information, which slowly evolves into a two-way conversation resulting in a more active position (DeRouck & Leys, 2009). Thus, links within the literature identify different information needs across a NICU experience and the role of the nurse in providing information.

Furthermore, Cleveland (2008) conducted a systematic review of literature surrounding the needs and behaviours supportive of parents during their time in the NICU. Cleveland (2008) included 60 studies in the review in which three of those studies were Canadian. Six primary needs were identified through the review: accurate information and inclusion in infant care and decision making, vigilant watching over and protecting the infant, contact with the infant, being positively perceived by the staff, individualized care and reassurance and a therapeutic relationship with healthcare professionals (Cleveland, 2008). In addition, four supportive behaviours were identified: emotional support; parental empowerment; a welcoming environment with supportive unit policies; and parent education with an opportunity to produce new skills through guided participation (Cleveland, 2008). Cleveland (2008) completed the review by making eight recommendations for nursing practice, as well as a recommendation for future research that focuses more on parental needs with emphasis on nursing care to meet those needs. Both systematic reviews highlighted that the majority of samples were Caucasian participants, which lacked diversity and underrepresented fathers

Apparent in the literature is the relationship between the parent and the nurse. Fostering cultures of partnership and getting to know the family are paramount to providing care geared towards the health promoting outcomes for infants and their families (McAllister & Dion, 2006). Further research was identified to focus on the needs of parents with particular emphasis on nursing care (Cleveland, 2008). Facilitative practices, such as positive social chatting, and information sharing can promote a trusting, therapeutic relationship with parents.

Summary

In the literature review, five areas were examined to provide background for exploring parents' experiences of nursing care of an infant with CDH in the NICU. The initial literature review revealed early NICU parental experience as a time dependent process with feelings of exclusion and separation, effects of hospitalization and the NICU environment, concern for the infant's safety and influenced by nursing care. Parents within the NICU are faced with a multitude of barriers to bonding and parenting during this transitional time. For example, Lutz et al. (2009) identified barriers such as the health status of the infant or mother, the inability to hold, touch or care for the infant, the infant's overall appearance, concerns about outcome, medical interventions and treatments, as well as poor quality interaction and communication with health care professionals. DeRouck and Leys (2009, 2011) further highlighted the importance of studying points of change, such as admission, to understand information needs of NICU parents. Ultimately, interactions with nurses were linked to the parental experience; in particular, nursing presence and practices impacted parents in the NICU (Askelsdottir et al., 2008; Cleveland, 2008; Obeidat et al., 2009; Rempel & Lee, 2007).

Limited Canadian literature, little fathers' involvement in the research, and lack of diversity of participants are identified as gaps in knowledge. The majority of research reviewed was conducted within the United States, United Kingdom or Scandinavian countries. DeRouck and Leys (2011) stressed that the added value of the concept of illness trajectory on parents remains a gap. Recommendations for further research were concerning parental needs with emphasis on nursing care and refining ways to support parents, as well as further research with parents of infants who had surgery in the first weeks of life (Cleveland, 2008; Diffen et al., 2013; Obeidat et al., 2009). Specifically, Rempel and Harrison (2007) highlighted the need to study CDH infants as an invaluable addition to their current research. Schumacher and Meleis (1994) emphasize that using transition as a central concept along with features of processes, identities, and roles "prompt nurses to consider patterns of responses rather than single responses, and to identify vulnerable and critical points during transitions for preventative work" (pg. 125). Thus, research specific to the Canadian context is recommended to further explore parents' experience and the impact of nursing practices during the early phase of hospitalization.

Chapter 3 – Methodology

There is no greater agony than bearing an untold story inside you
Maya Angelou

In this study, narrative inquiry was used to explore how parents of a critically ill infant born with CDH make sense of their nursing care experience in the NICU through storytelling. Each parent was faced with a hospitalized infant; however, each parent uniquely constructed their narrative to reflect their own personal context, meaning and interpretation. Narratives are “strategic, functional, and purposeful” to accomplish the means of the narrator (Riessman, 2008, pg. 8). I will explore key elements associated with my epistemological position or standpoint and the methodology, a constructivist understanding of narrative inquiry, that I used to promote the integrity or rigour of this study.

Standpoint

My standpoint is a self-reflection on my beliefs as a person, a nurse and a researcher. Reflecting on who I am and how I came to be studying this in this way was foundational for analysis by identifying and questioning my assumptions. Frank (2000) acknowledges that standpoint “reflects one’s own unique experience and asserts membership in a community of those who understand shared experiences in mutually supportive ways” (pg.356). Addressing standpoint enacts self-reflection, which is essential throughout the research process to ensure transparency.

I believe that nursing is a humanistic profession, as we are primarily concerned with our patient’s well being and health experience. Our profession is described as both an “art” and a “science”; this comprehensive view is present in a nurse’s diverse

knowledge base and vast scope of practice (Rodgers, 2005, p. 12). I believe we construct our knowledge from experiences of nursing and interactions with others.

The concept of caring is deeply rooted within the profession of nursing – a cornerstone to our identity (Yoder-Wise & Kowalski, 2006). I support Peters (2002), a post-modern author, views that, "the effect of 'caring' on a patient is so powerful that it can often be an essential part of the ultimate cure" (p.48). Above all, the act of caring is foundational to the patient and nurse relationship – paramount in our profession. Furthermore, Newman, Smith, Pharris and Jones's (2008) unitary perspective views the relationship as the central focus of the discipline. Thus, nursing is a caring, relationship-driven, humanistic profession that facilitates connections and opportunities for caring.

In the NICU, the nurse orchestrates the daily care and accommodates the sometimes-competing needs of physicians, families, and the patient. I believe that for nurses both the family and the infant are the "patient" as the well being of one is affected by the well being of the other. During my career as an NICU nurse I have supported, cared and advocated for complex, critically ill infants and families, including infants born with CDH. I am familiar with the context, daily stresses and environment surrounding the care of an infant who requires intensive care; however, I have not had a child of my own in the unit. My own personal and expert knowledge is within this specific setting. This idea is congruent with my constructivist epistemological groundings, which sees the researcher as bringing important knowledge as a tool to the research process.

I assume that health and well being are influenced by people's experiences and that one way to communicate these experiences is through telling personal stories. Stories can be interpreted in an attempt to understand another's world and to illustrate the

experiences of those in transition (Riessman, 2008). I assume that some parents will want to share their stories to improve the care that other parents will receive. I also assume that the story shared will be a co-construction between the participant and myself and will likely be oriented toward what parents believe nurses should know about their experiences and nursing care. I believe that nurses have the power as individuals to change over their life course by learning from/ with others. Therefore, I believe that most nurses want to continually improve their practices and the care they provide.

Constructivist Paradigm

Building on my philosophical standpoint, I will explore my constructivist epistemological groundings. Epistemology, the study of the assumed nature of our knowledge, can inform the methodology, which justifies our research methods and research actions (Carter & Little, 2007). Moreover, paradigms and patterns of assumptions/beliefs about knowledge construction guide the knowledge development and research process, ultimately influencing our epistemological groundings (LoBiondo-Wood & Haber, 2013). A constructivist paradigm was chosen to guide this proposal due to its congruency with my philosophical beliefs that knowledge is generated as a co-construction, and the fit with the practice-oriented purpose and narrative inquiry approach for this study.

The constructivist paradigm recognizes that our “realities” are created through engagement with others in our world, and that meaning is created instead of discovered. Similarly stories are constructed based on personal meaning with the goal of understanding, rather than discovered as truth (Crotty, 1998). Constructivism, underpinned by a relativist ontology, acknowledges multiple realities or that multiple

constructions of meanings and interpretations can emerge for different people within the same phenomenon (Crotty, 1998). Social “reality” is believed to be “ongoing, dynamic and reproduced by people acting on their interpretations and their knowledge of it” (Welford, Murphy & Casey, 2011, pg. 42). Thus, meaning is developed through interactions between people, which cannot be observed but must be interpreted (Haverkamp & Young, 2007).

Narrative Inquiry

According to Riessman (2008), narrative inquiry is consistent with multiple understandings of reality and influenced by social context and dominant discourses, which is congruent with my epistemological grounding. Duffy (2012) acknowledges that narrative research is interested in, “sense making, meaning-making, constructions, and reconstructions of identity and not in an abstracted factual account of ‘the truth’ of a life story” (pg. 424). Through a constructivist lens, experiences are explored through the eyes of the people in their lived situations, not as “truth” but as re-presentation (LoBiondo-Wood & Haber, 2013). Narrative inquiry recognizes the subjective nature of human beings who construct meanings to make sense of our experiences in the world (Gadow, 1995). Storytelling engages and invites the audience into the experience of the narrator (Riessman, 2008). The focus from a social constructivist standpoint lies in the “collective generation and transmission of meaning,” as well as a concern with the issues of power and community influences (Welford et al., 2011, pg. 42). Meaning refers to the subjective views of a transitional period, which is essential to understanding health experiences and health consequences (Schumacher & Meleis, 1994).

Narrative inquiry allows for exploration of different interpretations and perspectives through the openness of storytelling. People often construct and reconstruct their experiences through the act of storytelling (Bruner, 1987; Riessman, 2008). Storying takes past experiences and allows individuals to make sense of that experience in the present (Riessman, 2008). Narratives serve as illustrative platforms to reveal the “meanings, conventions, dominant beliefs and values of the time and place in which a person lives and develops an identity” (Duffy, 2012, pg. 421). Individuals do not have direct access to others’ experiences, so these experiences need to be communicated to understand and learn (Riessman, 1993). The veracity of the story would not be as important as the meaning, so instead the narrative focuses on the “shifting connections they forge among past, present, and future” (Riessman, 2005, pg.6). This narrative inquiry study was explored from a social constructivist and nursing standpoint, which was guided by Maureen Duffy’s and Catherine Riessman’s methodological writings.

The Researcher

Researchers grounded in this approach to inquiry are active in the research process, and their knowledge makes an important contribution to the research (Carter & Little, 2007). Narrative inquiry is congruent with this co-constructive researcher role, as the research is relational. Relational research is individualized and subjective, which acknowledges an “affirmative, affective connection between the researcher and the participant” (Carter, 2006, pg. 1067). The researcher and participant are active co-participants in the research process. The researcher’s role is that of an interpreter, not a reporter (Haverkamp & Young, 2007). The researcher is interested in deeper, multiple understandings rather than one more “accurate” understanding; therefore, the researcher

pursues a fusion of viewpoints with the participants (Haverkamp & Young, 2007). Thus, reflection and active self-awareness was required to understand how the knowledge was generated. Reflexivity will be explored further within methodology.

Recruitment Process

The recruitment process entailed a variety of methods. I started recruitment by putting up a recruitment poster (see Appendix A) in the Ambulatory Care Building where the follow-up clinic is located. The recruitment poster included information about participant criteria and participation expectations. Parents who were interested in the study contacted the researcher voluntarily for further questions and I would also determine whether the family was appropriate for inclusion in the study. Two potential participants contacted the researcher through this method; however, I had already completed recruitment, so they were not recruited for the study.

All participants were recruited through third parties, such as professional colleagues and staff at the NFU. All infants born with CDH at BCWH are followed by the Neonatal Follow-up clinic. These infants have follow-up appointments at four, eight and eighteen months and three years in the first three years of life. Four participants were recruited through third parties at the Follow-up clinic, while two female participants were recruited through a third party colleague in the NICU who was still in contact with the families.

The third parties were able to provide the recruitment poster to parents who seemed interested and might fit the inclusion criteria for the study. If the potential participant agreed to be approached then the third parties were able to refer potential candidates to me. I then explained the nature of the research, the participants'

involvement, any potential risks/benefits and confidential/privacy to potential participants. I was available to further answer any questions or concerns by telephone or email following the first interaction. Third parties were supportive of the research, but were asked not to pressure families into agreeing to participate. If interested, I then obtained full informed consent from the participant(s) by reviewing the purpose of the research, expectations of the participants, voluntarily nature of research, risks/benefits, confidentiality, privacy issues and what the families' participation would entail. Families were given time, at minimum 24 hours with no maximum determined, to consider their participation. Once participants voluntarily agreed to participate I then reviewed the entire consent form with them (See Appendix B). Once the consent form was signed, parents were given a photocopy of the consent and the original was kept in a secure location.

This study sought to recruit five to six parents. The inclusion criteria for the study were parents of an infant born with CDH who was admitted and treated in BCWH NICU. The infant must have been discharged within the past three years; this recruitment timeline was chosen for its congruence with the follow-up schedule and feasibility for eliciting parents' early experiences of nursing care in the NICU not overly influenced by subsequent parenting experiences. English was the first language of all participants.

This study sought to recruit both parents when appropriate. Fathers are underrepresented in present literature, so it was my intent to involve the father when possible. Due to ethics proceedings, I was only able to approach participants after a potential participant has consented to being approached through a third party. In the circumstances when only the mother was referred to me, I asked the mother participant to

pass along the information to the father. Although I asked women more than once to see if the father was interested in participating, I was not able to recruit many fathers. Parents were interviewed in the setting of their choice, to promote an environment where each parent could freely share their personal experiences. Each participant was interviewed separately to elicit personal narratives of the experience of that particular person as Riessman (2008) acknowledges that narratives serve different purposes for individuals versus groups. I was interested in engaging in the experience of the individual, so individual narratives align with this intention.

The Participants

The number of participants in this study was ultimately determined by the richness and quality of the narratives produced. Narrative analysis is ideal for smaller participant numbers to promote attention to “nuances of speech, organization of a response, local contexts of production, social discourses that shape what is said, and what cannot be said” (Riessman, 1993, pg. 69). Riessman (1993) emphasizes that narrative analysis requires comparative work; thus, to show variation it was essential to have more than one story to compare. For the purpose of this study, parent(s) referred to the infant’s legal guardian. I choose this broad definition of a parent in an attempt to encompass a variety of family structures. Doane (2005) recognizes the definition of a family as complex and uncertain in today’s world, so it was important to understand each unique parent and not to reduce each to fit a specific view of what a parent should be.

Seven parents participated in the study; five participants were female and two were male. All participants were married. Of the seven participants, four participants’ spouse’s participated. With the exception of one couple, each parent’s infant was

diagnosed with CDH prior to the birth, so parents were provided time to prepare for their infant's diagnosis. Preparing for the birth included reading about the diagnosis, speaking to other parents and reaching out to support networks. Two participants had healthcare experience, which was evident in how they related to healthcare workers in their stories; however, this healthcare background did not appear to affect their need for information.

Time since discharge to interview date was roughly eight months for three participants, two years for two participants and three years for two participants. Five out of the seven participants had university degrees. All participants were employed at the time of the interview, but two participants were currently on maternity leave. Five out of seven participants had other children prior to the birth of the infant born with CDH. All participants stated the hospitalization for their infant born with CDH was their first NICU experience. Six out of the seven participants' infants who were born with CDH were doing well "medically" at the time of the interview. One participant's infant had died a year prior to the interview.

Narrative Interviews

In narrative inquiry data collection primarily includes stories of people's experiences, in this case in-depth interviews with parents within three years of their discharge from the level three NICU and a follow-up conversation one month later to review emerging themes from the interviews. Interviews served as the primary data source with secondary data being observations made during the interviews and reflective journal notes. Interviews were approximately 35-50 minutes in length. Interviews were audiotaped and transcribed. Due to my experience level, my preference was for in person interviews; however, at the request of one participant a Skype computer interview was

conducted. All other interviews were conducted in the participants' homes or chosen location (for example, in a coffee shop).

The purpose of the interview, in the constructivist situated researcher, was to “gather information about the life world or everyday experience of the interviewee and that the researcher has the task of seeking and interpreting the meaning of these everyday experiences” (Duffy, 2012, pg. 429). Narrative interviews focus on the stories participants reveal (Kvale & Brinkman, 2009). Initially, I began by asking for some general demographic information. I then invited reflection and story telling by asking parents to “think back to when your baby was born, can you tell me about your early experiences in the NICU?” If participants were unclear where to start in their experience I asked whether they could share their first experience in the unit. The interview questions then sought to probe about nursing care are provided in Appendix C.

Throughout the interviews, parents moved back and forth through their NICU experience to provide background information to stories, emphasize meaning and assist in the re-construction of their own understanding of the experience. All participants highlighted the initial introduction into the unit, the time prior to surgery and the surgery itself as stressful. In addition, each participant emphasized issues with feeding as a prominent struggle during their time in the NICU. Often participants reflected on how they felt during the experience as compared to how they feel now after some distance. Each story began with their first experience in the NICU and seeing their infant for the first time. Although the study was focused on nursing practices, parents' narratives involved the multidisciplinary healthcare team within the NICU including respiratory therapists, doctors, occupational therapists and lactation consultants. Medicine and

nursing were the most prominent disciplines discussed. Interview questions focused on nursing care and interactions with nurses, which influenced the predominance of stories pertaining to nursing.

As a researcher, I was attentive and actively listening throughout the interviews to convey respect for parents and their stories. Kvale and Brinkman (2009) state that the role of the researcher in a narrative interview is to “remain a listener, abstaining from interruptions, occasionally posing questions for clarification, and assisting the interviewee in continuing to tell his or her story” (pg. 155). It is through non-verbal actions of acknowledgment of the power of the participant’s story that the researcher becomes a co-participant and co-producer (Kvale & Brinkman, 2009). I was flexible and sensitive to the changes in the participant’s willingness to continue. Narrative accounts have the potential to evoke emotions and promote reflection, which can be life altering for the participant (Duffy, 2012). For instance, the participant in one interview cried frequently throughout the interview when recalling her early experiences in the NICU, so it was crucial that I provided her time and support throughout her interview. During interviews I paused and allowed the participants every opportunity to share their stories at their own pace. I made my role as a researcher clear at the beginning of the interview and offered the services of a NICU social worker for any therapeutic support needed as a result of the interview.

I was present and “in-relation” with the parents to engage with them in a more meaningful way (Carter, 2004). Carter (2004) acknowledges being in-relation with participants as relating to our moral obligation of how we should also care for them. At the end of each interview I offered the services of a social worker for emotional support

as a result of anything explored within the interview. I also provided a hand-made thank you card to participants with a \$10 coffee card to show my appreciation for their time. In addition, a few days later I sent a follow-up email to the participant to thank them for their time and re-emphasize the availability of social worker support. All parents consented to being contacted with questions when I was reviewing the transcripts for the purposes of gathering further data and not with the expectation of confirming accuracy. The follow-up conversation served to promote mutuality of the research process and collaboration between the researcher and participant in mutually reconstructing knowledge. A script for the follow-up conversation can be found in Appendix D. I hired a transcriber to transcribe all interviews. I then reviewed all transcripts along with audiotapes to ensure accuracy. Data was managed using NVivo software for a learning experience.

Reflective Journal Notes: Reflection on the Research Process

A reflexive journal and observational notes were additional data documented throughout all the interviews and research process. The reflexive journal served as a space to record my thoughts after each interview and any decisions about the research process. I maintained a thoughtful, reflective journal throughout the entire process to make myself aware of emotional reactions, assumptions, bias, responses and experiences, which contributed to my analysis and fostered ongoing learning. A journal promotes critical self-awareness regarding “how the research was done and the impact of critical decisions made along the way” (Riessman, 2008, pg. 191). Reflection was a continuing examination of personal subjectivity to gain insight into the self. Bishop and Shepard (2011) stress that,

Reflexivity is particularly valuable to qualitative research because it brings honesty to the fore, asking us not to feign objectivity or reach post hoc conclusions, but to acknowledge that multiple factors, including our personal narratives, shape the data we produce and our interpretations of that data. (pg. 1285)

Thus, reflection helps address the moral tensions associated with interpretation and representation in qualitative work (Bishop & Shepard, 2011).

A journal was used to explore, expand and develop my understanding of the research process. I maintained notes from each interview regarding what stood out to me in the interview, as well as any other reflections that came to mind including discrepancies, questions, or connections to previous knowledge. Narrative inquiry views the participant as a co-author and the researcher as a co-participant in the exploration of a life story (Duffy, 2012). Furthermore, the researcher's presence within an interview can shape our participants' choice to reveal their stories, so reflection serves as an essential tool for integrity (Riessman, 2008). The researcher can be seen as an agent of change, and the re-telling of the narrative as a mutual exploration between the researcher and the participant (Duffy, 2012). The research was co-constructed based on "partnership, mutuality and reciprocity" (Carter, 2006, pg. 1067). The journal contributed to an audit trail of the research process. The purpose of the journal was to reflect on my own observations, interpretations and decisions before, during and after data collection. The intention was not to separate my reflections from analysis, but promote my awareness of co-constructions and practices of representations to enhance transparency of the research

process. The journal was an essential tool during analysis when considering themes, weaving connections and re-presenting participants' stories.

Thematic Analysis

Thematic analysis is case centered and concerned with content of speech and themes within the intact story (Riessman, 2008). In this particular study, I was interested in what is most salient for NICU nurses and other care providers in the care of parents of infants with CDH. According to Riessman (2008), thematic analysis “assumes that the accounts of individuals in a group resemble each other because the accounts are organized around the same theme” (pg. 90). Narrative analysis is interested in the interrogation of meaning (Riessman, 2008). Ultimately, narratives require interpretation and analysis to promote understanding (Riessman, 2008).

I drew from a variety of narrative research examples (Chase, 2005; Fraser, 2004; Gallant, 2012; Riessman, 2008) to analyze data, as well as used an adaptation of Fraser's (2004) work to explain the step-by-step process of data analysis. Fraser (2004) offers analysing personal stories line by line, which was utilized in this study due to its congruence with my level of experience and the clarity it provides to the research process. Fraser (2004) highlights seven phases of analysis. The phases are not meant to be linear in nature, but overlapping. My interpretations of the data are one possible reality and not the absolute truth of parents' experiences of nursing care. In this next section, I describe how Fraser's (2004) seven phases of analysis framed the thematic analysis of this study.

Phase one: Reviewing and reliving the interview.

Phase one was described as hearing the stories and experiencing each other's emotions. Eliciting what happened during the interview and what emotions, thoughts and interpretations emerged or were expressed are explored at this time (Chase, 2005). During each interview I was attentive to any emotions that were exhibited, feelings that were described, and body language. Directly following each interview I wrote a reflection about these observations, as well as what stood out for me in the interview. I then reflected on my own emotions, assumptions or thoughts that were evoked by the interview. I was careful to document the events leading up to the interview and the process undertaken during the interview. Finally, I reflected on my feelings about how the interview went and what take away lessons I could learn to improve my interview skills for the next interview. I saw this step as helpful to debrief about what went well and what I could improve on in the future as my development as a researcher. The use of a journal for this phase was ideal because a journal can provide information about "the time, place and emotional climates of the interviews" (Fraser, 2004, pg. 186).

Furthermore, I reviewed each audiotape with relevant questions in mind; such as what sense does the researcher get from each interview? Listening to audiotaped interviews and noting interaction between the researcher and participant provided insight into how the conversation and emotions unfolded (Fraser, 2004). Thus, the thoughtful, reflective journal contributed to my emotional reactions, assumptions, bias, responses and experiences, which contributed to the analysis and fostered ongoing reflexivity and methodological awareness (Riessman, 2008).

Phase two: Creating written text from verbal stories.

In phase two the interview data was transcribed. I hired a transcriber due to the lengthy nature of the activity; however, I immersed myself in the data despite having a third party transcribe. I immersed myself in each transcript by reading and re-reading while listening to each audiotape and reviewing my reflective journal. I uploaded each transcript into the NVivo program and reviewed each transcript with each audiotape also to ensure accurate transcription. This phase is concerned with the content of the interviews and producing a written text of stories. Riessman (2008) stresses the importance of transcription as “providing descriptive evidence of the precise words spoken or written by narrators strengthens persuasiveness” (pg. 191). I listened to each audiotape along with the transcribed text to note any pauses, changes in tones or nuances for analysis.

Phase three: Listening in different ways.

Phase three involved interpreting individual stories. Initially, I worked with a single interview at a time focusing on ordering the sequence of events within the interview data and identifying my own underlying assumptions that emerged. The purpose or meaning portrayed through the content of the story is the exclusive focus of thematic analysis while keeping the story intact and whole rather than fracturing it into thematic categories (Riessman, 2008). The purpose was to “disaggregate long chunks of talk into specific stories, or segments of narratives” (Fraser, 2004, pg. 189). This involved separating ideas, common themes, main points or particular words that emerged from the stories. I coded main points, common ideas and rich stories as I read through each interview. I made note of emotions and changes in tone throughout the interviews. I

reviewed my journal notes from each interview during this process to provide depth to my analysis. It was important to listen in different ways at this time to generate a dialogue between parts and wholes.

Phase four: Scanning across different experiences.

Phase four involved scanning across different domains of experience, such as intrapersonal, interpersonal, cultural and structural aspects. Intrapersonal aspects of the story relate to body-mind experiences, which can often be seen in self-talk or confessions to thoughts and feelings that may have been concealed (Fraser, 2004). I was interested in intrapersonal aspects of the parents' story to reveal how this may affect the individual personally. I noted when the participant confessed any thoughts or revelations of their experience or time in the NICU. Interpersonal aspects of the story are when the story involves other people; in particular, I was interested in the involvement of nurses in parents' stories. I ensured that I documented my own reflections and inner thoughts during this process when stories involved nurses or nursing care. I noted both negative and positive interpersonal stories with nurses to further my understanding of participant's nursing experience. Cultural aspects of the story refer to the cultural conventions inherent in the story. This may highlight dominant discourses present within the context of the NICU, having an infant born with CDH or other transitional aspects of the parents' experience. Lastly, structural aspects of the stories are when the narrator refers to "class, gender, ethnicity and other modes of social organization" (Fraser, 2004, pg. 192). I scanned across stories to note any references to structural aspects, as well paying close attention to whether the gender of the interviewee influenced their experience.

Phase five: Reading in different ways.

Phase five involved linking “the personal with the political”, which was most consistent with the social constructivist standpoint of narrative analysis (Fraser, 2004, pg. 193). Attention in this phase was brought to popular or dominant discourses or contrasting views. The emphasis was placed on “close reading”, which requires paying attention to the details and moving beyond the surface of the text within the story (Riessman, 2008). I reflected on my own understanding of the experiences of parents within the unit, unit policies and nursing practices to understand different aspects of participants’ stories. I also focused on the language parents used in their stories to describe others or the NICU culture to identify power influences. Thus, this phase was primarily concerned with “researchers deliberating how dominant discourses and their attendant social conventions constitute an interpretative framework for understanding stories” (Fraser, 2004, pg. 193).

Phase six: A look across all participant’s stories.

Phase six involved looking for commonalities and differences among participants. This can be done by comparing and contrasting the “content, style and tone of respective speakers” to seek out patterns (Fraser, 2004, pg.195). I compared codes from each individual noting commonalities or similar codes that fit under a larger idea or theme. Moreover, I compared the males’ narratives to the females’ narratives to note any differences or similarities of experience. I noted different tones that were reflected in each story. Researchers may encounter aspects of stories that are uncomfortable or unpopular; however, exploration of inconsistent or different findings may bring to light ideas that have been silenced. I paid attention to hesitations or calls for support in the participants’ stories. Riessman (2008) recognizes that analysis may “uncover social

practices that are taken for granted”, which may be helpful in understanding various nursing practices (pg. 194). I did not edit or ignore stories that were negative, but instead wove them into the appropriate themes to get a rich understanding of the parents’ experiences.

Phase seven: Writing academic narratives.

Finally, phase seven involved writing the academic narrative about the personal stories by a “process of pulling together threads of others’ stories, we will be telling stories of our own” (Fraser, 2004, pg. 195). I wrote a participant composite story to illustrate the themes and subthemes that emerged from participants’ rich narratives while protecting the identity of my participants. During this phase it was important to recognize the dominant or authoritative voice in the narratives (Chase, 2005). Chase (2005) emphasizes that narratives are “socially situated interactive performances as produced in this particular setting, for this particular audience, for these particular purposes” (pg. 657). In this case, I shared with parents my purpose for this research as a hope of improving nursing care for future families in the NICU, so parents shared their stories with this purpose likely in mind. A narrative analysis from a constructivist standpoint recognizes co-construction during both data collection and analysis/interpretation and writing. I had follow-up conversations with participants to promote co-construction of the findings. I presented my interpretations to participants and asked for their reflections and additions. Again the reflective journal served as a guide when writing up the study for “jogging memory and encouraging truthfulness” (Riessman, 2008, pg. 192). It was my hope that the narratives about parents’ personal stories of nursing care will provoke

nurses to re-examine their practices to improve the care of parents' of infants born with CDH in the NICU and promote facilitative nursing practices.

Ethical Considerations

This research study was approved by both the University of Victoria's Human Research Ethics Committee (HREC) and the University of British Columbia Children's and Women's Health Centre of British Columbia Research Ethics Board (UBC C&W REB). An application for Ethical Review of Human Research was submitted according to guidelines for application provided by both university research boards and the Tri-Council Policy Statement for ethical research practices. Once both the HREC and UBC C&W REB granted approval, participants were recruited using a recruitment poster (Refer to Appendix A), through third parties and word-of-mouth conversation.

All recruited participants underwent an informed consent process, which relayed information about the nature and purpose of the research study and expectations of the participant's involvement outlined in Appendix B. Each participant was fully informed of any risks, benefits or inconveniences the research could entail. The consent process allowed the participants to understand the research process and procedures, as well as the voluntarily nature of their participation. Parents approached for the study were fully informed that their participation or declination of the study would not affect or influence the care their infant will receive at any subsequent follow-up appointments. I communicated to the participants that it is possible to withdraw at any point. This consent form was revisited throughout my interactions with participants to ensure informed consent. Each participant was approached with respect and extreme sensitivity. This sensitivity was supported by fully explaining the purpose of the study, fully involving

them in the research process, obtaining ongoing informed consent, and by maintaining confidentiality. Confidentiality was important during the entire research process, but it especially required extreme awareness when writing the re-telling of the story to properly protect the identity of participants.

Narrative inquiry can involve constructing and reliving stories of heartache, triumphs, difficulties or emotional highs. Reliving and retelling these personal, intimate stories can often produce change or reflection on the part of the interviewee (Duffy, 2012). Carter (2006) emphasizes the need for researchers to be morally sound and reflective when conducting narrative research. Duffy (2012) urges the need for researchers to be “aware of the potential for profound personal change and intense emotional experiencing that could be generated through the process of narrative interviewing” (pg. 437). The researcher needs to be comfortable discussing difficult topics, as well as being fully present during interviews (Duffy, 2012). Support from a NICU social worker was offered at the beginning and end of every interview in case parents needed emotional support after exploring their stories in the interview process, as well as in a follow-up email and follow-up conversation.

Furthermore, Hardy, Gregory and Ramjeet (2009) acknowledge that the researcher and participant relationship can sometimes be a relationship based on power, which furthers the need for the researcher to be cognizant of this pitfall. I made clear at the beginning of each interview that my role was as a researcher and not as a therapist or as a nurse. I stressed how confidentiality is maintained in research to encourage an open research environment. I made explicit the purpose of the research to encourage participants to share both positive and negative stories of nursing care in the NICU. Often

times the interviewee can reveal more information or be led into a story that they were unaware they would venture into due to this “safe and secure relationship between the researcher and the participant” (Carter, 2006, pg. 1068). The story might be something that the participant didn’t intend to share. The researcher must be aware of the need to constantly re-approach the informed consent process due to the organic nature of the narrative interview (Carter, 2006). Since the re-telling of the story is a co-construction, the participant should be fully aware of what information he/she has contributed to the story, and the researcher needs to ensure that it is a voluntarily contribution. During the follow-up conversation with participants, I reviewed the themes and main ideas that emerged from the narratives and asked whether the participant was comfortable with the researcher utilizing these in the research, which provided an opportunity for the participants to be aware of the information they shared. In addition, it was of the upmost importance to review my work and self-critique my focus, motives and intrinsic goodness of my research. Reflection served as an invaluable tool during the research process to ensure ethical proceedings (Carter, 2006).

All data collected during the research was kept confidential. No names were utilized in the write-up of the research. Identifying information provided and consent forms were kept separate from transcription data and audio-recordings. All data was stored in a locked and secure password protected computer. The audio-recordings were kept by the researcher and erased upon completion of analysis. Transcriptions that were coded during the analysis process were only available to the researcher. All identifying information was removed from the transcriptions for analysis. A transcriber was

recruited, hired and paid to transcribe the audio recordings. The transcriber adhered to the ethics and confidentiality of participants as outlined by a contract (See Appendix E).

Rigour: Evaluation Demonstrating the Integrity of the Research

I utilized Duffy's approach to rigour to the work I completed. Duffy (2012) emphasizes the importance of producing trustworthy and credible research in narrative inquiry. Trustworthiness relates to how well a researcher can interpret the experience of a study's participant, which often is evaluated by means of credibility, audibility and fittingness (LoBiondo-Wood & Haber, 2013). Credibility would involve sharing the responsibility of the re-storying process (Duffy, 2012). This was consistent with my epistemological grounding as the research was a co-construction of meanings. A month following each interview I contacted each participant to discuss my understandings of their interview and the themes that emerged. I requested that each participant reflect on my understandings and let me know whether they resonated with what they had shared with me to ensure that research process was a process of reciprocity. Each participant identified the ideas as their own, contributed additional information and described my understanding as faithful to their interview, which added to the mutually constructed research product. One participant added to the ideas the concept of hope because she felt that she left it out of her earlier interview and after reflecting on her experience she felt that it was important. Creswell (2000) elaborates this interaction is an opportunity for participants to confirm the credibility of the information and interpreted narrative account, as well as provide the opportunity to add to the data to contribute to the co-construction. Thus, the faithfulness of the narrative account was a shared responsibility –

collaboration between the researcher and participant to co-construct the story (Duffy, 2012).

An audit trail of detailed notes and reflections of the interviews, as well as documentation of the research process, enabled transparency and demonstrated auditability. The research report clearly stated the research question and that my research data was primarily collected first accounts from parents. Furthermore, my detailed notes provided an outline of the steps in the research process and my analysis included reflection upon whose narrative voice was driving the re-telling of the story. Integrity of this research was promoted by using critical reflection through use of a journal to make co-constructions apparent, to explore the practices of representation and to reflect on the research process (Riessman, 2008). The primary purpose of the journal was to document the research process and promote reflection. Throughout recruitment I documented the setting, situation and circumstance of how I approached each participant. I wrote reflections in my journal regarding interactions, body language and questions asked by participants. Following each interview I immediately wrote my reflections, noting what stood out to me during the interview, the setting, the tone and any contradictions, feelings or questions that evoked. The journal notes and reflective practice were essential when developing ideas, emerging themes and connections during analysis. My journaling provided a platform to document my assumptions, bias and involvement within the interview.

Duffy (2012) offers another interesting criteria to evaluate narrative research. Duffy (2012) supports the evoking of emotion in the reader of the narrative research. Although some may argue this is not the primary function of narrative research, the

power that emotion holds in a story is undeniable. I choose the genre of narrative research for its ability to stimulate emotion and in turn encourage self-reflection and personal change. Stories of experiences, especially those of difficult transitions or events in life, “should” evoke emotion and could push towards change in the reader. In contrast, Carter (2006) argues against narratives that “shock and awe”, but instead the focus should be on morally proficient stories to help encourage change and a “more moral way of being in-relation with our patients” (pg. 1069). Parents’ everyday stories could provoke ‘shock and awe’, but most readers will acknowledge the moral responsibility we have to improve nursing care when we share these stories.

Summary

Narratives are not static but are representations of the current context the individual is experiencing – similar to how becoming a parent is not a single, static event. Through this lens the intended outcome of this narrative inquiry study was to explore how stories deepen understanding of specific nursing practices, which was congruent with the purpose of understanding parents’ early experiences of nursing care in the NICU to improve nursing practices (Haverkamp & Young, 2007).

Chapter 4 - Findings

Introduction

The themes that emerged from the analysis revealed the complexity of parents' experiences of having an infant born with CDH in the NICU. This narrative inquiry study included seven participants whose infants were born with CDH. Initial greetings and conversations were awkward and accompanied by nerves on each side. I was nervous as I navigated getting to know participants and gaining confidence with interviewing, while participants fretted about the state of their households and what stories would be most meaningful to my research. These authentic interactions prior to starting the recorded interview influenced the interview atmosphere and likely what the participant chose to share. It was through these conversations that we related to each other's life. Ultimately these interactions concluded with remembering what had brought us together.

Parents' early experience in the NICU was described as feelings of "not knowing" in relation to what to expect, the outcome, what was best for their infant, the care providers and the environment. Therefore, to cope with "not knowing", parents described a need to know through information, communication, involvement and partnership throughout all phases of care. A main overarching theme of "not knowing" and the need to know was foundational in parents' narratives and encompass parents' early experiences in the NICU. Parents' narratives illustrate how they were able to transition from not knowing to knowing, or passive to active parenting, over time and through identified needs. Three interrelated subthemes illustrated how nurses enabled or inhibited parents' needs for information and communication; partnership, power and participation; and nursing presence and caring.

Often in narrative inquiry the findings involve describing individual participants. I did not write individual stories, as the CDH community is small and I wanted to protect my participant's confidentiality. As a result, I created two 'composite participants' and a composite story. The composite participants and composite story does not encompass the entirety of all participants and their experiences, but serves the purpose of illuminating the experience of having an infant born with CDH in the NICU, providing a taste of the richness of parents' narratives, describing some of the participant population and illustrating the themes that emerged. Thus, in this chapter I will present my participants through a composite story, which will then lead into the description of the themes I identified through the thematic analysis.

The Composite Story of Lindsay and Murray

I named one composite Lindsay, a female, because five out of seven of my participants were female. Lindsay is in her mid 30s, married and had one other child prior to the birth of her infant with CDH. She is well educated, holds a bachelor's degree, with some background knowledge of science. I created another composite, Murray, because all my participants were married. Her husband, Murray, is in his mid-30s, employed and holds a bachelor's degree. Lindsay and her husband Murray received the prenatal diagnosis of CDH for their second child around 20 weeks gestation. They had time to read about the diagnosis and meet several times with the Neonatologist to discuss questions. As well, Lindsay had a tour of the NICU. Both Lindsay and Murray reached out to friends and family to share their news and ask for some space during the time of their child's birth. Lindsay and Murray relocated to the tertiary center city close to her expectancy date to ensure that her infant was born close to the care the baby would need.

Lindsay went into labour when she was term and delivered a baby boy, who was briefly shown to Lindsay in the delivery room before being whisked off to the NICU. Murray followed their baby boy, Stuart, to the NICU and witnessed the admission, while Lindsay stayed in labour and delivery to deliver the placenta and recover. This was Lindsay and Murray's first experience in the NICU.

Murray felt very alone and overwhelmed as he watched the NICU team hook his son up to the multiple machines and equipment. He appreciated one of the nurses for "walking him through" what they were doing to help his son. Although Murray had read about his son's diagnosis, the reality of seeing it was very difficult. He looked like a chubby little baby. Murray was at a loss as he was unable to do anything for his son as the team worked, which was very emotional for him. Despite the chaos, Murray felt a sense of calm from the NICU team. He wished his wife could have been there, so they could be with their son together and support one another. Murray started to worry about his wife, so he headed back over to labour and delivery.

Lindsay lay alone in labour and delivery. The nurse had left the room to give her a minute alone and to check some blood work. The nurse had assured Lindsay that Murray could wheel her to Stuart as soon as she did some vitals. Lindsay wondered what was happening to her son, how was he doing and what he would look like. It was agonizing to wait and not know what was going on over there. Lindsay sat up in bed and instantly felt a wave of nausea and an ache throughout her body. She looked up and saw Murray standing at the door. "The nurse says we can go visit him if you feel up to it", Murray said. Lindsay cringed as she swung her legs over the bed and Murray helped her into the

wheelchair. Within minutes they were washing their hands and Lindsay was being wheeled into the NICU.

Murray worried about Lindsay's first interaction with their son because he felt he had more time to adjust to the situation having watched the admission. Murray wheeled her into a dark, single room full of equipment. There lay Stuart in the midst of all this equipment. Lindsay burst into tears, so overwhelmed with exhaustion and emotion. The nurse smiled and described what was attached to him. Lindsay appreciated her calm voice and patience when she explained everything. She encouraged Murray and Lindsay to speak softly to their son and hold his hand. Soon Lindsay was too exhausted and overwhelmed with emotion and feelings of shock, so Murray wheeled her back to labour and delivery for some rest.

As the days passed, Lindsay was able to visit for Stuart longer periods. Lindsay and Greg still felt they did not know what was going on and the desire to know, to be involved and for care was unquenchable. Lindsay yearned for information to gain understanding about how her baby was doing, what the care was he was receiving, to trust the healthcare team, and to feel some control over the situation. Greg needed to feel a part of his son's care through any level of involvement, whether that included changing a diaper or just holding his son's hand. Initially Lindsay and Greg followed the nurse's lead with Stuart's cares and often sought information. The time leading up to Stuart's surgery was a very stressful time for both Lindsay and Murray. Stuart's condition appeared very fragile and at times they worried he might not pull through. Lindsay and Murray were relieved when Stuart was back from surgery and they could focus on recovery versus stabilization. Lindsay was looking forward to the time when she would

be able to hold him for the first time. In the meantime, Lindsay appreciated pumping breast milk for Stuart, which gave her an important role in his care and contributed to his well being even though he wasn't eating yet.

Over time, Lindsay and Murray pieced together an understanding of their son's diagnosis and current state by gradually accumulating knowledge from different nurses, health professionals, medical rounds and the Internet. They felt they got to know Stuart by being there at his bedside, watching his monitors, asking questions, and being involved in his care. At times nurses provided information and supported their involvement and partnership in their son's cares; while other times these needs were ignored, unsupported or not seen as important. Lindsay and Murray felt that at times they were not respected for the knowledge and experience they had accumulated as parents and the vital role they played in Stuart's life. They both felt a strong need to be considered a partner in their son's care.

Lindsay and Murray were grateful for the care they received in the unit; however, they were often frustrated by the differences in care they received and when they were prevented from being involved. In particular, the structured NICU environment, that seemed so important to Stuart's life at the beginning, seemed to inhibit his progress as he got better. They felt their son was an individual and deserved to have care based on his needs and not based on a set schedule.

As a result, Lindsay and Murray appreciated and needed nurses who advocated for Stuart's needs and best interests. Above all, nurses who continued to question the care that was being provided, especially when Lindsay and Murray had concerns. They were grateful to the nurses who were present and active in Stuart's care. "Present care"

involved taking their time, positioning him well, talking with him and assessing his pain levels. In particular, these nurses and others who were truly “present” showed concern for Stuart and took the time to explain things to Lindsay and Murray, offering them information without judgement. They are happy that this chapter of their life in the NICU is over.

Themes

There were resounding similarities and differences between each parents’ experience; for example, one participant described how she did not desire a lot of information early in her NICU experiences, but realized its importance later on which is in contrast to other participants and the composite story. Regardless of similarities and differences, each experience was unique to that specific individual’s perspective reflecting diversity. Seven pseudo-names have been created to protect the identity of my participants and present my findings: Angela, Greg, Sarah, Colleen, Mark, Eleanor and Maggie. The two married couples were Angela and Greg, and Sarah and Mark. Sarah and Mark were the only participants who were unaware of their infant’s CDH diagnoses prior to birth because it was not identified on Sarah’s pregnancy ultrasounds. Maggie’s infant passed away one and a half years following her discharge from the NICU, while other participants’ infants are currently alive.

Parents’ early experiences in the NICU were interwoven with stories of nurses and nursing care. Interpersonal aspects of narratives are “quite literally those that involve other people” (Fraser, 2004, pg. 192). The intention is not to create an illustration of a “bad” nurse or a “good” nurse, as each nurse often possess both strengths and

weaknesses, but to show how each practitioner could reflect on their actions and how they are interpreted by others to improve their nursing practice.

Analysis of the interviews revealed feelings of “not knowing”, which resulted in needing to know as the main overarching theme for parents’ early experiences in the NICU with three interrelated subthemes related to parenting needs to transition from not knowing to knowing. As time progressed parents started to know more and more about their infant and their environment; as a result, the needs identified through the narratives evolve as parents progressed from “not knowing” to knowing their baby. The three interrelated subthemes identified were the parents’ need for information and open communication; partnership, power and participation; and nursing presence and caring to support their development as parents. Parents also provided information regarding ways the healthcare team, in particular nurses, could address their needs during this tumultuous time.

Main Overarching Theme: “Not Knowing” and the Need to Know

Parents’ expressed in their narratives the need to know what to expect, what was going on and how to care for their infant; however, interestingly five out of the seven parents stated they felt a connection to their infant immediately despite feelings of “not knowing”, but often felt more like a parent the more care they could provide. Angela felt her first experience as a parent was that first meeting and even more so when she was able to speak to her son. Eleanor felt that, “she’s my baby 100%” and that “she slept under a different roof for two months and I lost no bonding with her”. Similarly, Colleen stated she “felt connected to him even in utero” and started feeling more like a mom when she was able to do something. Parents’ narratives illustrated how as parents they

needed to know what was going on, but “not knowing” did not prevent them from having a connection with their child.

In slight contrast, Sarah felt that when she got to hold her son was when she really started feeling connected to her son, which may have been compounded by the need for a transfer. Sarah’s experience was different due to the transfer, which may have delayed an initial connection with her son that was more concrete once she was able to hold and care for her infant. Maggie always felt like she “couldn’t relax with her like with my other kids”, so Maggie felt more like a “caregiver” versus a mom to her daughter. Maggie’s infant had immense healthcare problems during and following her hospitalization, which eventually took her life, so Maggie’s experience is unique from the others in that context. Maggie could have experienced a longer period of “not knowing”, which may have delayed her confidence in her actions as a parent and moving to a place of knowing. Despite parents’ descriptions of not knowing, most were still able to feel connected to their infant in the NICU setting and feel like parents. The progression of moving from a place of “not knowing” to knowing was thus more linked to their actions as parents. Parents felt like parents, but expressed a place of “not knowing” initially when they weren’t sure how to provide actions of parenthood, such as changing a diaper amongst wires and machines. Later narratives illustrated how parents knew how to make decisions, advocate and care for their child, which will be further explored within the themes.

Initially, all participants expressed struggles with “not knowing” during their early experiences in the NICU. Often this period was described as “overwhelming” and “very emotional” to participants, who felt “helpless” and “in shock”. The context and

environment of the NICU was new since this was the first experience in the NICU for all participants. A sense of “not knowing” what to expect, the nursing care, their infant’s diagnosis and how to care for and advocate for their infant were evident in all narratives regardless of whether the parents had prior knowledge of the diagnosis. The need to know was expressed in all parents’ narratives as essential to understanding what was “going on” and why. Through this need to know, parents’ developed their knowledge, skills and understanding to transition from a place of “not knowing” to knowing. Thus, parents felt an overwhelming need to know throughout their NICU experience to enable them to understand, be involved, interact and advocate for their infant—ultimately parents needed to know, so they could serve their role as a parent to their infant.

Initially parents described the difficulty of not knowing what to expect. Colleen told me in the interview that, “I kind of knew what to expect, but of course, you never really know” while Eleanor reflected how “everything’s new and you don’t know what to ask”. Participants felt helpless in the care of their child because they lacked the knowledge, but didn’t lack the will to want to help. Both Angela and Sarah expressed difficulty struggling with the not knowing what to expect in relation to the possible outcomes associated with the diagnosis of CDH. Sarah, who had no time to prepare, acknowledged how she “didn’t know what to expect” and that she was told that “every CDH baby is different” by physicians and nurses. She felt she didn’t really comprehend this statement at the time during the hospitalization and often asked questions to help her understand, but felt that “nobody could tell me what to expect”. Woven through the parents’ stories of their initial experiences is the acknowledgement that the NICU, their infant’s diagnosis and the care of their infant were all something new that wasn’t always

explained openly. As a result, parents' feelings of not knowing affected decision-making earlier in their NICU experience.

Sarah and Mark's infant was not diagnosed prenatally, so the birth of their child required a transfer of both Sarah and her baby to a tertiary center within the first 24 hours from giving birth. Sarah reflected on that process as, "hard because I didn't know what was going on." She expressed that she struggled with "not knowing really what's happening and my family had basically gone to the hospital, so I had to wait by myself, which was hard, before I'd get transported". An infant undiagnosed with CDH requires immediate transfer to a tertiary NICU for medical management, which is considered a medical emergency – in this case the infant is the priority and the mother is secondary, so often the mother's transfer can be delayed. Sarah's narrative expressed the complex nature of "not knowing what was going on" while being forced to wait, which is another example of not knowing what to expect. Interestingly, despite the difference of their infant's needs and experience, ideas and themes from Sarah's and Mark's narratives were similar to the others who did not experience a transfer except both their narratives highlighted how lonely that initial experience was because they were separated.

Parents acknowledged the need to know how to care for their infant. Angela struggled with, "you want what's best for your kid and you don't know right?" because of the circumstance and uniqueness of her child's diagnosis. Infants with CDH are extremely sensitive to light and noise, so often nurses encourage limited stimulation of these infants prior to surgery. Too much noise or too much handling can cause compromise in these infants. For Angela, the struggle was experienced as the desire to "want to be able to touch him and hold him", but limited stimulation was encouraged by

nurses with little rationale provided. Parents did not always know what to ask or what was important, so it was essential that nurses guide parents in this. Angela, noted:

It was just so different, cause we don't know right. It's all new to us. The whole thing is... like the nurses are the experts to us, can we touch... or like, you know.

We would really count on them to let us know what interaction is ok.

Similarly, other parents acknowledged in their narratives that their experience as parents thus far “hasn't been normal” as it was different than their previous children. Sarah talked about the difference as,

Not being able to hold your child—that was difficult. Like going back to the room and not being able to bring him back with me, was so bizarre—I've just had a baby, but I have to go leave him elsewhere in the hospital.

Although Sarah wanted to hold her infant she expressed that she was “reluctant to touch him in a lot of ways” because “he's sick”, so time was often spent “watching the monitors”. Therefore, parents' initial actions were often passive, such as watching the monitors, during periods of not knowing.

Parents need to know their infant and the care their infant needed caused them to seek out other ways to know. Similar to Sarah, Greg and Angela often talked about how they watched the monitors to see “how he was doing”. Angela expressed concerns with getting to know her infant in an environment like the NICU. Angela shared her worries with me,

My biggest concern too was he's got—there's all these RTs and nurses and like I'm only coming in at these certain points. My thing was he's not going to know me. How is he going to know who is mom is right? That was really hard.

Angela didn't have control over what her son experienced, which made this difficult for her. Angela's husband Greg comforted her by pointing out how their son's "heart rate goes down" when Angela would "go and softly sing to him or talk to him", which helped Angela interact with her son. Thus, parents had to cope with the unusual circumstance of getting to know their infant in the NICU to understand the care their infant needs.

Through parents' narratives I recognized the power that the health provider held. For example, Angela viewed the nurse as "the expert", which prevented her from questioning or being involved in care at times. Angela and Greg each described a situation where different nurses gave them contradicting information. Angela was frustrated earlier on when she was encouraged to touch her child minimally,

I just thought she was being a control freak, like she knows best—and you know, as a new mom, you think, well, you want to touch your baby, but if she said, it's best for him, he's having surgery—if he's calm and he's well rested and not over-stimulated, it's going to be better outcome for him. I would have understood at that point.

Another nurse Angela encountered had the lights on and allowed her touch her infant as frequently as she wanted; unfortunately, her infant experienced compromise and deterioration. Angela had the "whole guilt feeling" from the incident, but also blamed this shift in her infant to the care the nurse provided. She wondered, "why did they let me do this right? Because I didn't know better". Angela reflected on how she would have preferred knowledge to promote understanding, so that she could do "what was best". Parents needed to know how best to support their infant to better play their active role as parents, like making informed decisions, within the NICU.

Evident in narratives was the lack of empowerment felt by parents at times of “not knowing”. Parents’ narratives expressed frustration when they didn’t understand the actions, care and individual who provided care to their infant. Eleanor highlighted the difficulty of “just not knowing” who was taking care of her infant, but she also acknowledged that “obviously that’s part of the NICU is you’ve got strangers looking after your baby”. Eleanor struggled with the concept of “who is going to be on the next day?” which she felt was not communicated well. These reflections show how parents wanted to know who was taking care of their infant. Parents understood that in the NICU environment they didn’t have control over a lot of aspects, but they yearned for the knowledge and information to help them understand.

Not knowing extended to not understanding what was considered normal care within the NICU. The concept of a primary nurse is prevalent in many NICUs across North America. Primary nurses are nurses that are with you for the entire duration of your stay in the NICU; every time that nurse is on a shift she will be with that infant. Some NICUs have parents select primary nurses, while others assign nurses to promote continuity and consistency of care. Eleanor and Maggie both expressed not understanding the role and purpose of a primary nurse until it became essential for their infants’ care.

Maggie mentioned,

It took me probably five to six weeks to even get a primary [nurse], cause I really didn’t understand what good a primary was. They told me about it. They told me about it right away, but they didn’t explain what it was.

Eleanor re-emphasized this confusion by stating in her interview: “That’s one thing that I wish would have been much more clearer going into the NICU was the concept of a

primary [nurse]. We knew that there were primaries [nurses]. We didn't know how it worked". Eleanor said that it wasn't until she was in "very hamster wheel type scenarios" with her daughter's feeding issues that the Charge Nurse took her aside and explained how and why she needed a primary. That conversation occurred well into Eleanor's daughter's stay in the NICU. Thus, parents' narratives described the access of information not being clear, especially when they were unsure what to ask and not knowing what was considered normal nursing care. Parents' expressed to the need to know and the rationale behind knowledge to understand and impact the care of their infant.

Furthermore, introduction into the NICU differed between male and female participants due to the circumstance of labour— only the males in the study observed the admission process in the NICU. While the mother remained in labour and delivery or in transit, the father was present to cope with the admission, subsequent care and transition into the NICU. Mark, whose infant required transport to a tertiary NICU, illustrated in his narrative this difficult, lonely admission process, which was described as:

Mind-boggling and extremely difficult to be alone in that situation with no knowledge of what was really happening at that point and not having my wife there, as support on my side either. Like I said, she was in a bed and she was in no shape to do anything anyway. She couldn't get up and we couldn't hug or hold or anything like that.

Another father, Greg, described the admission process into the NICU as, "overwhelming, but more just kind of feeling almost robotic. You're just watching, right? You don't know what's going on?" Providing information during times of not knowing appeared to "be

helpful”. Greg acknowledged, “I think it helped that they were explaining what they were doing”. Both fathers acknowledged the importance of knowing what was going on during this chaotic time to gain a sense of control over the situation.

Parents’ narratives further described the need to know what was going on. Greg emphasized the need to understand as:

That was probably overall the biggest thing for me at least—was knowing what was going on. Even from the very beginning—just and maybe it’s different, but I’m a numbers guy, so seeing the monitor, seeing the numbers on the monitor, what we’re watching for, what they’re watching for, because I want to be watching for the same kind of thing. You know? Cause just sitting there, staring at your baby, you feel helpless and knowing information, you’re not really anymore helpful, but you at least feel like you know what’s going on, you’re not just sitting there, staring at your baby in this condition.

Needing to know what was going on was also important as knowing that something was being done for their infant if there was an issue. Greg described a physician he favoured as,

She told us whatever we wanted to know, good or bad, and we found that really helpful, just understanding, because – again, even though you’re obviously in no way are you in control or can you change anything, it was comforting knowing when there’s a concern something’s being done.

Thus, knowing what was going on allowed parents to feel that they understood what their infant was experiencing and provided some knowledge of how they can help their infant or feel apart of their infant’s care.

Without information or knowledge for why things were happening, parents were left to worry. Sarah described a situation when her infant was having difficulty, but the nurse did not appear to be doing anything, which resulted in distress. Sarah reflected on her concerns as,

I think she wasn't explaining what was going on and that's what I wish would have happened. I would have rather her explained this is not uncommon; we're just going to wait and see if things settle down. We're not going to intervene yet. We're going to see if he does, what he does for himself or something. Just talk to me about it, so I could kind of try and settle myself down, but yeah. I think that was the one time I almost lost it.

In contrast, Colleen described her initial experience as very powerful due to the information provided to her by the nurse. Colleen stated,

She was so very helpful with calmly telling me what was going on. I felt she had control over his health which was just what you need right—that's number one, but then she also had enough confidence and ability to tell me... to tell me, I needed to know everything that was going on. And I needed to know why. Not everyone needs that, but that's what I needed, and she gave it to me. She told me, like everything she was doing and the rationale for everything and the subtle differences and why she's doing it and it was great.

Despite the fact that the parent did not have control over the situation, it was acknowledged in all narratives that knowing what was happening made parents feel better in the chaotic, unknown NICU environment. Parents looked to all healthcare workers to

understand, but often turned to nurses to understand what was going on and drive knowledge exchange at the beginning.

Through information, encouragement, observation and involvement, parents began to feel empowered, confident and knowledgeable about the care of their child and their integral role—transitioning from a place of not knowing to knowing. Greg, Mark and Angela all noted that NICU staff had asked them during their stay whether they had healthcare backgrounds because “they seemed to know more about CDH than any of us” even though none of those participants had healthcare backgrounds. Mark felt he “started understanding what the numbers meant on the machines”. Colleen voiced that, “I understood why they were changing the tidal volumes” and “I could anticipate when they were going to make changes because I understood it so much”. This attention to detail, information and their infant were all examples of how parents became experts of their infants in the NICU. Parents began to gain significant awareness of the NICU environment, their knowledge of their infant and their contribution to the team; thus, over time parents transitioned from a place of not knowing to knowing and passive to active parenting.

As a result, parenting in the NICU began to involve advocacy to protect their infant and their role as a parent. Angela noted how at the beginning parents depend on nurses to let them know what was good for their infant, but Greg acknowledged how over time nurses were acknowledged as “highly trained”, but “not trained on your baby” if they’ve never cared for his son before. This reflection is interesting because Greg acknowledges how parents start to hold important information that is key to the care of the information and the importance of exchanging this with the nurse. With different

nurses throughout an infant's stay, parents become the consistent figures who spend their time getting to know their infant through "watching the monitors", questioning healthcare professionals, being present for rounds and participating in their infant's care. Greg talked about how "we'd see a new nurse and we were just – you'd need to be there with him because he was with somebody who hasn't had him before". Angela emphasized the important role that parents play because "there's things that I think the charts don't have", and parents share with new nurses for better care of the infant. For example, most participants talked about how they knew when their infant needed a suction based on his activity and vital signs—which was sometimes ignored by nurses who did not know their infant as well. Thus, parents' narratives illuminated the developmental process the parents move through in the nursery and the importance of the nurse-parent relationship being a two way process of knowing where both contributes knowledge to the care of the infant.

Ultimately, parents' experienced "not knowing" what to expect, what was best for their infant and the care provided to their infant earlier in their experience due to the context of their infant's diagnosis, the NICU environment and the healthcare team. Parents identified their need for information and open communication; participation, power and partnership; and nursing presence and caring throughout their NICU experience. These needs evolve as parents' transition from "not knowing" to becoming more knowledgeable about their infant, their environment and their infant's care needs that result from this diagnosis. Parents' narratives illustrate how healthcare workers, in particular nurses, can enable or inhibit parents' needs and ability to get to know and care for their infant.

Subtheme One: “Knowing” – Information and Open Communication

The sense of “not knowing” influenced parents to seek information or greatly appreciate those that provided information. Most participants in response to their infant’s diagnosis anticipated the need to know and importance of information prior to the birth of their infant. Several parents in their narratives described preparing for the unknown and the CDH diagnoses, which links to how parents’ described the need to know what to expect. Five out of seven of the participants had time to prepare because their child was diagnosed prenatally, but even the participants who knew the diagnoses before had narratives that acknowledged the vital need for information throughout their stay in the NICU. Even early on, parents linked information to getting to know their infant and knowing what to expect. Angela supported this by stating:

I feel better knowing—and we knew beforehand at 20 weeks, we found out about his condition, so I had most of my pregnancy to research. I have a science background, a research background, so I had all that chance to research and then you’re sitting there for hours staring at these monitors—so I wanted to know, what is this? You can’t control it, but the more you were informed... I felt the more I was informed during rounds, I could see where is he at? Is he doing better? You started to learn the terms and a bit of the lingo.

Information and subsequent understanding was often described as making parents “feel better”; perhaps it provided a sense of control in a situation where they have very little control. Colleen and Eleanor reflected that although they prepared for what was to come, it didn’t necessarily prepare them for the experience. Eleanor stated that she got a tour of the NICU prior to her daughter’s birth and read the NICU handbook cover to cover, but

still struggled with not knowing where to get breast pumping equipment. Although preparation was expressed as helpful, it did not change the need for information and the difficulty of “not knowing” upon admission to the NICU.

Admission into the NICU is illustrated by participants as mostly positive despite not knowing exactly what was going on. Colleen and Greg emphasized how “helpful” and “powerful” it was when the nurse explained to them what was happening at the beginning. Greg appreciated “as they were hooking him up, I do remember they were somewhat explaining” and I think that “explaining what they were doing” was “helpful cause obviously I can’t do anything”. Furthermore, Colleen described the nurse as “very good at telling me what was going on and what she was doing”, which was “helpful” that she “had enough confidence and ability to tell me”. Participants’ identified information that included what was happening right now to their infant provided a sense of “calm” in moments of chaos, such as admission, which helped build trust and fill the need to know.

Information needs were prevalent in all the narratives as being of the utmost importance to parents. Parents emphasized in their narratives that all information was helpful, but that knowing what was happening right now was most important to them. A sense of trust was apparent in parents’ narratives when information was provided during times of high stress. Colleen commented about how she “connected really well with the early nurses just because I trusted them so much” due to the information exchange that occurred. Greg described how this trust was built:

There were nurses that were firm, but we knew that they were being firm because they were there to take care of the baby. And we knew because they were open

and explaining reasons—giving us reasons for things—you know, when they were firm about something, you know, we knew we could trust them.

Greg described information received as “helpful cause obviously I can’t do anything, but it was nice knowing what was going on”. Thus, information and partnering with parents was expressed to provide a sense of control in an acknowledged uncontrollable environment.

In contrast, when information was supplied poorly during a stressful situation this was not helpful for parents. For example, Mark expressed frustration with physicians who did not provide accurate information,

They were trying to buffer it or make it not seem as bad as it was which was certainly something I never wanted. I wanted all of the information and I wanted the truth of it and they weren’t very good at giving that to me.

Present in all the narratives were struggles and frustrations when information was withheld, provided inaccurately or not provided during stressful circumstances. Mark expressed frustration with information being withheld from nurses by stating,

I wanted to know exactly what every piece of machinery in that place was doing for my son to help him out and the nurses in there, I think they did their best to answer the questions, but probably and no fault of their own – they were probably just giving me the bare minimum—enough that they were hoping that I would be satisfied with what they were giving me for answers and it didn’t matter what answers they gave me, it wasn’t enough.

Angela’s narratives also highlighted the power nurses held, as gatekeepers to the infant – controlling what information was provided at the time, which leaves parents helpless.

Maggie often thought, “What else are they not telling me yet” when new information came her way that didn’t appear to be “new”. Without the rationale for nursing and medical practices, parents are left to assume the reason why, which was noted in some narratives to result in frustration or distress.

Participants’ narratives all identified a need for improvement with communication and information sharing. Surprisingly, Eleanor compared the NICU with the current school system to suggest improvements. Eleanor mused,

You hear stories about school systems and teachers using texts to communicate with parents now a days and almost like --- wouldn’t that have been great to have woken up in the morning and gotten a text to say, “Hi I’m Julie, I’m your baby’s caregiver this morning. When you call in or when you get here, I’ll be here”.

Colleen stressed that to work in the NICU you need “really high communication skills”, so “if that’s not taught, it needs to be taught”. Parents’ narratives voiced the need for improved communication delivery in the NICU setting to combat the sense of “not knowing” and influence partnership. Mark described the information he needed as clear and concise to the questions he asked, which supported wanting to know both the good and the bad. In contrast, Angela and Greg both acknowledged the importance of providing accurate information while still providing hope. Information was important, but there was also a described need to maintain hope for the family. Thus, the importance of understanding your audience and the information needs of parents is essential when delivering consistent information in the NICU.

Participants recognized the complex balance of the amount and kind of information that was exchanged but emphasized how important it was to understand the

needs of the individual. Greg stated, “we don’t expect them to be magicians, but we’d like to know what they’re thinking and what’s going on”. Mark reflected on the importance of health professionals understanding the needs of parents in relation in his comments:

As the professional dealing with that, and obviously you’re dealing with an array of emotions from different people in different situations and probably with different intelligence levels, they have to be the ones that figure out what kind of person they’re dealing with.

Moreover, the importance of understanding your audience was further illustrated by Mark described a particular doctor that deflected his questions,

I just wanted to be told in clear and concise, you know, tell me what I’m asking. If you can’t tell me what I’m asking, don’t try to deflect the question or handle me in some way. I understand what’s involved in handling a person, you’re giving them non-information to shut them up and I knew that I was being handled and I didn’t like it and neither did my wife.

Mark needed open, honest and direct communication, but instead at times experienced inauthentic communication such as the deflection from this particular physician. Mark described his experience as digesting information and needing information faster, while Maggie acknowledged that she preferred, “little chunks of information at a time and then I just need to deal with that and then go onto the next one”. Therefore, adapting information by assessing the parent’s response was seen as essential to determine fit.

Maggie’s narrative was unique from the others in regards to information exchange because she felt that at the beginning information was “going in one ear and right out the

other”, but it didn’t really bother her at the time because she had “a lot of faith in God”. This faith provided her with “a huge peace, so I didn’t question a lot of things” at the beginning. Maggie expressed less frustration with her information needs in the unit as compared to others’ narratives; however, Maggie reflected later, “I wish I understood better” at the beginning because she felt her discharge teaching was “very compact”, “like cramming for an exam”, which was “way, way, way too much information”. Maggie was also the only participant who only held a high school degree, versus other participants who had bachelor degrees or a technical certificate, which emphasizes the need to understand the health literacy of each individual— how an individual receives and digests information. Although all the narratives highlighted the importance of information, each individual is unique to how and what information they like to receive.

As time progressed parents started “putting the pieces together from the different nurses” and started to “learn your baby”—transitioning from “not knowing” to knowing more. From the participants’ perspectives they struggled with not knowing about the environment, their child and the NICU culture, but information and open communication helped supply parents need to know. The experiences where information was withheld or not provided honestly created high stress for parents, which exemplified the power position healthcare workers held over parents. As a result of this power struggle, parents started taking a more active role in their information seeking to get to know their infant. As parents got to know their infant, they desired respect from the healthcare team for the unique knowledge they had developed.

Subtheme Two: “You’re Not the Parent, I’m the Parent”— The Need for Participation, Power and Partnership

Parents appreciated the opportunities they had to participate in aspects of their infant’s care to build confidence and their role as a parent – to transition from passive to active parenting. Participation helped build confidence and influenced feelings of contribution to their baby’s care and partnership with the team. Maggie and Sarah talked about how comforting it was to have the routine of pumping breast milk. Sarah described the routine of pumping as,

I felt like I was doing something that was participatory... like I was working towards making him stronger and better, so I felt like at least I could do a role. I can’t hold him. I’m not the one controlling any of the dials or what’s going on, but at least I can go do my job, which is to go and pump, so that was good.

Maggie talked about how important she felt pumping was for her daughter—“I had never breastfed my other kids. It didn’t work for me. I really hated it to be honest, but I thought this is one thing I could do for [her]”. Maggie and Sarah both acknowledge how pumping was something they could do for their infant at a time when they could do very little.

Therefore, parents felt a need for a role or job within their infant’s care to promote feelings of partnership within the team – the idea that they were contributing.

Similarly, parents appreciated nurses who encouraged their involvement and provided education. Mark recalled in his narrative the “encouragement, the enthusiasm in her [the nurse’s] voice to encourage us, that we can do this” to be involved and information that was “open and explaining reasons—giving us reasons for things”. Initially, CDH infants are quite acutely ill, so there is minimal opportunity for parents to

be involved in the care of their infant. Despite this aspect of care, parents appreciated the nurses that would “engage us in helping with our [infant]”, “would talk to us”, “provide education and not judgement” and “talk us through” what they were doing – so even though parents couldn’t do it at that time they could understand it and be “a part of this now”. This involvement in their infant’s care provided a parenting role and fulfilled their need for a job and purpose within the team. These opportunities allowed parents to progress from “not knowing” to knowing, from passive to active parenting.

Parents needed encouragement from nurses about involvement because although they wanted to hold their infant and care for their infant, but they were also reluctant to “rock the boat”. Angela appreciated nurses who said, “Do you want to hold him? It’s really good to hold him’ or ‘do you want to bathe him?” and “really encourage you to start caring for him”. Mark expresses the need for encouragement to hold his son’s hand in the following narrative:

I mean obviously we couldn’t do that right at the beginning. They didn’t want us to do too much, but there were some [nurses] that would encourage us to hold [his] hand, which was really tough in the beginning, the first time you hold your son’s hand when he’s in that position, it’s really tough, you’re afraid that if you’re going to touch him, you’re going to break him or something.

Mark felt that some involvement in care, regardless of how minimal, helped “made us feel like we were part of the team now which was something we needed as well”.

Involvement during periods of not knowing helped parents feel they belonged and were a part of the care of their infant. Mark felt that, “Every time you get to do a little bit more, it means that something is going right along the way”; parents involvement in their

infant's care gave parents a role, a hope for the future and a positive impact. Parents also viewed their increased involvement and the nurses' decreased involvement as an example of their infant progressing towards home. Thus, involvement in their infant's care through encouragement from nursing was necessary and appreciated in parents' narratives.

As parents spent more time in the NICU being involved in their infant's care and "putting the pieces together" from nurses parents wanted to be recognized as parents—as holding important information and needing freedom. Parents moved from a place of not knowing to knowing and then needing to be considered partners in their infant's care.

Parents described the need for a collaborative relationship with the team. Angela felt that,

It would be nice, like when you start off, each new nurse, if they do kind of maybe come and talk to you. I know there's the report and you guys have all the charts and everything, but just coming and saying to the parent – so how has it been? Is there anything you want me to know about your baby? Because it's not just about—there's things that I think the charts don't have.

Angela wished that nurses had "not just [said] this is my name and I'll be your nurse for the day", but instead tried to "get the real story" from the parents. The need to be respected for their contribution to their infant's care was clear. Furthermore, parents wanted acknowledgement of their role as a parent, the knowledge they hold and its importance in their infant's care. Colleen's narrative often talked about stories of conflicts with nurses that were passing "judgements" on her parenting. She remembers one particular nurse "always telling me whatever I was doing was wrong" and was "super overcritical". She recalls a time when the nurse removed all the things in the crib, which mom had put in because "I wanted him to be stimulated", but the nurse complained about

the items to Colleen and then removed all of them the next day without asking. Colleen felt, “Teach me, right, and let me decide. Cause you’re not the parent, I’m the parent”. Parents’ narratives illustrated the need to be recognized as “still being the parent” despite being in the NICU.

Angela described times when she was felt pushed away from the bedside when she was providing care or corrected in a negative way by a nurse saying “no, no, no”, which made her “feel like really bad and guilty”. Angela acknowledged that nurses were the experts, but that also her role was vital because “you’re still the parent”. Angela wished during the breast feeding process that nurses “put themselves in the shoes of the mom” to understand why “to start to [breast] feed, you want to be relaxed, you want to have some privacy and just you know – not have someone staring at you”. As parents developed confidence in their parenting skills, they struggled with the constraints of the NICU.

Angela and Greg appreciated the space that was provided for them to just be parents with their son, while still knowing the nurse was around if they needed anything. The need for space was also described as freedom in some narratives. Mark and Sarah appreciated the freedom the nursing staff gave them by letting them go on walks with their son attached to a saturation probe. Mark recalls, “We’d go grab a coffee and grab our camera and take as long as they would let us. Push it right to the maximum amount of time that they’d let us go”. All the narratives identified the need for the time, space and opportunity to be parents to their infant.

With this growth in confidence and knowledge, parents shared stories of freedom and advocacy, as well as stories when their concerns and role as a parent were not

supported. Eleanor, Colleen, Greg, Maggie and Angela all expressed experiences when they did not feel they were taken seriously or their infant's care was not taken seriously in the NICU. Maggie remembers that she would try to say "could you come over here and do this?" when her daughter needed a suction and nurses would respond, "oh yeah, yeah, we'll be right there", while Maggie watched "my baby struggle" and felt this wasn't important to them. Maggie felt that she needed a "primary" nurse after those experiences because then her baby "becomes important to them, enough to maybe hurry it a little more". Colleen described being angry when a nurse put her own needs before her son's. Colleen remembers having her son's surgery postponed multiple times and the day he finally went to surgery the surgery time was delayed. Colleen was upset with the nurse that day for complaining about her coffee break, Colleen felt, "My son's going in for surgery and I'm worried about his health. I'm worried about him dying and she's worried about her freaking coffee break. So that was really hard". When Colleen brought this concern forward to the charge nurse, the charge nurse told her to "suck it up" and let the nurse stay with her son because "she's got good skills". Colleen often felt "like a bit of a troublemaker" when she brought concerns forward and felt "like I couldn't speak to anyone" or "if I did, it wouldn't be taken seriously". Colleen felt she was a "strong advocate and it still kind of sucked" because she "was worried that my concerns if I brought them forward too often wouldn't be taken seriously and I was concerned that just my credibility would be decreased". Colleen's narrative illustrates the power struggle that exists within the NICU and how parents emerge into their parental role through advocacy. Thus, the concerns described in parents' narratives were very serious to

parents and acknowledgement of these concerns were similar to acknowledging the role of the parent, but alas sometimes these acts of the parental role were met with resistance.

Similarly, Eleanor described a situation when she didn't feel supported by her nurse when she noticed her daughter's gastrointestinal tube site was looking a little red. She brought this concern to her nurse and the nurse replied, "oh, no, no, it's fine, it's fine" and that "surgery had already been by", so the nurse didn't do anything about it. Eleanor felt that "it was kind of a concern that was blown off". When Eleanor called in that night to see how her daughter was doing, the night nurse informed her, "We've started her on antibiotics for her infection" because when the nurse got on shift she noticed the site was "looking very, very red". Eleanor was angry and thought,

Why did the nurse have to come and start her shift to determine there was a problem? Why wasn't the nurse who was finishing her shift determining there was a problem—especially since it was brought up earlier in the day?

Eleanor wished the reaction had been instead "mom has a concern, let's find out" instead of being "blown off". Ultimately, parents' experience and knowledge growth needs to be considered seriously to promote collaboration within the healthcare team. Participants' narratives illustrated how parents' knowledge was not always respected in the NICU in relation to the care of their child as evidenced by concerns not being taken seriously or heard.

Hence, initially parents' appreciated encouragement to be involved in their infants care, but as parents began to know their infant better they voiced the need to be respected for their knowledge and advocacy role. Encouraging involvement and respecting the knowledge parents developed over time of their infant's care both contributed to parents'

sense of partnership and parenthood within the NICU. When parents concerns or the care of their infant and knowledge of their infant were not taken seriously then this sense of partnership was threatened and a power struggle was evident.

Subtheme Three: “Treating My Baby Like a Baby and Not a Task”— Nursing Presence and Caring

Emotional, physical and mental presence of the nurse was evident in parents’ narrative to impact parents’ experience; moreover, nursing care that was attuned to the infant’s needs and parents’ needs was viewed positively in parents’ narratives. Initially infants born with CDH are often critically ill and require one to one nursing care and the help of many to manage the needs of the infant. This physical presence of the nurse and the team was acknowledged in narratives as impacting parents. Angela was impressed that,

He always had a nurse beside him 24/7—I mean I wasn’t expecting—I guess that intense care. Because I remember the first thing that shocked me, he was in there all hooked up and I think one of the nurses needed to step out of the room for a minute to get something, but then she had to call someone else to come in, she wouldn’t even leave him for a minute—so that made me feel better, but also it was a bit scary, he can’t be left alone.

Mark recalls the admission scene as very “emotional” and “tough to see what was going on”, but he noted that “for all the stuff that was going on around him, I didn’t see a lot of panic around me either, which was calming”. Physical presence of the nurse and team was calming for parents initially.

Furthermore, Sarah and Mark appreciated the aspect of teamwork in the NICU. Sarah loved how “everybody was on hand”. Sarah’s impression of medical rounds and the number of people involved in her son’s care was described as,

I remember coming to see my son in the morning and there was—I can’t even remember the number of people that were beside his room. I thought, my God, what’s going on, it’s like a convention or something. Why are these people here? And everyone is chatting outside [the room] and I stopped them and said what’s going on. They said we’re just talking about [your son]. I’m like, okay, you’re all talking about my son? That’s awesome!

Sarah appreciated the teamwork and collaboration at the beginning because “everybody’s got their ideas as to what they can do to improve his care which is great”.

Parents’ narratives also described how nurses provided a calming presence in how they interacted with parents. Sarah and Colleen also commented on the “calming presence” nurses possessed during initial visits to the NICU and the information that was exchanged. Presence was acknowledged as being present for the infant, but also being present for the family. Sarah recalls being very emotional during her first visit to the NICU, but her nurse had “good presence” and patience by “stay[ing] with her. She didn’t make me feel like I was rushing her or I was inconveniencing her”. Sarah felt supported because her nurse didn’t shy away from her emotions during that time.

Being present also referred to awareness in the healthcare provider. During this time period, parents were acutely aware of nurses who paid attention to their infant and “cared” about their infant through “little things” and “attune” to their baby’s needs. Caring was described as little things like writing on the infant’s white board “all his

requirements” and specific details such as, “I like my left side up and when you suction me, I like this” along with drawing “Winnie the Pooh characters”, which Sarah felt made “an environment that’s babies”. Sarah and Colleen noticed nurses that “treated my baby like a baby and not a task”. Sarah described treating my baby like a baby was “talking with him”, wiping him down when he was “stinky” and styling his hair. Greg noticed attentive nurses as, “when they were in the room, they were always watching him, watching the monitors, caring for him, always doing something to sort of monitor him”. Angela appreciated “nurses that were really aware of when he was in pain” by “giving him a bolus to just help for whenever they handled him” or to “give him a bit to calm down”. Angela described one particular nurse that “always put her hands on his head and legs and wait[ed] until his heart rate went down”. Colleen talked about how nurses “didn’t just stabilize him. They stabilized him and then made him comfortable” by “little things” like putting a “chix in between his legs to make sure that it was softer than just being against a tube”. The extra “little things” that parents described let them know that nurses “cared” about their baby and their needs. Ultimately, parents felt that nurses partnered in their infant’s care when they paid attention to the details, which aligned with the care the parents would want provided to their infant.

In contrast to attentive and attuned nursing presence, parents’ narratives illustrated times when they had “absent” or the odd “disinterested nurse” that was just “doing the motions” or when nurses were “just doing it as a job and getting it done and moving on”. Sarah noticed when nurses had her son “stay put and would do what they had to do, but then would leave him and there wasn’t any interaction”. In some narratives presence also referred to physical presence. Maggie talked about she “I hated it when one

nurse would go on a break and then there's four babies to one nurse. Absolutely hated it. I hated it and it terrified me". In fact, Maggie would have to watch her daughter's oxygen saturations drop and her color change because she needed suctioning, but no one was available. Maggie felt that she had to watch her infant "struggle" because she wasn't important or high priority to nurses at times in comparison to other infant's needs. Parents' narratives illustrated how they were attuned to how present emotionally, physically and mentally their nurse was to their infant, which seemed to influence their NICU experience.

Nursing care that was not attuned to the infant's needs was described as "too regimented" or "not really in tune to what was happening, just kind of following a set of instructions". Greg remembers one nurse that "she had her book and she'd be spending more time reading her book then not, then just, check the clock, okay it's time for me to do this kind of thing". Greg recalls a situation when "The fluids would be building up and need to be suctioned. At this point, we had learned what it sounded like and we could tell he's gurgling or whatever, like he needs some suction", but the nurse's response was, "oh no, it's not time for him to be suctioned". Greg remembers finally "an RT⁷ walked in and was like, he needs to be suctioned and so they suctioned him", which made Greg frustrated with the nurse—"why weren't you paying attention or are you only playing it out?" Greg felt that some nurses stuck to a schedule, which wasn't necessarily fitted to an infant's individual needs. Mark felt nurses "have their schedules – like [he] needed to be fed at this time. He should be bathed now. He should be this. He should be there", which he understood that nurses needed to see things happen within a "timeframe" and he tried

⁷ Respiratory Therapist

“not to take anything like that personally” as a parent. Angela, Greg and Mark all mentioned inflexibility of nursing care in the NICU. Greg described a time when “we could tell he was getting hungry beforehand”, but “we were only allowed to nurse him on a schedule”. Although parents talked about how information and participation was important, care that was “too regimented” and not aligned with what their infant might need was distressing. These situations are all opportunities in which nurses could have made decisions with parents instead of individually determining the care to be provided.

Continuity of care was highlighted in parents’ narratives as influencing consistency and differences in nursing care, which was seen as an issue. Eleanor often wondered, “Who is going to be there the next day?” as her daughter’s nurse. Eleanor felt that “the biggest question mark was always that continuity of care” when it comes to her daughter’s care. Mark also remembers feeling that he would love to have seen “that face everyday, to see that consistency alongside” care more often. Maggie remembers “counting the days thinking, that’s awesome, she’s back again” when one nurse worked four night shifts in a row with her baby because “they get to know the baby and you just feel more comfortable that somebody isn’t new coming in getting the low down”. Moreover, Angela remembers her and Greg had a bit of “weird experience having so many different nurses” because “they’ve very different how they let you interact with the baby” and it would be “really confusing like when it came time for breastfeeding him—everyone had different advice”. Parents appreciated a consistent person who got to know their infant, so they could be comfortable. Both Maggie and Eleanor acknowledged “primaries” as being more invested in the care of the infant, responsive to their concerns and responsive to their infant’s needs as they also got to know the infant.

A model of consistent care that was viewed favourably by parents was primary nursing. Primary nursing was emphasized strongly in two narratives highlighting the benefits of this type of model of nursing care after the initial acute phase of hospitalization. Initial parents experienced one on one care for their infant, so concerns of continuity did not seem to come up in parents' narratives until their infant was cared for in two to one nursing assignments. Eleanor described a primary as someone who has "taken it on themselves to care about the ongoing prognosis of that baby" and who "went out of the box to fix things and to ask questions and to challenge things". Eleanor recognized, "I know how much she did and I know that it was not always in her best interest to do so, but it was in the baby's best interest" about her primary's actions. Eleanor described her primary as a partner in her infant's care, which exemplified collaboration and knowing each other through a two way process. Moreover, Maggie remembered that, "it's a good feeling when your primary comes to work and you know they like being with their babies and they're excited to come to work to take care of your baby", which made Maggie "feel safe" and made her "feel like I could go home". Maggie thus viewed her primaries as a trusted partner in the care of her infant, which provided relief to her. Although Mark, Greg and Angela also recognized struggling with inconsistencies, Sarah didn't feel the need for a primary nurse because she felt that the care was good despite not having great consistency.

Parents' narratives illustrate how emotional, physical and mental presence of nurses and healthcare providers, as well as the consistency of care provided impacted parents' involvement in the NICU environment, their infant's care and their active role as a parent. Nurses and healthcare providers who demonstrated a caring presence seemed to

be attuned to parents' needs and the needs of their infant, as well as parents' vital role in the infant's care. Undoubtedly, the physical, mental and emotional presence of the nurse is interrelated with the concepts of information, open communication, participation and partnership.

Summary

The main theme of needing to know and three interrelated subthemes that emerged from participants' narratives illustrate the developmental progression of a parent's experience of getting to know their infant born with CDH within a NICU. The composite participants and story illustrated the development of parents from "not knowing" to knowing through knowledge attainment, confidence building from involvement and observation of their infants care – moving from a passive parental role to an active parental role. Thus, the themes, composite story and participants illuminated the increasing role that parents played in their infant's care and how they exercised their parental actions in the beginning through a need to know.

Nurses facilitated parents' transitions of becoming an active parent to their infant born with CDH by being present for information sharing, encouraging involvement, "treating my baby like a baby and not a task", providing care that was attuned to the baby and respecting the role of the parent. Parents gradually accumulated knowledge and learned through experience, observation and interactions with others to grow and develop as parents. Commonalities and diversity among participants were present, adding to the authenticity of findings. Parents' narratives illuminated how nurses had the power to facilitate or inhibit empowerment of parents' development. Parents struggled with differences in nursing care and the "absent nurse", which reflected stories of "regimented

care”, information being withheld, not being taken seriously, not having their infant’s care taken seriously and not being recognized as the parent. As a result, parents’ experienced feeling not supported in their evolving role as parents and helpless in the care of their infant. These actions may or may not be intentional by nurses, as only parents were interviewed in this study, but they were experienced and interpreted nonetheless.

Ultimately, parents are the consistent figures at the bedside and supporting them to assume their parental role is an essential component to the care of the infant; thus, nursing care that incorporated parents’ involvement, promoted and respected parents’ knowledge growth and attuned to the infant’s needs and parents’ concerns resulted in positive experiences in parents’ narratives. Regardless of the similarities or differences between participants’ stories, nurses were viewed as enablers, as well as inhibitors to the parents’ journey through the NICU and becoming a parent for their baby as illustrated in the composite story.

Chapter 5 – Discussion

The purpose of this narrative inquiry study was to explore stories of parents' early experiences of a NICU hospitalization with a particular focus on the nursing care during the transitional time of becoming parents to an infant born with CDH to gain an understanding of their experience to highlight gaps in care, areas for improvement and the needs of this specific population. Narrative inquiry methodology, derived from the works of Maureen Duffy and Catherine Riessman, guided exploration of seven parents' stories. Parents' stories illustrated the complex transitional experience of having an infant born with CDH in the NICU and revealed the overarching theme of needing to know as a result of "*not knowing*" in relation to the environment, the culture, the care provided and their child's diagnosis. Ultimately, parents transition from not knowing to knowing more about their infant through the need to know, which allowed parents to assume a parental role that included advocating for their baby. As time progressed, parents sought respect and acknowledgment of the unique knowledge they held about their infant and their role as a parent. The three subthemes that emerged further expanded on what influenced and how nurses influenced parents' needs: information and open communication, participation, power and partnership, and presence/caring.

In this section I will discuss the importance of this study, understandings from the findings, links to relevant literature, limitations, knowledge translation plans and implications for care and future research.

Significance of the Study

The study illustrated how parents progressively assumed a more active parental role over the trajectory of their experience by accumulating knowledge, experience and participation. Many of the experiences within the three subthemes overlap and influence one another along with parents' need to know to build on their parental role development. For example, parents' talked about how information made parents feel better and promoted a sense of trust, which contributes to feelings of partnership. Information was also important when involving parents in their infants' care, which ultimately requires the emotional, physical and mental presence of the nurse. Parents' narratives described situations when communication broke down, information was withheld, they were prevented from being involved or their concerns were not heard; these stories of struggles illustrated how we as nurses can be enablers or inhibitors of parents' development and involvement. Finally, parents' narratives call for capacity-building interactions and education for adjusting to having an infant with a congenital anomaly, who requires surgery and an NICU stay, to meet their needs as parents and as individuals seeking healthcare support.

The process of having an infant admitted into an NICU was an extremely stressful experience for parents. In particular, exploring parents' stories of infants born with CDH facilitated an understanding of how stressful the experience was to have an infant born with that particular diagnosis, needing care in the NICU and requiring surgery. No studies specifically focused on parents' experiences of nursing care in the NICU for infants born with CDH were located in the literature; however, relevant literature to the topic was examined in the literature review that focused on transitions, infants that

required surgical intervention, extremely sick infants, infants born with congenital anomalies and facilitative nursing practices in the NICU. Some of the findings from this study confirm and expand upon the current literature. Ultimately, having an understanding of parents' experiences of nursing care for infants born with CDH can help inform nursing practices and enhance support and services to this population.

The NICU and Surgery As a Stressful Experience

This narrative inquiry study adds to the small body of literature of infants requiring surgery in the NICU, as well it is the first identified qualitative study that focuses primarily on parents' experiences of having an infant born with CDH in the NICU. All parents in this study identified surgery as an important event in their infant's hospitalization, which was described as extremely stressful. These findings are comparable with Joseph et al.'s (2007) findings of 22 fathers of infants requiring surgery in the NICU reporting elevated levels of stress, especially when seeing their infant in pain. In this current CDH study, parents told stories of struggles when they felt their infant was in discomfort and parents' appreciated those nurses that were emotional present to the infant's needs—providing a bolus of narcotics, taking their time with care or providing calming techniques for comfort. One participant voiced at the end of their interview the immense level of stress and trauma he experienced from his time in the NICU. This finding may contribute to Chen et al.'s (2007) findings, of 53 parents of infants with CDH, that suggests parents' experience a large emotional strain dealing with the potential long term outcomes of their infant's diagnosis. Therefore, this current study adds to the literature on parents' of infants that require surgery by illustrating the complex experience of multiple transitions and magnitude of stresses that parents of

infants born with CDH endure during their time in the NICU, along with descriptions of how they seek or gain knowledge and confidence through the subthemes.

Parents' narratives illustrated how over time knowledge, participation, observation and interaction with their infant and others helped foster confidence, improve their NICU experience and combat stress. Comparable to Meleis's (2010) description of role transitions, parents' narratives described the difficult transition experience in the NICU by incorporating new knowledge, altering behaviours and changing their definition of a parent, as compared to their previous children, to cope with change and the unfamiliar environment. Most of parents of infants born with CDH became well immersed in the technology, lingo and complexities of their infant's diagnosis—to the point that NICU staff commented how well they understood CDH. In response to this parents go above and beyond what is required of a parent to survive in a medical, technology-laden world to care for their infant and cope with the stress of the NICU and the stress of surgery. Parents' actions in Rempel and Harrison's (2007) study were pertaining to the survival of their child, while Ray's (2002) findings of "parenting plus" referred to the effort parents demonstrated toward developing relationships for their child with others. In contrast, the parents in the current study exhibited parenting as the unique efforts that parents directed towards involvement in care, the pursuit of information about what was happening now and understanding their child's diagnosis, the NICU environment and the technology needed during uncertainty and certainty. Undoubtedly, parents of infants born with CDH must cope with multiple periods of certainty and uncertainty within the NICU in regards to their infant's diagnosis, the need for surgical intervention, the potentially unknown future prognosis and the NICU environment.

Nursing Presence

This study contributed to the growing body of knowledge regarding presence in the nursing literature. Parents acknowledged through their stories the benefits to their experience when the nurse was physically, mentally and emotionally present to their needs and their infant's needs. According to Finfgeld-Connett's (2008) findings from a meta-synthesis, presence is "characterized by sensitivity, holism, intimacy, vulnerability and adaptation to unique circumstance", which results in improved mental well being for nurses and patients (pg. 710). In this current study, parents told stories of when nurses took the time to acknowledge their emotions and showed they "cared" when they treated their infant like a person and not a task. These nursing behaviours described in parents' narratives are similar to Dunst and Trivette's (1996) help-giver attributes in effective caregiver practices. Dunst and Trivette (1996) acknowledged active listening, empathy, compassion, warmth and caring through presence and circular questioning as key to capacity building and personal control. These findings are consistent with the current study as parents acknowledged feeling better when their nurses were available to share information, assist in caring for their child, encourage involvement and advocate for parents' concerns, while remaining attuned to the needs of the infant. These findings are also similar to Pepper et al.'s (2012) findings that parents need nurses to be genuinely present, be available and be approachable for parents.

Furthermore, parents' stories of nursing presence could be comparable to Iseminger, Levitt and Kirk's (2009) transcendent practices and enhanced nursing presence in their model of transformative nursing presence. For example, Iseminger et al. (2009) describe some transcendent practices as awareness, skilled communication,

respectful listening and flexibility, which were present in parents' narratives when the nurse adapted a schedule or teaching in response to the needs of the infant as well as the family. Moreover, parents told stories of when their nurse was physically present, but also providing the family privacy and space, which is similar to Reis, Rempel, Scott, Brady-Fryer and Van Aerde (2010) subtle presence in their Model of Negotiated Partnership in the NICU. Reis, Rempel et al. (2010) defined subtle presence as, "being 'present' in a highly skilful, artful manner", which included providing parents with positive affirmation and remaining close in physical distance to parents while also providing privacy and space.

Presence was identified in parents' narratives as ideal, but barriers to the concept of nursing presence within actual practice and the NICU setting could exist. Iseminger et al. (2009) illustrated barriers to nursing presence in their model of transformative nursing presence; perceived time constraints, burnout, lack of self-reflection, lack of moral courage and lack of a supportive environment were all elements acknowledged to contribute to a nurse's ability to provide presence. Burnout in nursing could be due to a variety of issues, which erodes the desire to connect with our patients (Iseminger et al., 2009). Perceived time constraints are related to "low staffing ratios, high patient acuity, discomfort with intense, meaningful communication and perceived low value of the activity" (Iseminger et al., 2009, pg. 450). The NICU is a high patient acuity unit with fluctuating staffing needs based on unpredictable births, which can result in short staffing on some shifts. Hessel (2009) highlights how presence isn't based on quantity of interactions, but quality. Hessel (2009) notes that time is a "limited commodity in healthcare" in regards to workload, but Iseminger et al. (2009) suggests that quality

interactions may promote clustering of care, increasing efficiency and decreasing additional calls for assistance.

There are acknowledged barriers to providing nursing presence, but there are also facilitators that are identified in the literature. Self-reflection is seen as an important tool to promote openness, self-awareness, flexibility and willingness to embrace presence (Iseminger et al., 2009). Iseminger et al. (2009) highlight the importance of a supportive environment for nursing presence, which includes peer encouragement, modeling by leaders, reinforcement through continued education and potentially the role of a Clinical Nurse Specialist (CNS).

Undoubtedly, the enactment of nursing presence is influenced by organizational, personal and structural supports within a unit. The current study provides illustrative narratives of the multidimensional concept of supportive nursing presence and responsive nursing care by providing a perspective of presence from a NICU lens and within the context of CDH.

The Nurse-Parent Relationship: Knowing Each Other as a Two Way Process

This narrative inquiry study highlighted the important two way knowledge exchange between parents and nurses in the care of an infant born with CDH, which supports the current body of knowledge in the NICU parenting literature by developing on the relationship between partnership, participation, information and communication on becoming parents in the NICU environment. Initially the nurse provides a significant amount of information to parents and parents feel the need to know a lot. Over time, parents become knowledgeable and experienced with their infant. The parents' sense of knowing is then an asset to the nurse's care of the infant— both now hold important

information in the care of the child that requires collaboration and knowing each other as a two way process. The findings of this current study are similar to De Rouck and Leys (2011) research findings that parents want to be treated as equal partners in a collaborative relationship that includes open communication and individualized information, but are richly illustrated through the information and open communication subtheme and interwoven through the other subthemes. This current study acknowledges how parents want to be heard and respected for what they do know, which develops over time. Ultimately, as time progresses parents have increasingly more knowledge to contribute to their infant's care, which needs to be acknowledged by the healthcare team and utilized—information needs to flow both ways.

Some of the findings from this study confirmed previous research that focused on the initial information and communication needs of parents in the NICU. For instance, De Rouck and Leys (2011) integrative review identified high information needs for parents in the NICU that change based on the illness trajectory of the infant, which healthcare providers need to understand to adapt and deliver information appropriately. Parents in my study identified information and knowing what was going on as important to their sense of control and understanding. Parents identified in their narratives that information should be individualized taking into consideration how someone digests information as well as their emotional status when providing information. Moreover, the need for accurate and timely information and open communication was apparent throughout all seven of the narratives, which is comparable to Cleveland's (2008) systematic review that highlighted the importance for accurate information. Therefore, honest communication

and information was essential to parents' knowledge growth and development as a collaborator.

Additionally, parental involvement in their infant's care was strongly supported in the literature (Cleveland, 2008; Erlandsson and Fagerberg, 2005; Obeidat et al., 2009; Lutz et al., 2009; Smith et al., 2012). Lutz et al.'s (2009) integrative review also identified the link between partnership and participation with information and open communication by highlighting the impact of interpersonal relationships in the context of the early parenting experience. Lutz et al. (2009) supported the idea that unsupportive behaviours such as "inadequate information and communication, restricting access to infants and engaging in unhelpful or judgemental relationships with parents" as examples of non-supportive partnership that adversely affected the developing parent-child relationship. This is comparable to examples of non-supportive partnerships present in participants' stories of struggling to know within the NICU in regards to inadequate, inaccurate or withheld information; judgmental communication; their concerns not being taken seriously; inhibition of their role as a parent; lack of presence of their healthcare provider and the regimented structure of their infant's care and the unit.

In contrast, Cleveland's (2008) systematic review identified four supportive behaviours: emotional support; parental empowerment; a welcoming environment with supportive unit policies; and parent education with an opportunity to produce new skills through guided participation. The current study illustrates these supportive behaviours in stories of nurses encouraging parents' participation, positive information exchanges and being flexible with cares to meet the infant and parent's needs and concerns. Parents' needs change as a parent develops more knowledge about their infant, which promotes a

shift for nurses to recognize the parent as the growing expert. In this study, information, communication, participation, partnership, presence and structure seemly all unfold together within a developmental interpersonal process between a parent and a nurse. The nurse has the ability to positively or negatively impact all aspects of the journey. Parents' narratives support need for consistent capacity-building actions from nurses to support their involvement, education and role in their infant's care. This narrative inquiry study extends the current knowledge by providing a multidimensional, illustrative perspective that a narrative inquiry approach brings while illuminating the unique view of parents of infants born with CDH, which is currently absent in the literature.

Other Contributions

An unique aspect of this study as compared to previous studies was that majority of parents felt connected to their infant despite the NICU environment. Parents' narratives described feeling welcomed at the initial visit to the NICU and expressed feeling a connection to their infant earlier on with the exception of two participants. In contrast, Aagaard and Hall (2008) meta-synthesis revealed five themes that focused on ownership – parents felt like an outsider and felt alienated within the NICU. Of the two participants that expressed they did not have an immediate connection to their infant, one participant acknowledged that holding her infant promoted a feeling of connection while the other participant didn't feel connected until much later in her child's life. This particular participant's infant had complex, chronic health problems, which this parent felt inhibited her from relaxing around her child and feeling like a mother. None of the narratives expressed that the healthcare team had ownership of their child, but narratives

did illustrate times when they didn't feel like they actively participated as an equal partner in their child's care.

Limitations of the Study

The aim of the study was to gain a better understanding of parents' experiences of nursing care for infants born with CDH. Even though in-depth stories were generated from the interviews, the study and experiences are limited to the seven parents that participated. Furthermore, there were only two male participants in the study, which might have limited the fathers' experience in the NICU for infants born with CDH.

Although the stories that were presented in the interviews were rich, these stories and experiences may not be transferable to other practice settings. The findings from this study are constructed from my interpretations of the narratives the parents chose to share. All parents' experiences were in one specific NICU; thus, these experiences might only be relevant to that specific unit. The data consisted primarily of the one interview from each parent; however, there was a follow-up conversation with each participant to share and discuss the major ideas and themes the researcher interpreted from the interview. The follow-up conversation provided parents the opportunity to identify the ideas interpreted as their own, aligning with their NICU experience, or an opportunity to modify the idea or disagree with the findings to contribute to the co-construction of the findings. All parents in the follow-up conversation identified the themes and ideas interpreted as their own. Despite this agreement from participants, the study could have included multiple interviews to illustrate a deeper description of parents' experiences.

Parents could have struggled with putting all aspects of their experience into words, which would mean the study would be limited by parents' ability to express their

stories and my own ability to interpret these stories. Lefkowitz et al. (2010) documented the stress parents experience during this early “acute” stage of transition as being high with some indicators for post-traumatic stress disorder. Moreover, Pinelli’s (2000) correlational study of 124 Canadian couples whose newborns were admitted into the NICU identified higher levels of anxiety in mothers than fathers in the acute phase of hospitalization. In addition, parents may not have felt totally comfortable to share all their stories because I am a nurse within the unit and organization; however, parents may have felt more inclined to share deeper concerns knowing I am a nurse from the unit and organization in hopes of influencing nursing care for future parents. Thus, multiple factors could have affected parents’ ability to express their experience or digest their experience in the NICU.

On the other hand, parents could have found it meaningful to have an alternative outlet to voice their concerns, stories and experiences. The narrative interview could have served as a therapeutic release or help parents develop and revise their identities as parents. Ward (2009) interviewed 27 American parents of infants with various conditions regarding their beliefs in participating in Neonatal research and their decision to participate in research during their stay in the NICU. Parents described their decision to participate in neonatal research as a meaning making process, which involved the generated themes of making sense of chaos, their own vulnerability and taking control of their situation. It was noted that the time provided for decision making affected control. Parents’ reflected on the control participating in research provided because it was a choice. This was apparent in the findings of this study as one participant voiced during her interview that it felt good to talk about her daughter and to remember her experience

in the NICU. This finding is consistent with Kvale (1996), who sees that the process of interviewing as bringing about changes in awareness and meaning for the interviewee that the researcher must be aware of.

The themes that emerged were commonalities across experiences with in-depth examples and illustrations; however, these may not be the experiences of every parent that is admitted to the NICU for infants born with CDH. Despite these limitations, the seven parents' experiences illuminated possibilities within this specific context.

Future Research

Further research is needed that focuses on parents' early experiences of nursing care and collaborative practices in the NICU for infants born with CDH across multiple hospital settings and longitudinally. Research that focuses on how we build and maintain collaborative partnerships with parents during this initial period needs to be further explored. A multidisciplinary team provides care to an infant born with CDH and their family, so research should reflect this diversity—future research conducted by various disciplines could enrich the literature. Future research should still take into consideration the cultural aspects, needs, experiences and perspectives of the participants. Further research utilizing different methodologies, quantitative and qualitative, are needed to identify specific strategies for collaboration between parents and the NICU team working with infants born with CDH and provide rich descriptive data for research inquiry. Moreover, research that focuses on the experiences of fathers' would be essential to explore as this study was limited to only two male participants. Identifying at risk or marginalized population would be important to ensure we are acknowledging all experiences within the NICU.

In addition, research from the perspective of the nurse who cares for infants with CDH might be useful to gain an understanding of the other side of the parent-nurse interaction to identify further ways to improve this partnership and collaboration. The continued education of nurses about CDH and teaching expertise would be an interesting avenue to pursue through research to gain a better understanding of how we are supporting the teacher in the NICU setting.

Implications for Practice

Transitions are highlighted in the literature as pertinent to nursing therapeutics and research due to health consequences associated with transitions (Schumacher & Meleis, 1994). In particular, this study presented a view of becoming parents to an infant born with CDH in the NICU. The findings illuminated the relationship between the NICU, healthcare providers and parents that impact learning to be a parent in this complex and very particular situation— a perspective grounded in caring, collaboration and the nurse-parent partnership in the NICU. Although the study findings cannot be generalized to all populations, the findings could be applicable to most NICU parent populations; understanding of the transition experience for parents of infants born with CDH encourages nurses to be aware of parents' individualized needs and changing concerns in the NICU to evaluate our interactions in light of these findings.

At the foundational level, how we interact, educate and collaborate with families includes how we communicate and what information we share. Within that exchange is how we relate to parents and infants in the NICU through our physical, emotional and mental presence, which is the very nature of our work as nurses. On an organizational level, models of care, policies and procedures influence how we are able to provide care

and the environment in which that care is provided. Lastly, all these elements are interrelated and influence the perception of power and contribute to how collaborative partnerships are established as demonstrated by the themes and subthemes from this current study. The recommendations are based on the findings in parents' narratives that how we interact, empower and collaborate with parents in the NICU to be of the utmost importance to parents' feelings of "knowing/not knowing" and their NICU experience.

The following are specific recommendations for nurses who work with parents who have infants born with CDH in the NICU:

1. Parents appreciated when nurses showed genuine care to the infant and by being emotionally, physically and mentally present to parents' questions and concerns. Taking the time to actively listen to the concerns at hand or if time is not available then explaining to the parents what you need to do before being able to have the time was important to building a collaborative relationship with parents. Asking open ended to gain a better understanding of parents' concerns and illness experience. Parents appreciated being acknowledged as a key player to their infant's care; an example of this is asking parents about their infant's typical behaviours to incorporate into your assessments and understanding of the individual patient. As a person, put yourself in the parents' position to provide empathy, compassion, warmth and active listening.
2. Parents were receptive to receiving information with the purpose to empower and involve them in the care of their infant. Identify the parents' strengths, individual information needs and literacy level. Utilize your skills, knowledge and competence to offer information individualized to the parent. When providing

information or teaching, focus on only a few points and then evaluate how well that was interpreted to ensure parents understand the information you are sharing. Take into consideration parents' needs and concerns may change over time, so check-ins will be an essential tool throughout their stay in the NICU. For example, asking a parent what is new with their infant from their perspective or what concerns they may have at this time at the beginning of your interaction may be helpful.

3. Parents found it helpful to have relationships with nurses who shared information, collaborated on decisions, engaged parents' involvement and respected parents' knowledge. Parents appreciated when nurses acknowledged the parent's role in their infant's life as essential. Assess parents' understanding to mutually decide cares and education focuses. Share your experience and expertise as a nurse as you both have information that is crucial to the care of the infant. Empower parents by involving them in cares. Commend parents on individual and family strengths as observed by patterns of behaviours. Work collaboratively with parents to problem-solve concerns and issues.
4. Parents appreciated nurses who were responsive to their infant and parent's concerns. Parents' narratives described their knowledge depth and growth throughout their time in the unit, so over time this knowledge or concerns can contribute to the care of the infant (i.e. identifying illness or behaviour changes). Consider that a set schedule of care might not meet the needs of their infant.

The following are specific recommendations for nurse educators, advanced practice nurses (APN) or nurse leaders working with parents of infants born with CDH and nurses who care for this population in the NICU:

1. Parents found it helpful when managers or leaders were responsive to their concerns. If the parent has come to you as a leader/APN/educator then likely these concerns are very important to this parent, be receptive through active listening to these concerns, which could model behaviour for frontline nurses. Promote collaboration between the bedside nurse, the team and the parents to work out these concerns. Role model collaborative practice that involves the parents as partners on the team.
2. Parents appreciated the availability of information. It might be important to support the availability of information and resources to both bedside nurses and parents. Provide up to date information on CDH for a resource for the bedside nurse to assist teaching and familiarity with the defect. Have health literacy appropriate resources for parents if possible. Be a resource for parents and nurses.
3. Parents' narratives recognized the value of information sharing and fostering health promoting teaching/learning situations. Encourage self-reflection in practice to improve skills and teaching abilities, which is supportive of nurses' education practice growth.
4. Promote scheduling that supports consistency of caregivers for this population. Conduct check-ins with nurses to ensure they are coping with the complex needs of parents.

Knowledge Translation Plan

I intend to publish the research results to increase translation of knowledge and expand understanding. Primarily this understanding can enlighten nurses, nurse leaders and health care providers who interact, facilitate and enable parents of infants born with CDH during the initial phase in the NICU. Increasing knowledge of parent's early experiences of nursing care and identifying elements that support parents' involvement and transition to parenthood could potentially promote awareness and support the development of future NICU families. Moreover, the findings will be presented to the healthcare team at BCWH. The re-telling of parents' stories will be presented to frontline health care workers—nurses, physicians, social workers and respiratory therapists—during education days to translate and illustrate the knowledge generated. I will provide the composite story for illustrative purposes along with practice recommendations. The hope would be for nurses to re-evaluate their practices in light of these findings to determine whether they could improve their approach to better meet the needs of parents.

In addition, this study could also be relevant to nursing leadership and management to promote change that supports the parents of CDH infants during this transition. As a result, I will present the findings at the monthly nursing leadership meeting and monthly Neonatal Research team meeting. The Neonatal Research team also has a biannual newsletter, which I will submit my findings to further translation of knowledge as these initiatives could support our family-centered care practices. In addition, I will be emailing a summary of my findings to all the participants, as well as the two potential participants who were unable to participate due to timing. I will consult with the health team regarding the possibility of creating a poster for the family lounge to

visually translate research findings to parents. In the end, narrative research encourages nurse-client interaction to understand the parent's story and promote awareness of the individual.

Summary

Parents' experiences of nursing care in the NICU for infants born with CDH are complex and diverse. Parents appreciated "knowing what's going on", getting to know their infant through involvement, collaborating with the team as a partner and having the presence of the nurse and NICU team. The need to understand what the individual parent's needs, concerns and health literacy level caring for infants born with CDH in the NICU was important to the infant's care and the ongoing care management of the family. Above all, the study illuminated the need to recognize parents as knowledgeable members within the multidisciplinary team and the nurse's ability to facilitate communication, information sharing, partnership, power, participation and coordination of care, which impacts parents' transition from passive to active parenting positively or negatively. The continued need to improve collaboration with parents in the NICU setting to develop better care for the complex health care needs of infants born with CDH and the families that care for these infants is a clear priority for future care.

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Appendix A

SUBJECT RECRUITMENT POSTER



UVic



Are you a Parent whose infant is/was admitted in the NICU at B.C. Women's Hospital for Congenital Diaphragmatic Hernia (CDH)?

I am a Registered Nurse and Masters of Nursing student at the University of Victoria interested in parents' early experiences of nursing care in the Neonatal Intensive Care Unit (NICU) whose infants were born with congenital diaphragmatic hernia (CDH). The purpose of this research project is to gain a better understanding of how nursing care is experienced by parents of CDH infants in the NICU in hopes of improving care in the future. I would like to invite you to share your experiences. You must speak English at a conversational level to participate.

Only one 1-hour interview about your experience and one 30-minute follow-up phone call or email will be conducted. Your interview will be audio-recorded and a written record will be made from the recording. A follow-up conversation may occur by phone at a time that is convenient for you. Your identity will be protected and confidentiality assured. You may end your participation at any time. There are no costs to participation in this study and it will not impact your infant's care in any way. You may choose not to talk about anything that you are not comfortable talking about. The interview will be in the form of a conversation at a time and place that you choose. All questions related to the interview and the research study itself will be answered for you.

If you agree, I will meet with you to review the study and consent form in more detail.

If you agree to participate, I will set up a time to conduct an interview that is most convenient for you. Sincerely, Nadine Lusney, BScN, RN, MN Student

Appendix B

SUBJECT INFORMATION AND CONSENT FORM



Stories of Parents' Early Experiences of Nursing Care Whose Infants are born with Congenital Diaphragmatic Hernia (CDH) in the Neonatal Intensive Care Unit (NICU)

Site Principal Investigator: Dr. Anne Synnes, MDCM, MHSc, FRCPC
Division of Neonatology, Department of Pediatrics,
University of British Columbia

Co-Investigators: Nadine Lusney, BScN, RN, MN student
School of Nursing, University of Victoria

Supervisor: Dr. Lenora Marcellus, RN, BSN, MN, PhD
School of Nursing, University of Victoria

You are being invited to participate in a study that is being conducted by Nadine Lusney, BScN, RN. I am a registered nurse and graduate student in the School of Nursing at the University of Victoria. As a graduate student, I am conducting this research as part of a thesis requirement for a Master of Nursing degree.

Voluntary Participation

Your participation is entirely voluntary, so it is up to you to decide whether or not to take part.

Before you decide, it is important for you to understand what the research involves. This consent form will tell you about the study, why the research is being done, what will happen to you during the study and the possible benefits, risks and discomforts.

If you do not wish to participate, you do not have to give any reason for your decision not to participate nor will your decision influence the care received by your infant in any way during his/her subsequent follow-up care.

If you have any concerns about your rights as a research subject and/or your experiences while participating in this study, contact the Human Research Ethics Office at the University of Victoria by email or by telephone or the Research Subject Information Line in the University of British Columbia Office of Research Services by email or by telephone.

Introduction

You are being invited to participate in this study because you are a parent with an infant with a diagnosis of CDH who was cared for at BC Women's Hospital NICU in the last three years. I would like to hear your story of your NICU experience.

Purpose of the Research

The purpose of this research project is to learn more about what you thought about the care you and your infant received from nurses in the early part of your stay in the NICU and how we can do a better job of caring for you and your infant.

Importance of this Research

Research of this type is important because it may help us better understand what challenges parents who have infants in the NICU face. The information gathered from the individual interviews cannot be generalized to all parents and other hospital populations, nor is it the intent of this study. Instead, by exploring the each parent's NICU experiences of nursing care, it is a hope that we can see common themes that will help neonatal nurses to improve their practices with parents. On a broader scale, it is hoped that this research study will inspire all nurses to look at how they care for all families and provide the best care that they can.

Study Procedures

If you agree to voluntarily participate in this research, your participation will include a one-hour interview to share your experience and one 30 minute follow-up conversation by email or telephone to ensure I clearly heard your experience. To minimize any inconvenience to you, the interview can take place in your home, at my office, or at a place of your choice at a time that works best for you.

I will take written notes and an audio recording of the interview. Also, I will collect information such as your infant's date of birth, occupation, level of education, marital status and when your baby went home from the NICU as part of the interview process. This information will be transcribed by a third party and will be analyzed by myself.

Themes that are generated through the interview will be shared with you (in a phone call or by email) to make sure that they clearly tell your experience within one month of your interview. I will write a report about these themes and share it with you if you are interested.

Inconvenience

Participation in this study may cause some inconvenience to you, including the time for the interview. However, every effort will be made to arrange the interview at a time and place that is convenient.

Risks

By participating in this research you may experience an emotional response to past experiences. To prevent or to deal with these risks the following steps will be taken:

- I will ask all questions respectfully and sensitively.
- Possible interview questions can be provided to you before the interview if requested by the participant.
- You will be encouraged to answer only those questions you feel you are able to.
- If you are feeling upset during any part of the interview, I will pause, reschedule or end the interview altogether.
- I can refer you to a NICU Social Worker or physician if you have an emotional response to make sure you get some support.

Benefits

The potential benefits of your participation in this research include the opportunity to explore and discuss your own story of nursing care while being a parent to an infant born with CDH in the NICU. The findings of this study will hopefully result in nursing care that is more meaningful and individualized to the needs not only of parents of infants born with CDH, but also other families in the NICU. In addition, what we know in health care about the NICU stories of parents may be expanded, and shared.

Withdrawal

You may withdraw from this study at any time without giving reasons for your decision. If you choose to enter the study and then decide to withdraw at a later time, your data will NOT be used. If you withdraw, all collected data will be destroyed. You may also choose not to answer any specific question asked during the interview process.

Confidentiality

In terms of protecting your confidentiality, you will have face-to-face contact with only myself as the researcher and you will decide what personal identifiable information you wish to share with me. No one will be told of who participated and who did not participate in this study. Audio recordings will be numerically coded (your name will not be on it) and kept in a locked filing cabinet available only to myself. Audio recordings will be transcribed and tracked through number codes or a pseudo name of your choice. Audio recordings will be erased after data analysis is completed. In published reports, my completed thesis and presentations, your name will be replaced with a pseudo name of your choice. I will keep one list of participants' names, addresses, phone numbers, e-mail addresses (if applicable), and pseudo names for the purposes of staying touch with you to let you know about the study. This list will be kept in a password protected computer file on a secure network separate from the transcribed data and will be destroyed at the end of the study.

I will protect your confidentiality and the confidentiality of the data by not sharing the audio recordings and transcribed data with anyone. All data will be kept in a locked filing cabinet and password protected computer. A paid transcriptionist, who will also be confidential and sign a contract, will transcribe interviews. Confidentiality and your identity will be protected if research findings are shared in any publications or presentations. Audio recording data from this study will be erased after data analysis is completed. The only copy of the participant list will be erased/destroyed at the end of the study. Transcribed data will be kept for the possibility of secondary analysis only with your permission. No identifiable information will be used for secondary analysis.

Transcribed data will be kept for the possibility of secondary analysis by the researcher only with your permission. No identifying information will be kept for secondary analysis

Please initial if subject agrees to have the interview data used for secondary analysis.

I would like to share the results of this study with others in the following ways. When my thesis is complete, the final document will be kept at the University of Victoria and will be accessible to the general public online. No names or identifiable information will be written in the report. All presented reports will protect your identity by changing any identifying information or features. Results of the study will be presented to the frontline multidisciplinary team in the NICU in the hopes of improving care. Sections of the thesis may also be published in scientific journals/books or publicly presented while adhering to ethics of anonymity and confidentiality.

If consenting to receiving the results, please provide your contact information to which the results can be mailed at the time of study completion.

Name: _____
Address: _____
City: _____
Province: _____ Postal Code: _____
Phone number: _____

Remuneration or Reimbursement

Your participation in this study is voluntary, participation in this study will not cost you anything, nor will you be offered any payment for your participation.

In signing this document you are in no way waiving my or my child's legal rights against the sponsors, investigators, or anyone else.

Contact Information for the Study

If you have any questions or desire further information with respect to this study, you may contact Nadine Lusney. You may also contact my supervisor at the School of Nursing if you have any questions.

Consent

I have read and understood this informed consent form. I have had the opportunity to ask questions and to discuss this study with the research team, and my questions have been answered to my satisfaction. I understand that my participation in the above study is entirely voluntary, and that I may refuse to participate, or may withdraw from the study at any time without any consequences to my involvement with B.C.'s Children's & Women's Hospital. I have been told that I will receive a signed and dated copy of this consent form for my own records.

Participant/Parent signature	Printed name	Date
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Signature of Researcher Obtaining Consent	Printed name	Date
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Appendix C

Interview Script/Questions

Prior to starting the interview, I will explicitly state the following:

Before we begin it is important to know that I will be talking to several families about their experiences in the NICU, I would like to audio record this conversation so that I can make sure that I capture all of your experiences and that I don't miss anything. That being said, no one other than me will know that you specifically said these things. The audio recordings will be transcribed as answers to the questions, without any identifiers, and then the recordings will be destroyed. When we report the findings from these interviews I will not include your or your baby's name, so there is no way for anyone to know specifically what you said. The findings from this research may be presented at scientific meetings, or published in a scientific journal, but we will never identify the names of people or publish any identifying characteristics of parents who participated in this study.

I am telling you all this so that you know what you say will be kept confidential and that you can feel free to tell me about all your experiences: the good ones and the bad. We are doing this because we want to make sure that we can make experiences better for future parents who are going through the same things you did.

My role during this time will be as a researcher, not a nurse or a therapist. If at anytime during this interview you become upset or wish to stop, please let me know. I have contact information for a social worker that I will provide to you for any emotional support during or after this interview.

Do I have your permission to audio record our conversation?

Do you have any questions for me before I begin?

After I have answered the subject's questions or concerns I will turn on the audiotape if the participant consented.

Draft of Interview Questions

1. As you know I am interested in your early experiences, after your infant was born and admitted to the NICU. Can you share an experience about your early interactions with your infant? When did you start to feel like a parent?
2. Thinking back to when your infant was born, can you tell me about your first experience with a NICU nurse? What was that experience like for you?
3. As a nurse I am interested in how nurses could support parents better during this experience. What was it like for you to interact with the nurses?
4. Did you develop any relationships with any nurses? What were those experiences like for you?
5. Think of a time when a nurse supported you. What was that experience like? How did you feel?
6. Think of a time when nursing care did not feel supportive. Can you describe nursing care that was not supportive? Do you have any suggestions to improve nursing care for other parents in similar situations?

Appendix D

Follow-up Email/Phone Call

In the follow-up email/phone call, I will explicitly state the following:

I want to thank you for sharing your experience with me. The purpose of this follow-up conversation is to review with you some of the ideas from your experience you shared in your interview and to see if you identify these ideas as your own.

I want you know that what you say in this follow-up conversation will be kept confidential and that you can feel free to tell me how you feel about the ideas I present to you: the good ones and the bad. I am doing this because I want to make sure that I have captured your experience that you shared with me.

My role during this time will be as a researcher, not a nurse or a therapist. If at anytime during this conversation you become upset or wish to stop, please let me know. I have contact information for a social worker that I will provide to you for any emotional support during or after this interview.

Do you have any questions for me before I begin?

After the researcher has answered the subject's questions or concerns I will state the following:

I want to share with you the ideas that I interpreted from the interview.

(The researcher will then present the themes that have surfaced from the participant's interview with supporting quotes). If you are comfortable, can you please tell me how do you feel about these interpretations?

The researcher will listen to the participant's response and document in the field notes any comments or concerns the participant brings forward. The purpose of the conversation is not to confirm accuracy, but to have some presence of member checking. The stance of the researcher would be to listen to the participant.

At the end of the conversation (lasting anywhere between five minutes to 30 minutes), the researcher will thank the participant again for their participation in the study. The researcher will provide her contact information in case the participant has any questions; in addition, the researcher will provide the participant with the Social Worker's contact information in the off chance that the participant is interested in any emotional support.

Appendix E

Contract for Transcription of Interview Tapes



You have agreed to be a transcriptionist in a study entitled, “*Narrative Inquiry: Stories of Parents’ Early Experiences of Nursing Care whose Infants were born with Congenital Diaphragmatic Hernia in the Neonatal Intensive Care Unit (NICU)*” that is being conducted by Nadine Lusney, BScN, RN.

I am a graduate student in the School of Nursing at the University of Victoria and you may contact me if you have further questions by email or by telephone. As a graduate student, I am conducting this research as part of the requirements for a Master degree in Nursing. You may also contact my supervisor at the School of Nursing if you have any questions.

If you have any concerns about your rights as a transcriptionist and/or your experiences while participating in this study, contact the Human Research Ethics Office at the University of Victoria by email or by telephone or the Research Subject Information Line in the University of British Columbia Office of Research Services by email or by telephone.

This contract for transcription of interview tapes constitutes an agreement between Nadine Lusney, Principal Investigator, and _____, transcriptionist. In agreeing to this contract, I _____ agree to the following:

- Audiotapes are to be transcribed verbatim, and in detail, according to the formal instructions of the principal investigator.
- As the transcriptionist, I will maintain the confidentiality and privacy of the participants. I will repeat no part of the participant dialogue and if I am aware of the identity of participants, I will not reveal this information to anyone.
- The audiotapes, flash drives, and hardcopies of the data, when not being actively used by me for transcription, will be kept in a locked filing cabinet or a locked box supplied to me by the principal investigator.
- Once tapes and transcriptions (disks and hardcopies) are returned to the principal investigator, I will erase any and all computer files pertaining to this research.
- Payment will be made upon completion of transcripts at a rate of \$20.00 per hour of work. It is expected that each one-hour tape will require three to four hours of transcription time.

Your signature below indicates that you understand the above contract conditions and that you have had the opportunity to have your questions answered by the researcher.

Printed Name, Address & Phone Number of Transcriptionist

Signature of Transcriptionist

Date

Printed Name, Address & Phone Number of Researcher

Signature of Researcher

Date

Printed Name, Address & Phone Number of Witness

Signature of Witness

Date

A signed and dated copy of this consent form will be left with you, and a copy will be taken by the researcher.