

The Influences of the Neonatal Intensive Care Unit Microsystem on Mothers' Experiences

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## **Abstract**

The goal of this project was to explore mothers' experiences of caring for infants in the Neonatal Intensive Care Unit (NICU) using a *microsystem* perspective. This perspective focuses on the structure, processes and people and in so doing allows for a critical exploration of how these elements work together to influence mothers in the NICU. The research framework involved an institutional ethnography to explore care delivery, relationships, and discourses in the NICU. Data was collected using nonparticipant-observations, interviews, and collection of discourse artifacts. There is clear evidence that caring for an infant in the NICU can result in significant increases in maternal stress and associated outcomes. Results from triangulation of the data indicated that being separated from the infant and learning to mother in the unit were particularly salient experiences retold by the mothers. These experiences were affected – either positively or negatively – by different elements of the microsystem including consistency in communications, increased opportunities for mothers' inclusion in decision-making and infant care and lastly, access to more support resources. Implementing improvements to the microsystem could better empower mothers adjusting to parenthood within the NICU context.

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## **Chapter 1: Introduction**

Having a baby in the neonatal intensive care unit (NICU), where preterm or extremely ill infants are cared for by specialized staff, can be one of the most stressful experiences in a parent's life. The NICU can often overwhelm and frighten parents with its highly technical equipment and the presence of critically ill and preterm infants, giving parents the impression their infant is vulnerable and possibly in danger (Doering, Dracup, & Moser, 1999). Mothers, in particular, report higher levels of anxiety, depression and hostility than do fathers (Doering et al, 1999). Maternal stress developed from caring for a child in the NICU can result in a variety of mental health issues, including difficulty developing an attachment to the infant and an increased risk of postpartum depression (Morey & Gregory, 2012). Research has also shown that "prematurity might also compromise the quality of interactions between the preterm infant and the mother, which may lead to poorer outcomes in subsequent development of the infant" (Reis, Shannon & Gempel, 2009, pg 175).

The negative experiences of mothers in the NICU can be mediated with system level improvements. The focus in the system level literature, however, tends to be directed in two areas: first, prenatally to prevent prematurity and second, to reducing mortality rates of premature infants. Specifically, NICU interventions often focus on improving quality of nursing care, equipment or new surgical methods to improve infant outcomes (Burns, 2005). Interventions that can include mothers are often still focused on what mothers can do to improve the infants' outcomes, not improve the experience for the mothers. Additionally, research on the function of NICU microsystems is limited; most studies have focused exclusively on staff satisfaction with little examination on parental experiences (Reis et al, 2009) or explore the experience of parents without considering systemic influences (Aagaard & Hall, 2008). Thus, there remains an important gap in our knowledge of how the NICU microsystem influences the experience of the mother.

The primary research question for my thesis is: *how does the NICU microsystem influence mothers' experiences?* This question requires an understanding of how the NICU functions as its own system with independent set of rules, processes and staff, within a larger hospital system and even more broadly within the Canadian health care system. I will explore the specific social structures, relationships and contexts that create a lived experience for the individuals within it.

The objective of this thesis is to make a valuable contribution to the field of health systems research, specifically in the field of maternal and child health by developing a deeper understanding of how health systems can influence the experiences of mothers receiving care. Viewing the operations within this unit from a *microsystem* perspective – that is, a focus on the structure, processes, and people within the unit – allows for a critical exploration of how these various elements work together to achieve effective care delivery outcomes for the infant and their family. Not only is this lacking in the literature but it is also an important gap to fill so as to provide more knowledge about how individuals understand, experience, and navigate the health care system. In doing so, this thesis offers insights into opportunities for improvement in health care structures.

## **Background of the NICU**

The neonatal intensive care unit (NICU) is a medical unit dedicated to treating high-risk infants born either preterm, with serious medical issues or requiring complex surgery (American Academy of Pediatrics, 2012). According to March of Dimes (2015), the NICU is a nursery, which provides twenty-four hour care to sick infants by health care providers with special training in this specific population. There are generally three levels of care for neonates, although, there is some literature that indicates a fourth which would include pediatric surgical subspecialists. The first level of care provides basic care to stable newborns. The second level provides care to infants born below 32 week gestation and weighing under 1500grams. The third level of care provides sustained life support, respiratory care and a wider range of specialists including pediatric anesthesiologists (American Academy of Pediatrics, 2012).

There is an abundance of research on parental distress in the NICU; the majority explores mothers and fathers together as parents (Ward, 2001). There are few studies on the differences between mothers and fathers coping with this stressful situation. One study that did compare mothers and fathers found that mothers reported higher levels of stress than fathers did. Mothers experienced more stress about their infants' vulnerability while fathers were more anxious about their parenting role (Doering et al., 1999). For these reasons, I will focus only on the maternal experience and how mothers are influenced by caring for their infant in an NICU.

### **Thesis Organization**

This thesis is organized into six chapters. In this first chapter I provide an introduction to the issue being explored, state the research question and set the foundation for what this thesis will discuss. The second chapter will offer a theoretical framework to demonstrate how this thesis is grounded within specific theories. Following this will be a review of the literature on maternal health and wellbeing in the NICU, a background of microsystem research and then an exploration of the literature on NICUs. The fourth chapter will offer a description of the methodology used for data collection and the structure for data analyses. The fifth chapter will examine the results that emerged from the data analysis. I conclude this thesis with a sixth chapter providing a discussion on how the results answer the research questions and are related to the literature. This will include a description of the limitations, contributions to future research and recommendations.

## **Chapter 2: Theoretical Framework**

This thesis research was conducted to explore how an account of individuals' experiences of a specific hospital unit can contribute to health systems research. As such, it is grounded in systems thinking which draws from multiple disciplines including public health, sociology, and psychology, to reflect the intricacies that make up a complex system. Basically, systems theory is a way to understand social organization (Boulding, 1956). It is focused on exploring the elements within a system and the relationships the elements have among each other and also with their environment (Begun, Zimmerman and Dooley, 2003) Systems thinking is a way to explore healthcare issues by examining the multitude of elements that are working in tandem and influencing each other to produce an outcome. In the case of this research it was applied to identify the elements across the healthcare system that contributed to a specific experience for a population.

More specifically, Ecological Systems Theory (EST) provides a model and structure for this research. EST is a theory developed using a systems thinking approach, and models how environmental and interpersonal factors influence each other. It conceptualizes systems through several different levels to illustrate environmental and contextual factors closest to an individual. I separately define and describe each of these concepts in this section and conclude with a description of how they are related and used together within a framework to inform this thesis research.

### **Systems thinking**

Systems thinking originated from Ludwig von Bertalanffy, an organismic biologist who argued that organisms could be viewed as a complex whole system, as opposed to a single unit of analysis. Bertalanffy's findings about systems thinking is often represented by the common phrase, "more than the sum of their parts" to demonstrate that systems are dynamic, influential and adaptive. With contributions from economist Kenneth Boulding, physiologist Ralph Gerard and mathematician Anatol Rapoport, Bertalanffy developed General Systems Theory. This theory is meant to be "applicable to more than one of the traditional departments of knowledge" (pg 45), reflecting the interdisciplinary nature of systems thinking and its

relevance to studying issues such as health, which itself draws on multiple disciplines (Checkland, 1999). Kenneth Boulding in his popular paper, *General Systems Theory- The Skeleton of Science* (1956) describes the theory as providing “a framework or structure of systems on which to hang the flesh and blood of particular disciplines and particular subject matter in an orderly and coherent corpus of knowledge” (pg 198).

It is important to point out that systems thinking is an approach developed from general systems theory and is an action-oriented *process*. That is, it is more concerned about the process of thinking systemically than it is about using the system as a single unit of analysis. Bertalanffy used the term system interchangeably but for the purposes of this thesis, systems thinking will be used to refer to the *process* of thinking (Currie, 1999). Peter Checkland (Currie, 1999) identifies four core ideas that capture the process of systems thinking and illustrates the concept of an “adaptive whole”. They are outlined below in Table 1 with examples to apply the ideas.

**Table 1- Examples of Systems Thinking**

Core Idea	Example
<i>Emergent properties</i> : Seeing the entity as a whole that is separable from its environment with properties that can be considered single entities on their own	A car- when disassembled it has no use but once all the parts are assembled it is considered a mode for transportation.
<i>Layered Structures</i> : The whole has smaller wholes within it with their own emergent properties	A university has smaller properties in the form of departments and faculties but is also part of a larger whole, which is the sector of higher education.
<i>Communication &amp; Control</i> : An understanding that the entity must have processes for communication and control either of which can be automatic or created by humans	The human body and hunger cues. Hunger is a sign to our brains that the body requires food and increased nutrients.

Using systems thinking to address health care issues has become more common in health research (Peters, 2014; Trochim et al, 2006). Its popularity and relevance was illustrated in a report by the Institute of Medicine titled, *Crossing the Quality Chasm: A New Health System for the 21<sup>st</sup> Century*. This report provides recommendations about how the healthcare system can be improved using a systems thinking approach. In regards to looking at health care as whole system the authors of the report write “A health care system can be defined as a set of connected or interdependent parts or agents- including caregivers and patients-bound by a common purpose and acting on their knowledge” (Trochim et al., 2006, pg 538). By exploring health care using a systems thinking approach there is also relevance in human ecology, social determinants of health and population health. As such, ecological systems theory is another tool to use to understand public health issues.

### **Ecology Systems Theory**

Ecological systems theory (EST) applies the process of systems thinking in a model that illustrates the levels of system that influence human behaviour. It identifies elements and interactions that occur across and within structures that systems thinking is interested in exploring. Urie Bronfenbrenner, a developmental psychologist, whose research focused on the ecology of human development, introduced this concept of *ecological perspectives*. According to a glossary by (McLaren & Hawe, 2004), “an ecological perspective encompasses context in the broadest sense of the word to include physical, social, cultural and historical aspects of context as well as attributes and behaviour of persons within” (pg 6). An ecosystem for the purposes of research in social sciences refers to this context to include all the elements listed by McLaren and Hawe (2004) but with parameters to demonstrate a system and the environment. When thinking about humans and their behaviour, Bronfenbrenner developed the concept of human ecology. Human ecology is a way to understand human behaviour and development by considering how we react and change due to our interactions with the environment and institutional structures. It is similar to biological ecology in that no system works independently, but rather are all interconnected and work with internal and external elements (McLaren & Hawe, 2004).

In most of Bronfenbrenner's work on human development and ecology he emphasizes interrelationships of processes and their differing contexts. EST is presented as a theory of human development that is concentrated on this interrelatedness of which is bound by context, culture and history. When Bronfenbrenner discusses engaging in ecological research, he emphasizes that the meaning is found in the interactions. He also mentions that one of the requirements for ecological research is regarding in how the environment and process that occur within it need to be examined in systems terms. For health systems research this theory is beneficial. For the purposes of this thesis, EST will be used as the theoretical framework to aid in exploring the interactions, environment and processes in the NICU and how this impacts mothers.

At the centre of the model is the individual with its own set of characteristics such as age, gender and health. The individual is nested *within* the microsystem. The microsystem encapsulates all the elements that are available and accessible to the individual in an immediate setting. These are often groups of people such as family and friends but can include social groups that can shape individuals' set of values, for example religious affiliations. Encompassing the microsystem is the mesosystem, which includes larger settings that might be important to an individual's development at a certain level of time, such as a school. Next, there is the exosystem, which includes formal and informal social structures that extend beyond the mesosystem. These structures most often control the settings and set the boundaries for the elements identified in the mesosystem. The outer most layer of the model represents the macrosystem. This layer is fundamentally different from the others in that the elements are related more to social and culture norms developed by society. Figure 1 illustrates the model for EST demonstrating the systems and the interactions that exist among them. Table 2 provides descriptions of the definitions for each level of the system as defined in the EST literature.

Figure 1 Bronfenbrenner’s ecological theory of development from McLaren & Hawe (2005).

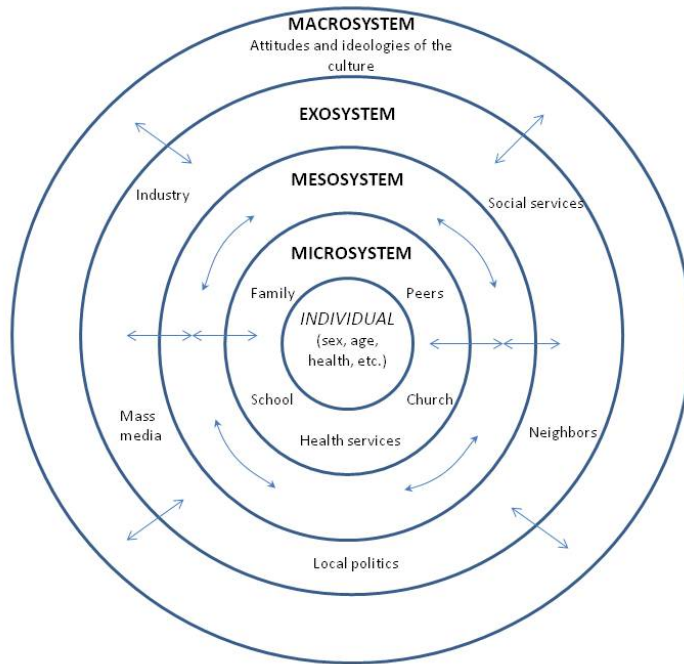


Table 2 Ecological Systems Theory Definitions from Bronfenbrenner, 1997 pg. 514-515

System Level	Definition
<b>Microsystem</b>	The complex relations between the developing person and environment in an immediate setting
<b>Mesosystem</b>	The interrelations among major settings containing the developing person at a particular point in his or her life.
<b>Exosystem</b>	An extension of the mesosystem embracing other specific social structures both formal and informal, that do not themselves contain the developing person but impinge or encompass the immediate settings in which the person is found, and thereby influence, delimit or even determine what goes on there.
<b>Macrosystem</b>	The overarching institutional patterns of the culture or subculture such as the economic, social, educational, legal and political systems of which micro-, meso-, and exo-systems are the concrete manifestations.

While Bronfenbrenner’s theory is applicable for areas of health systems research, it can lack specificity and context to issues moving beyond human development. Kingry-Westergaard and Kelly (1986) offer another perspective to the ecological approach provided by Bronfenbrenner.

They propose a contextualist epistemology for ecological research. Their model emphasizes the role of social context and how this shapes the experience of the participants. “Persons and systems become understandable when they are considered part of a multilevel, multistructured, multidetermined social context” (Kingry-Westergaard & Kelly, 1986, pg. 25). They highlight that social context is mutually agreed upon by the transactional relationship between the observer and the observed. Further, there are four facets to this ecological approach: theoretical propositions, the social construction of ecological knowledge, the collaborative style and social processes. Table 3 summarizes these four facets:

**Table 3-Theoretical Propositions from “A contextualist epistemology for ecological research.” by Kingry-Westergaard, C. & Kelly, J. (1986). *Metatheory in Social Science: Pluralisms and Subjectives* Pg. 23-31. University of Chicago Press.**

<b>Facet 1: Theoretical Propositions</b>	This facet identifies ten propositions, which summarizes the affects of the transactions between persons and settings. The ten facets can be referenced in Appendix 1
<b>Facet 2: Social Construction of Ecological Knowledge</b>	This describes how individuals behave as a result of the context they have created based their experience. It recognizes that individuals create social constructs based on their own experiences and perceptions.
<b>Facet 3: The Collaborative Style</b>	This facet describes the transactional relationship between the researcher and the participants. It emphasizes that the researcher and participant work together to identify and understand a social context and it’s relevance to the phenomenon being studied.
<b>Facet 4: Social Processes</b>	This last facet explains how roles and social norms create social structures. It is by understanding how these social processes work that we can understand how they impact people and settings.

The research undertaken for this thesis applies a systems thinking approach using the model from Bronfenbrenners’ ecological systems theory. Applying this theory to the hospital system, and the NICU more specifically, provides the context and specificity as outlined by Kingry-Westergaard & Kelly and utilizes systems thinking to explore experiences set within a microsystem. Using systems thinking adds to the theory being used by continuously testing how elements work together and offer new opportunities to create health improvements (Peters, 2014).

## **Chapter 3: Literature Review**

This section will review the literature on why it is important to study mothers in the NICU. Research in this field takes the perspective that it is important to study mothers to improve outcomes for the infant. The literature is generally concentrated on factors that will improve infant development such as attachment or parenting behaviours. By exploring this, there can be a better understanding of how this unit affects mothers and how system elements can play a role in shaping the overall experience. I begin by providing a background on how mothers are affected by the experience of having an infant requiring special care. Following this, research on clinical microsystems will be described to provide a framework and foundation for how the NICU is situated within a health systems context. From there, I address the functions within the NICU and introduce how these elements will be organized for my thesis. Lastly, I describe how the NICU and its various elements influence mothers, infants and the entire family and provide a proposed conceptual model.

### **Mothering in the NICU**

The literature on mothering in a NICU illustrates that mothers can experience a variety of negative health outcomes. These can include: disruptions to the initial attachment between the mother and the infant, increased risk of postpartum depression, anxiety and there is some evidence of difficulty producing breast milk (Morey & Gregory, 2012). This suggests that developing a maternal identity may be an issue when parenting in the NICU, which prompts the question of how the infant could also be affected.

In a quantitative study by Doering et al, (1999), it was determined that both parents experience high levels of stress when their infant is admitted into a NICU. There was however, a notable difference between fathers and mothers, which requires further exploration. They found that mothers not only experienced higher levels of stress, anxiety and hostility but also difficulty accepting and adjusting to their infants' health status. To compound this issue further, mothers perceive the NICU as more threatening to their child's welfare than fathers, which results in increased distress. So, while there is considerable stress placed on both parents in the NICU, mothers experience this at a higher degree.

Research in social science disciplines found psychological consequences as an outcome of an NICU stay. There is an increased risk of maternal depression from mothers caring for an infant in the NICU and this can lead to negative outcomes for infants (Swartz, 2005). Mothers of very low birth weight infants are shown to have increased depression after delivery than mothers with normal weight babies. This depression can last up to four months following delivery (Korja et al., 2008).

In sum, mothers and infants are significantly impacted by the experience of the NICU. There are several elements, which play a key role in exacerbating these negative outcomes such as issues with organizational processes, relationships with care providers as well as perceived power inequalities. Studying these elements of the microsystem using an ecological approach will allow for more specificity of the functions of the elements and the specific impacts they have.

### **The Clinical Microsystem**

The previous section reviews how mothers are affected emotionally by caring for a preterm infant. This section will review the systemic elements that can contribute to this experience. There will be a review of clinical microsystem literature, and then in depth summaries of studies associated with each system element. From what we understand of the ecological approach described by Kingsy-Westergaard & Kelly (1986) environmental and interpersonal influences must be considered when studying a concept or phenomenon. This is particularly relevant to my research as it is these interactions I want to explore further to understand their implications on outcomes for mothers. It is therefore important to develop an understanding of the NICU from an ecological, systemic perspective.

Reis and colleagues (2009) define a clinical microsystem as a smaller, functioning unit that delivers care from a larger macrosystem. This microsystem is organized with a very specific purpose, set of patients, staff and technologies to treat a specified population. This is supported by research from Nelson et al (2002) in which they describe a clinical microsystem as a biological organism that uses different elements to achieve a common goal. They discuss how

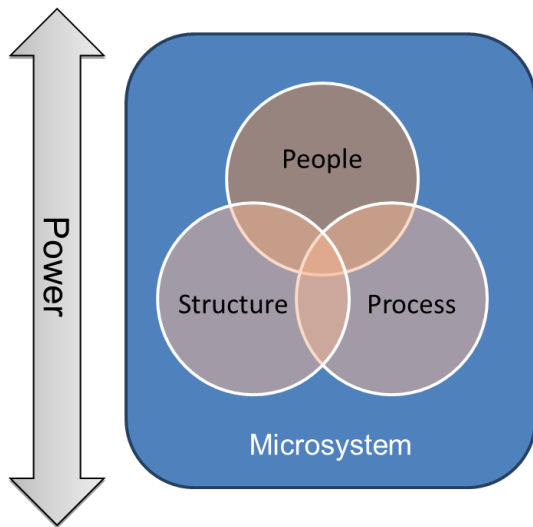
patients interact in these specialized units with staff that have distinct roles and responsibilities as well as the processes that are unit-specific. These interactions produce patterns or outcomes directly related to the goal of the unit. Former work on clinical microsystems was focused on quality and cost outcomes but more recent research is using clinical microsystems to assess patient-outcomes (Nelson, 2002).

Previous research on microsystems has found that studying healthcare from this targeted, specific approach can increase staff satisfaction and morale. Further, parents' experience increases in consistency in care giving, which can ultimately impact overall satisfaction with the healthcare experience. Effective communication and collaborative healthcare provider relationships are two of the significant outcomes of clinical microsystems, largely due to the consistency of care providers (Reis et al, 2009).

### **System Elements of the NICU**

As mentioned in the previous section, using an ecological approach to study a clinical microsystem can help to understand social contexts as well as the impacts the elements have on the unit and patient experiences. There are three common elements that are consistently referred to in the literature on clinical microsystems and the experiences in the NICU. These elements include processes, people and structure. It is important to recognize that while each has its own function, they all work together and have overlapping characteristics, which achieve a common goal - effective, consistent care delivery. This has developed into a model that will be referred to throughout my proposal as the elements of the NICU microsystem. An illustration of the model for the elements of the microsystem is provided below:

Figure 2-Elements of the Microsystem



Each system element in the NICU will be explored next.

### **People**

Some of the key people within the NICU are the healthcare professionals working within it. It has been argued that, “the relationship between healthcare providers, particularly nurses, has been identified as a key factor affecting a mothers’ experience in the NICU” (Reis et al, 2009, pg. 176). Indeed, literature describing the effects of patient-provider relationships is abundant. Understanding the effects of having positive relationships with the providers in the NICU is crucial. Qualitative studies by Swartz (2005), Heerman et al, (2005) and Hurst (2001) all suggest that mothers’ concerns with being labeled as “difficult” increase overall stress levels and anxiety and create negative relationships with care providers. Mothers felt as though by voicing their opinions or concerns they would further alienate themselves from the nursing staff in which they want to develop trust and a feeling of inclusion (Hurst, 2001).

### **Processes**

An ethnographic study conducted by Hurst (2001) found that mothers feel a lack of inclusion and empowerment in the NICU as a result of structural boundaries. The structural boundaries she explores includes a lack of consistent communication flow and issues of continuity of care. For example, her study described mothers’ inability to evaluate their infants’ status and needs, due to flawed organizational processes such as gaining access to the right information at the

right time and from the right source. Other studies by Reis et al (2009) and Heerman & Wilhelm (2005) indicate a need for processes to include increasing parental responsibilities for the mothers. This may mean coaching and educating mothers on how to handle their infant amongst the various technologies or treatments being implemented in the unit.

Another process-related issue mothers experience is an abundance of waiting and feelings of uncertainty. Mothers were often left without answers and or clear understanding of diagnosis or treatments for significant lengths of time. This suggests a lack of care consistency and reinforces the absence of dependable communication. When there are disruptions to care consistency, mothers perceive their infants' and their own safety to be at risk (Aargaard & Hall, 2008). Hurst (2001) also describes how allocation of nursing resources can cause periods without adequate nursing staff or long delays in care delivery and information. This resulted in mothers feeling sceptical and doubtful of the care consistency in the NICU.

While the research indicates various issues with communication flow there is a gap in identifying the source of these inconsistencies from a systems perspective. There are general comments about providers' inconsistent communication but not why this occurs in the first place and where there may be other opportunities to increase or improve patient communication. In general, this literature suggests that a lack of information flow and consistency in care can negatively impact mothers.

### **Structure**

Some of the most salient structural influences in the NICU which emerge from the literature are that the equipment and even the design of the NICU are unique to its population. A number of researchers emphasize the isolation of the NICU from the rest of the hospital, Sheila Sim (2000), for example, describes the experience of entering an NICU like "entering another world...There are rituals to mark the crossing of the threshold into this highly technological environment" (Sim, 2000, pg 255). Margaret Cohen (2003) provides a similar description about entering the NICU. She writes in her book *Sent Before My Time: A Child Psychotherapist's View of Life on an Neonatal Intensive Care Unit*,

“One enters the neonatal intensive care unit (NICU) through a locked door. From the very beginning one has strong thoughts: this is a world apart- privileged people have cards that open the door, others have to wait until they have entry. There is a sense that what is inside is fragile and that what is outside may be dangerous.”

- Margaret Cohen, 2003, pg 1

They write about the separation in that what is inside the NICU is for a very different, vulnerable population. There is a lack of information on how the unit is structured influences the way people, specifically patients and their families, use it. The majority of research on the structure and design of the NICU mostly focuses on how the environment influences the health for the infant. The literature includes vast studies on lighting, noise and room temperature.

Carter et al., (2008) comment on the lack of research on parental experiences of NICU environment and design. In their study comparing private NICU rooms with an open bay NICU with many beds. The results of this study found that private rooms facilitated a more family-centred care approach and was preferred by parents. They did find that some parents reported enjoying the open bay with many beds because open concept enabled more dialogue with nursing staff.

Notable studies, such as Doering et al., (1999), reference the influence of parents seeing their child in an unfamiliar unit. This study illustrated that maternal distress came from increased perception from the abundance of highly technical medical equipment in the NICU that their infant was abnormal.

## **Power**

Power, as features in this literature, is an endemic feature cross cutting people, process and structure. A power struggle between the mothers and the care providers is a particularly common theme within the literature. Morey & Gregory (2012) identify the greatest source of stress mothers' experience in the NICU is the loss of the maternal role. They emphasize the

importance of including the mother in parenting duties such as diaper changing and feeding as well as promoting mother-infant bonding activities such as kangaroo care. A meta-synthesis on the literature on parenting preterm infants by Swartz (2005) also emphasizes the importance of nurses facilitating the mothers' role in the NICU in order for the mother to develop a maternal identity.

Hurst (2001) also found that mothers perceive an inequality of authority over their infant in the NICU as the nurses have significantly more knowledge and experience of the technology, processes and procedures in the unit. Hurst (2001) describes that mothers felt they needed to negotiate and gather information on their own to develop a feeling of inclusion. This is reinforced by Heerman & Wilhelm (2005) in which they describe mothers' feelings that the nurses had "custody" of the infant, as they were the primary caregivers. Mothers described this experience as feeling like an "outsider" or "stranger." From the literature, it is clear that these four elements play a large role in how the microsystem functions and is experienced by patients.

### ***Gender in the NICU Microsystem***

From the review of the literature above, we know that there is a struggle between nurses and mothers. This struggle is often a power conflict about ownership of the infant and care delivery privileges between mother and nurse. What is lacking is any form of analysis about how gender may influence this relationship. When gender is mentioned, it is within the context of gender differences between parents and not in the context of health care professionals and parents. This illuminates a gap in the literature that might provide significant insights into how mothers experience the NICU.

### **Synthesis of Literature**

Below is a table that captures the key information regarding the system elements that were gathered from the literature review. It offers a quick overview of the salient information pertinent to the microsystem perspective used for this thesis.

**Table 4- Literature Synthesis**

<b>Processes</b>		
<b>Salient information on issues within unit processes that created distress:</b>		
	Lack of access to consistent communication and information	Hurst, 2001; Heerman & Wilhelm, 2005
	Periods of waiting and uncertainty	Aargaard & Hall, 2001
	Allocation of nursing resources	Hurst, 2001
	Lack of maternal inclusion and education in care delivery	Hurst, 2001; Reis et al, 2009; Heerman & Wilhelm 2005
<b>People</b>		
<b>Salient information on the relationships between mothers and care providers in the NICU</b>		
	Relationships with providers- a key factor in parental satisfaction	Reis et al, 2009; Heerman & Wilhelm, 2005
	Maternal distress as a result of being worried about how they would be perceived by providers in the unit	Swartz, 2005; Heerman & Wilhelm, 2005
	Consistent communication is necessary for positive relationships	Hurst, 2001
	Nurses have the greatest role to play in including mothers in the care	Swartz, 2005
<b>Structure</b>		
<b>Salient information on how the NICU is perceived and experienced by others.</b>		
	The NICU is a unique system, with equipment, staff and social rules that distinguish it from others.	Sim, 2000; Cohen 2003; Carter et al, 2003; Doering et al, 1999.
<b>Power</b>		
<b>Salient information on the power differences between mothers and the healthcare system</b>		
	Feeling a lack of maternal identity or giving up the maternal role to providers creates distress	Morey & Gregory, 2012; Hurst, 2001; Heerman & Wilhelm, 2005
	Perception that providers have the expertise and act as gatekeepers to the information	Hurst, 2001; Reist et al, 2009; Heerman & Wilhelm, 2005

Once I developed a familiarity with the main messages in the literature, I was able to identify gaps and discover how my research would fill them. Below is a table identifying the messages in the literature and then highlighting the areas where more research is needed.

**Table 5- Areas of knowledge gaps**

What we know from the literature	Critical knowledge gaps
- <i>There are inconsistencies in communication flow as care delivery.</i>	- <i>Why there are inconsistencies</i> <ul style="list-style-type: none"> <li>○ <i>Is it a process issue or are health providers not offering the accurate information?</i></li> </ul>
- <i>Positive relationships with providers have the most significant impact on NICU parental NICU satisfaction</i>	- <i>What is needed for “positive relationships” with providers?</i>
- <i>Mothers feel a loss of authority in the NICU</i>	- <i>What is needed for mothers to feel empowered?</i> - <i>How can processes or patient-provider relationships be improved to facilitate power balance?</i>
- <i>Mothers experience increases in stress, depression and anxiety when they have an infant in the NICU</i>	- <i>What roles do the elements of the system play in exacerbating or improve these symptoms?</i> <ul style="list-style-type: none"> <li>○ <i>Processes</i></li> <li>○ <i>People</i></li> <li>○ <i>Structure</i></li> </ul> - <i>How can the microsystem be improved to meet the needs of mothers in the NICU</i>
- <i>Mothers experience greater stress than fathers- specifically due to the perceived feelings of threat of the NICU</i>	- <i>How can the NICU be less threatening?</i>
- <i>Mothers are significantly impacted by a power struggle with nurses in regards to caring for their infant in the NICU</i>	- <i>There is a major lack of research on the influence of gender in this research.</i>

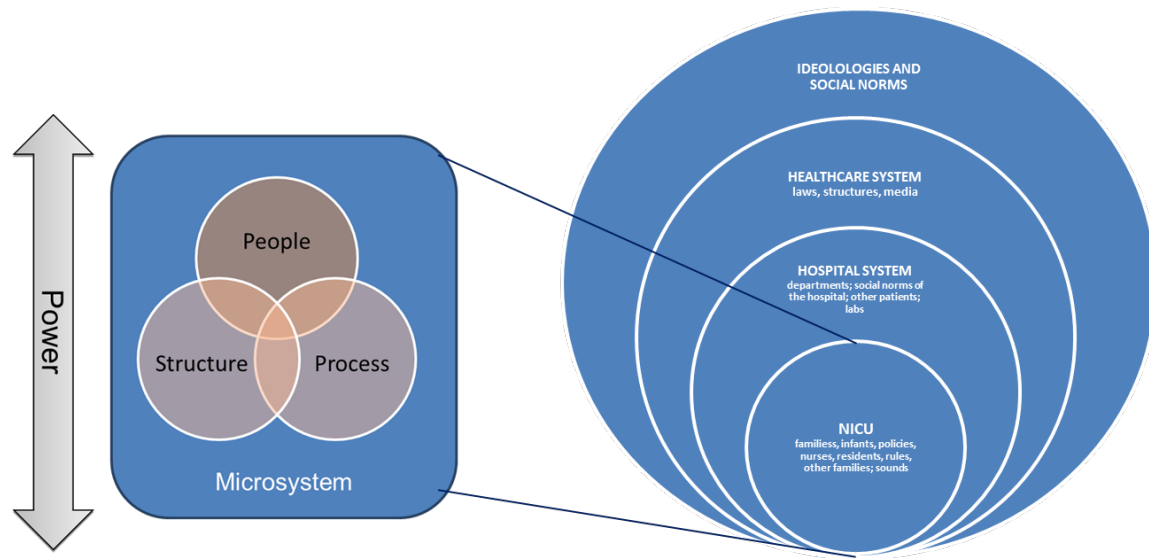
It is due to these knowledge gaps that I am using a clinical microsystem perspective when studying the impacts of the NICU on the maternal experience. Viewing a hospital unit with a micro systemic lens will enable me to study the unit as a single entity with very specific processes and people.

### **Proposed Conceptual Model**

Figure 3 below represents a draft conceptual model of the application of Bronfenbrenners ecological systems theory (EST) (outlined in the last chapter) to my thesis research on the influence of the NICU as a micro system on maternal experience At the centre of the model is

the mother who embodies a particular set of demographic characteristics and interpersonal factors; these factors interact with factors at the other levels to help create meaning of a particular experience from a systems perspective. For example, someone at the age of ten may react to their environment or other people differently than someone who is forty years of age. The specific microsystem of interest at this particular juncture of their lives is the NICU, which includes its own set of staff, rules and environment that is specific to that microsystem. Next, is the mesosystem, which includes the broader hospital system within which the NICU is situated and other units, processes, and people. Encompassing the mesosystem is the exosystem, which means the broader healthcare system, which includes how healthcare has been structured and regulated in Canada. Lastly, ideologies and social norms that regulate behaviour is the overarching system that encompasses all the levels below. While there is structure to this model from an individual unit of analysis (the mother) to a larger encompassing perspective, each system influences and interacts with one another. This was demonstrated in my thesis research and will be discussed in detail in the discussion section of this thesis.

Figure 3-Conceptual Model of Influences of the NICU Microsystem on the Maternal Experience



## **Chapter 4: Methods**

### **Methodological Approach**

This research was conducted using a qualitative research design. Qualitative research is based on understanding specific phenomena by providing researchers with tools to explore the deeper meanings within these experiences (Creswell, 2010). It is less focused on predicting outcomes and is grounded within the social context in which the experience occurs. This has been particularly significant for my study as my research goal was to understand the impacts of a particular context (the NICU) on a specific population (mothers) (Lee, 1999). The purpose of using a qualitative research approach was to gain a deeper understanding of the experience of a group of individuals and the meaning their experience has in a greater social context.

In the case of my research, the group of individuals was mothers with an infant in the NICU, the experience was about caring for an infant in the NICU and the greater social context was the hospital and the broader healthcare system. Further, it allowed me as the researcher to provide subjective interpretations and offer a higher level of flexibility than other approaches. To ensure for clarity and focus, I used a tightly bound approach. This was achieved by including a well-defined research purpose and scope, a confirmed theoretical framework, a selective set of research questions and specific sampling and analysis techniques (Miles & Huberman, 1994).

### **Institutional Ethnography**

Institutional Ethnography was the specific qualitative approach adopted in this research. IE was developed by Dorothy E. Smith, who referred to it as “sociology for women” (Campbell, 1998, pg 56). It is a way to explore, explain and understand the experience of others who are subject to ruling relations. The concept of “ruling relations” is what institutional ethnography is grounded in and borrows perspectives from feminism (Campbell, 1998). It is based upon the notion that people’s experiences are constructed by these institutional discourses. Institutions are not meant as social organizations but rather the complex web of social structures in society more broadly such as education, health care, and law and the social rules we have created within them (Grahame, 1998).

I employed an institutional ethnographic methodological approach to the research design to achieve the objectives of my research study and answer my research questions. This design facilitated understanding the beliefs, attitudes and behaviours of a culture sharing group which form a traditional ethnography (Creswell, 2010), as well as taking into consideration the impacts of institutional values and processes from a gender perspective (Campbell & Gregory, 2002). In an institutional ethnography, the aim of the researcher is to 'take the standpoint' of the individuals whose experiences provides the initial catalyst for investigation (Smith, 2006). This particular design was a good fit for this study as a major component of institutional ethnography is to consider the effects of the institution that impact the make-up of the social context in which people experience "everyday life" (Campbell & Gregory, 2002). For example, a previous institutional ethnographic study interviewed young homosexual men not as a population of subjects but as informants knowledgeable about the experiences of school life for homosexual youth (DeVault & McCoy, 2012). The same can be true for this study- the mothers being interviewed are informants to shed light upon life as a mother with a child in the NICU.

Smith (2006) identifies three stages when conducting an institutional ethnography: 1) identifying an experience, 2) identifying the institutional processes that shape the experience and 3) exploring these processes to develop an understanding of how they influence the particular experience. In this study the institution being considered was the clinical microsystem of the NICU. This means examining all the elements within the system and considering how they work together to create a lived experience for mothers in the context of hospital setting. Therefore, it was these lived experiences in the NICU amongst the mothers that is the unit of analysis for my research. Using lived or common experiences as units of analysis are common in institutional ethnography where *"the intent is to bring forward voices and experiences from the margins, with a view toward offering rich material for reflection and identifying topics for future research"* (McCoy, 2005, pg.792).

Further, the methods employed to produce an institutional ethnography rely on interviews, observations and textual artifacts. While not a primary consideration for traditional

ethnographies, a crucial element of institutional ethnography is that language and texts are largely viewed as shaping the experience and culture of the individuals (Smith, 2006). According to institutional ethnography, texts and discourses within the institution create meaning and provide information about the ruling relations. As such, textual artifacts such as public signs, information handouts and pamphlets, as well as professional discourse, were included in this study to understand how these contribute to the social context. Smith (2006) highlights the significance of text-based discourse in health services and how they are used to describe care pathways, which influence the relationships between nurses and physicians.

Another contrast to traditional ethnographies is that institutional ethnography includes the standpoint of the subject performing the research of the everyday problem. It is a collaboration between the ethnographer and the subjects to understand the influence of broader system processes on everyday experiences, and in particular how this is mediated through texts. My own standpoint as the ethnographer for this study will be provided towards the end of this chapter. The next section will provide a description of the data collection methods.

### **Research Site**

All data were collected from Neonatal Intensive Care Unit at The Ottawa Hospital, General Campus in Ottawa, Ontario. This unit is a 24-bed level III inborn unit and is the designated high-risk referral hospital for Eastern Ontario, Southeastern Ontario, Western Quebec and Baffin Island. As such, there is a wide range of populations represented in this hospital unit. Further, as this is a level III unit, when infants progress and no longer require this intense level of care, they can be transferred to a special care nursery at the Civic Campus. If an infant regresses and requires more intensive care or has complex surgical needs, they will be transferred to the Children's Hospital of Eastern Ontario. It is also important to note that this is the primary teaching hospital in Ottawa and the unit cycles through residents and fellows regularly.

## **Ethics Approval**

This research project gained ethics approval from the Ottawa Hospital Research Institute and the University of Ottawa Research Ethics Board (Appendix ). The ethics approval process for my thesis began with introductory meetings with administration at the Ottawa Hospital Research Institute (OHRI) in the fall of 2013. After this meeting, I was referred to the clinic managers at the research site to discuss the feasibility of my study. After this meeting, the next step was to secure a local principal investigator. In order to do this, the research study would need to be formally presented at one of the monthly Clinical Round meetings with the Neonatology team at The Children's Hospital of Eastern Ontario (TOH). After this presentation in the winter of 2014, a local investigator was selected for this study.

I then met with the investigator to review the ethics submission process. This required obtaining a package from Human Resources that contained my account information for the online ethics portal at TOH. Because this research was collecting data from one site and being analyzed at another, I required a contract to protect the data. This required several signatures and a description of how the data would be transported, managed and protected between sites. After the contract was complete and amended to my ethics application, it was submitted. In July of 2014, the research project was approved and the administrative review at The University of Ottawa could commence. During the administrative review, I was required to gain security clearance and obtain a name badge for my entrance into the unit.

All participants signed a consent form for observations and interviews. They also gave consent to being audio recorded. The ethics approval for this project included collection of artifacts and observations of the staff. To inform the staff of the unit's participation in this study, the clinic manager of the NICU sent communications to the staff including details of my research and what it entails. My photo and the purposes of my research were posted in the waiting room to identify who I was and the purpose for my presence in the unit. The data was collected over a two month period from September to October 2014.

## Data Collection Methods

There were three phases to the data collection process to allow for rich descriptions and a deeper understanding of the effects of the NICU on mothers. The section provides an in-depth description of the data collection strategy, the sample and research site as well as the issues that arose with the data collection. The following are the phases, which will be followed by a detailed description of each phase:

- *Phase I included gathering insights through non-participant observation activities of the clinical management processes in a NICU. Traditional institutional ethnographies include participant observation activities, however, due to the clinical nature of this setting, non-participant observation was the best fit to gain valuable insights.*
- *Phase II included the collection and analysis of language and text-based discourses that are relevant to the NICU.*
- *Phase III included semi-structured interviews with six mothers who had infants currently in the NICU.*

The purpose for using a number of phases was to allow for triangulation of the interviews, observations and text discourses. The phases were conducted simultaneously with collection of discourse artifacts and observations being completed first due to participant scheduling.

### **Phase I- Non-participant observation**

Non-participant observations were completed from September 2014 to October 2014. This provided ample time to become familiar with the staff, comprehend the processes and get a general understand of the culture within the unit. As discussed by DeVault & McCoy (2012), work in the field will often include informal interviews and discussion, as the researcher will often engage with the front line workers. It is an opportunity for me to ask questions about processes and organizational structures to the nurses, physicians and administrators to gain insight on the functions of the unit specifically and also the institution. The intent was to spend

time in the NICU as a non-participant observer, which entails observing the processes and people from a distance without getting involved in any activity (Creswell, 2010). This phase also informed the text I collected, as I needed to develop an accurate understanding of the practices in the unit and the relevant discourse and language that is used regularly. For example, through observations I learned how policies or social rules were communicated such as breastfeeding pamphlets and parental leave forms.

One of the primary objectives of the observation phase was to develop an understanding of how the microsystem functions. It was particularly important to develop an understanding of the processes, cultures and social norms of this particular unit and capture them in real time. To this end, I took notes as I observed and ask probing questions to gain deeper knowledge of the unit. Further, I was actively taking noted on my own perceptions of what was occurring between the care delivery team and the mothers and families in the NICU to be able to reflect for possible researcher bias. Lastly, I observed the unit at different times to observe if there are any differences that occur during the day versus at night, weekdays verses weekends as well as if there are any impacts during nursing shift changes.

### **Phase II- Discourse artifact collection**

The third phase of data collection included gathering texts and artifacts that are provided or publically posted within the unit. These texts allowed me to conceptualize the processes and unspoken values that are communicated within the unit (DeVault & McCoy, 2012). This was a crucial part of the research design in that these textual processes illustrated common practices within the institution and has been compared by Smith (2006) as being similar to the function of the central nervous system running through the body connecting different sites. These texts include hard and electronic copies of information handouts, intake packages and communications about the unit for each day. Additionally, textual discourse will also be included to understand the language and way issues are framed in the everyday world of the NICU. These texts hold meaning and contribute to the processes within the NICU and therefore needed to be captured and analyzed.

### **Phase III- Semi-structured interviews**

The second phase of data collection included six in-depth interviews with mothers in the NICU. The purpose of the interviews was to collect data on several dimensions of the experience, which include clinical, parental and social perspectives. The participants for the interviews were selected using a convenience sampling strategy. Participants were recruited from the site of the observation phase. As a condition of the ethics application, only a member of the immediate care team or administration within the NICU could make initial contact with potential participants. As such, research assistants, residents and nurses assisted in recruitment processes. Once initial contact had been made and the participant agreed to learn more, I approached to discuss the study and gain consent.

Inclusion criteria for the participants include being a mother of an infant who was currently in the NICU and has been in the unit for a minimum of five days. Exclusion criteria includes mothers under the age of eighteen, cases involved with social services, infants whose survival is uncertain and families experiencing tremendous distress. Further, mothers who had not yet been in the unit for five days were excluded due to the lack of familiarity of the unit. The interview protocol can be referenced in Appendix B. Consent forms were distributed prior to the interview to explain the research purpose and possible risks of participation (see also Appendix C).

The purpose of interviewing in an institutional ethnography is to use the descriptions from the participants to uncover power dynamics and organizational processes that have considerable impacts (DeVault & McCoy, 2012). The interviewer and informant work together to produce a map of institutional processes, which can illustrate a chain of action (DeVault & McCoy, 2012). With this perspective, the mothers who are being interviewed provide a form of insider knowledge about the social organizations and processes that contribute to everyday life in the NICU.

The interviews lasted approximately 60 minutes in length and were held in the private family rooms available in the unit. The interview followed the chronology of events leading to the reason for needing care in the NICU. I began the interview by asking questions about the participants' current family situation and the pregnancy. The purpose of this was to get a sense whether the participant was aware the pregnancy was high-risk and cautioned about the possibility of requiring NICU care. Then I went on to inquire about labour and delivery. These questions were asked to determine when the participant became aware of going to the NICU. Then I asked NICU-related questions such as the relationships with nurses, residents and neonatologists.

Although the interview had a structure, the questions were asked depending on the answer the participant provided and if there was opportunity to probe. For example, participants often claim to have a favourite nurse or some they did not like. This created an opportunity to ask questions about what qualities make a nurse someone's "favourite" or what the nurse did to upset them. Further, it allowed the interview to feel less formal and more intimate; more like a conversation than an interview with questions and answers. The subject proved to be emotional for the participants as most of them became visibly upset so gaining trust and showing compassion was important.

### **Sample and Recruitment**

The research site was selected using theoretical and convenience sampling. Theoretical sampling was used due to the ethnographic nature of this study. It was selected based on the experiences of a point in time in mothers' lives. Convenience sampling was also applied in that the stakeholders were willing and interested in contributing to the purposes of the study (Eisenhardt, 1989). Consent was required from all participants involved in phases I and II. As previously mentioned, ethics approval for this research indicated that a member of the care team, which can include a nurse, a physician, or another member of the NICU team must initially contact the participants prior to the researcher. Initially, communications were sent to the NICU staff from the unit manager and the Site Chief introducing the study and the principal

investigator. The NICU staff manager then communicated this to the remainder of the staff so that everyone was aware I would be there doing observations and asking questions.

On my first visit to the NICU, the Neonatology Site Chief for The Ottawa Hospital and the Children's Hospital of Eastern Ontario, gave me a tour of the unit and introduced me to the residents, fellows and neonatologist on duty. On my second visit I was introduced to the research team for the NICU. They were able to include my study in their list of studies for recruitment of participants and began recruiting and making initial contact with mothers on my behalf. Recruitment of participants took place September 1, 2014 and was completed on October 22<sup>nd</sup>, 2014. While recruitment was taking place I was able to complete my field notes, observe the unit and also collect the artifacts.

### Reaching Saturation

For the purposes of my research, I drew upon the definition of saturation from Bowen (2008) as the point in which no new information is being presented. In regards to the interviews, saturation was achieved in that the same themes appeared with no new information by the sixth interview. While small details altered from participant to participant, the content regarding the experience remained the same. For example, the most significant impact of the NICU reported was the separation from the infant. Additionally participants talked widely about the role of nurses as having a positive or negative affect. Secondly, saturation was accomplished in regards to the observations in that the same issues were occurring and I began repeating my notes. Lastly, the artifact collection was confirmed as being complete once I had all the copies of posters within the unit and the information disseminated from the clerk at the front desk. It was this triangulation of all three sources that confirmed saturation had been achieved.

### ***Researcher Standpoint***

The process of stating your standpoint emphasizes the importance of identifying how you are situated in the research based on your background, beliefs and feelings. Stating my own assumptions and biases is also a tool that can help to ensure validity within the data but also to

be accountable to the population being studied (Allen, 2000). Understanding my own position and beliefs about this issue allowed me to identify my biases and be aware of them throughout the research process. For example, I am not a mother, which could have made it difficult to relate to the participants and engage in reciprocity. To overcome this I tried to ask questions related to what it means to be a mother. Although I am not a mother, it felt easier to connect to the participants because of our gender. As members of the same gender, there was a shared sense of empathy and connection about what it means to be a woman.

As a qualitative researcher, I appreciate my role as the 'tool' used to capture what the participant has experienced through conversations and becoming familiar with the institution, in this case the culture of the NICU. This required collaboration not only with the participants but the other staff on the unit. Therefore, it was important to develop trust, credibility and rapport with the individuals in my study. This collaborative process was an especially significant step in the research process as there can be a hierarchical relationship between the researcher and the participants. In an effort to diminish this power difference I introduced myself to all staff in the unit and described my study. I also explained that I might reach out to them for assistance in understanding because this was not my everyday world. The objective was to empower them and create a sense of partnership.

The approach was similar with the participants. At my first introduction I explained the purpose of my research and how by understanding this issue from their perspective we could improve health care systems and ensure more positive experiences for future mothers. Further, I emphasized how there were no correct or incorrect answers to any of the interview questions, but that my role was to understand their experiences and capture them accurately and most importantly, to work in tandem with them to develop a deeper understanding of their experiences to address an important gap and create new knowledge.

## **Data Analysis**

From the literature review and performing the interviews, there was a sense of what could be potential codes and categories; my goal was to see if the data had information aside from my initial assumptions. This was a crucial part of institutional ethnography in that the researcher must be aware of assumptions and biases. In an effort to accomplish this I used an inductive approach by line-by-line coding to begin my analysis process. Examples of line-by-line codes include “nurse shift change; breastfeeding difficulty; housing.” At the end of this process, I had ninety-nine codes, largely descriptive but some were emerging as potential categories. A descriptive code is usually one word that captures the meaning in the text (Saldana, 2009). The potential categories were codes such as “Breastfeeding.”

From there I reviewed the entire list of codes to search for similarities among the codes so they could be grouped and organized. This resulted in the creation of seventeen categories. An example of a category included “Support” and codes within this category included “spouse; family; friends.” The development of codes and categories was an iterative process that evolved throughout the analysis. With the research question in mind, the categories were analyzed and narrowed down to four overarching dimensions that answer the question about how mothers are influenced by this experience. These four broader dimensions include: separation from the baby, relationship with nurses, inclusion in care and communication. These four broad themes encapsulate the most categories and codes throughout the data.

In an effort to understand the relationships between these dimensions, I mapped them out on large flipchart paper. This provided an opportunity to view how the themes related to one another and if there were subtle messages that were not apparent from the coding. Ultimately what came from this mapping were new ways to view the data. It illustrated that the experience of being separated from the baby and the relationship with nurses were mediated by communication and inclusion. The overarching element that tied all of these together was power, a crosscutting dimension in both the system’s theory and IE methodological approach.

The next step in my data analysis included exploring how these results related to the elements of the microsystem described in the literature review: structure, people and processes. Using the mapping on the flip chart paper I could see how the categories were aligned with the elements. For example, nursing relationships could be considered within the people element. Organizing the categories among the elements was not mutually exclusive. Some codes could fall into both, emphasizing that systems overlap and influence each other. This was seen with the code “discharge.” This code could be applied to processes as well as structure. Discharge is a formal process that creates a lot of excitement but it is also related to the structure of the NICU in that being placed in a specific location could implicitly mean sooner discharge.

This analysis strategy proved effective in that it produced the outcome as experienced by the mothers involved, rather than the assumptions I had based on previous literature or items that stood out to me. It also illuminated relationships and interactions that had not been directly said but were consequences of one another. For example, according to participants, favourite nurses were the ones who provided open, frequent communication, which contributed to a positive experience. Further, this strategy allowed me to understand the experience from a systems perspective. I was able to take the key messages from the data and see where it fit into elements of the microsystem. The results of this analysis are provided in the results section.

### **Trustworthiness**

Lincoln and Guba (1985) claim that there are five domains to establish trustworthiness in a study, which include credibility, authenticity, transferability, dependability and confirmability (Creswell, 2010). In an effort to establish credibility, I triangulated the data from the three different data sources. These sources include mothers with infants in the NICU, my own observations of the unit, as well as texts and discourse artifacts. The data from these sources were corroborated in an effort to ensure consistency and truth and will also identify incongruences and gaps. Further, my participant observations enabled me to spend time in the field developing relationships with the care delivery team so I was able to ask for clarity on processes, roles and the texts or discourse being collected. This ensured I have correctly understood the semantics and terminology that is used in the everyday world of the NICU. It

also allowed me to learn about the culture of the unit and how the microsystem flows and functions. These activities contributed to ensuring authenticity and trustworthiness (Campbell & Gregory, 2002). This provided an opportunity for me to confirm that I have captured the experiences accurately and also facilitate the researcher-informer collaboration as mentioned previously (Lincoln & Guba, 1994).

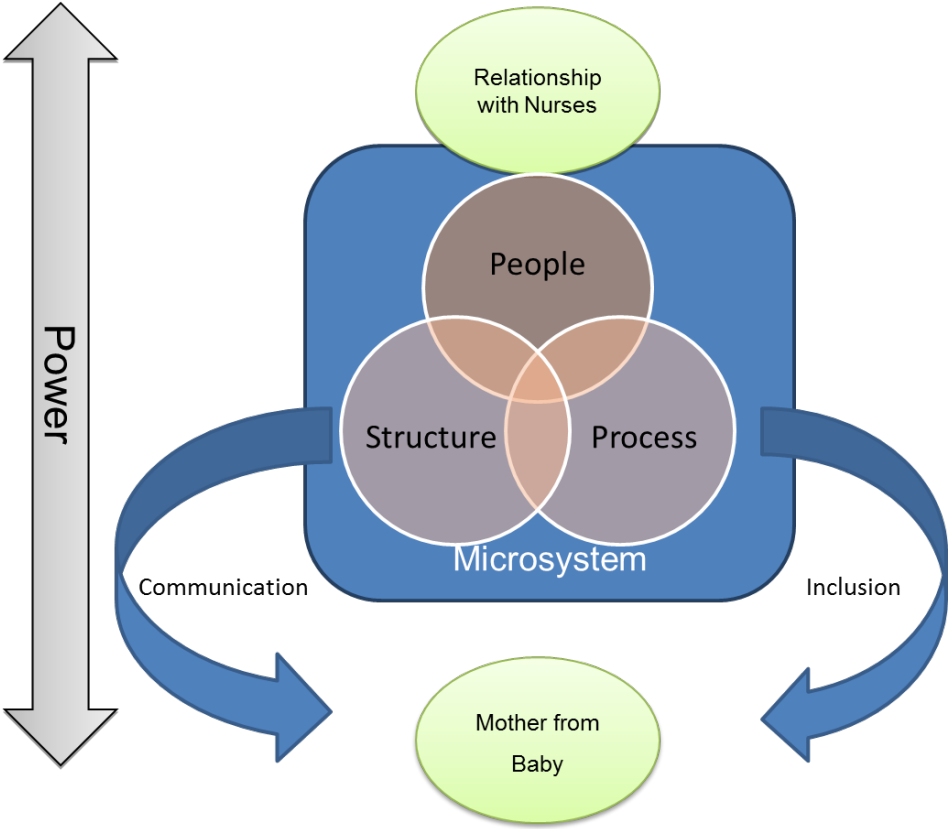
My researcher standpoint was provided previously to protect against possible researcher bias. Additionally, providing rich and thick descriptions that provide enough details for readers to make their own decisions is an important tactic to achieve transferability (Creswell, 2010). I have ensured that each of the elements and experiences are well-described using examples such as quotes from interviews or texts as well as detailed depictions of my own observations in my results sections have also contributed to trustworthiness. Lastly, in regards to security and confidentiality, all data was stored on a password-protected computer and USB key. Identity details for all of the participants will be removed from reports to ensure anonymity as agreed upon in the ethics approval.

In the next chapter I explore the thematic results from the data analysis more deeply. It offers a description of the themes that emerged from the data and link between the three sources of data. It will consider how mothers were impacted by the separation from their infants, their relationship with nurses and factors, which may have mediated this. In addition to that, a microsystem lens is applied to the results to suggest the influences systems have on experiences.

# Chapter 5: Results

As mentioned in Chapter 4, the data from my study both elaborated and augmented on the initial systems approach I undertook. One of the most salient themes of the interviews with mothers was their separation from baby, an issue I address first. How the microsystem of the NICU mediated that experience structurally, through its process and people, and the nurses in particular was illustrative. What also emerged were two key dimensions of communication and inclusion which act as mediators. Figure 4-A Model of the Mothers' Experience in the NICU Microsystem provides a representation of the results and the output for data-mapping process.

Figure 4-A Model of the Mothers' Experience in the NICU Microsystem



This section is organized from personal, internal microsystem experiences into the broader macro-level influences. It starts with the impact of being separated from the infant and discuss

the microsystem elements. While reading through these sections it is important to keep in mind that these are all overlapping and influencing one another at a time.

### **The Personal Micro System of NICU Mothers – Separation for Baby**

The key theme that emerged from the interview data was the experience of being separated from the infant, within the unit and being physically away from the hospital. It includes data about the feelings associated with being physically separated, the lack of support and how the NICUs policies might affect the separation. Participants discuss the emotional toll of going home without their baby, such as feelings of stress, anxiety and guilt:

*“It's stressful cause I don't get to hold him. I don't, even now, I'm not pregnant anymore but I don't have a baby at home either.”-Mother 6*

*“He was pretty much gone the entire day, cause after the C-section I was in bed .... So like that was really stressful for me.”- Mother 3*

*“There was like just a, a miscommunication or, I don't know what it was, um, so, but for us, for my husband and I, the biggest one was leaving the hospital and not having anyone that came”-Mother 1*

*“So that made a big difference for sure. I mean, you could hear babies cry in the hallway but it's definitely not the same having a baby”- Mother 2*

Participants also mention the lack of preparation about this separation or about what to expect emotionally when your infant is in the NICU. From the interview data, participants reported feeling left unsupported with the distressing experience of going home without a baby. There is no formal counselling or resources provided which participants identify as something they could have benefitted from:

*“So the fact that there was no professional counsellor that comes and just to talk to you before you go home without a baby.”- Mother 3*

*“There was no counsellor ... There was nobody that came to, because mentally it's very, it's pretty hard. It's something that you don't think it could happen to you, but it happens.”- Mother 5*

Additionally, some of the processes and policies in the unit did not provide enough time for mothers to feel like they have parented or bonded with their infant, which further emphasized this separation. This resulted in increased feelings of guilt in some situations. Other times, participants attributed this to the nurse on staff at the time, an issue that will be expanded upon in the following section.

*“Sometimes I wished it could be longer, like at first it was an hour max sort of deal so I felt anyways I didn't really get more than an hour. I got to hold him for like two hours, once three hours and I felt like it was just random and it was just the nurse that day and how she felt, kind of as to how long I could hold him.” –Mother 4*

One participant acknowledged her feelings about the separation and accepted that the NICU is the safest place for her infant. She also mentions her confidence in the nurses caring for him. Having nurses who want to care for the baby seems like it reassured her about the separation

*“So it's not like having her at home and like crying and you know taking care of her, so it was, yah, the fact that, you know, the time question in coming to the hospital and, but I wouldn't have it any other way. Because like I said, she needed to be here.” Mother 4*

*“It's not that I feel stressed, I just miss him. But at home, I know I can phone anytime and, and now they're fighting to have him, so I know, like he's in good hands.”-Mother 5*

These results highlight two issues in regards to the effects of being separated from the infant: the first is regarding the emotions related to the separation and the second is centred on how

the system influences this separation. This could be from lack of preparation to procedures that limit mother-infant interaction. The next section will explore these microsystem elements and how they have a role in shaping the mothers' experiences.

### **Microsystem Elements**

Elements of the NICU microsystem include the people, process and structure that make up the NICU microsystem. These elements are not mutually exclusive and do overlap to enable the system to function as a whole. This section will describe the results beginning with the structure because this will provide a sense of what mothers initially encounter at the beginning of their NICU experience. The structure will be followed by the people element and then a description of the processes. The data that were related to microsystem elements were often observed or understood through the nonparticipant observations and the artifact collection. In this section, these data are presented with supporting quotes from the participants experiencing the microsystem.

### **Structure**

Understanding the setting and environment the study took place in offered insights into the social context, which exists within the unit. By exploring this context, it became clear that this unit truly functions as its own microsystem, with its own set of social norms and rules, outside of the broader hospital context. Exploring how the unit is situated within the hospital illustrates how this unit differs from the other units on the floor.

The NICU at the General Campus of The Ottawa Hospital is located on the 8<sup>th</sup> floor. This is the same floor for gynaecology and the mother baby unit. Although this makes sense from a systems perspective in an effort to keep similar units and resources close, this structure has an unintended impact on the mothers in the NICU. Having the NICU close to triage and the mother-baby unit means that mothers from the NICU often come face to face with healthy pregnancies and families leaving with their healthy infant. Two participants commented on this and expressed the emotional toll it took to be exposed to this on their trips in and out of the

NICU. One participant described how encountering other pregnant mothers around the hallways contributed to her feeling “set off” and quite emotional:

*“yah, it's right there, so I saw a lady, a pregnant lady waiting for the elevator”- Mother 6*

*“Coming down the hallway from the room to see her, you know, there are pregnant moms cause we're right there”- Mother 4*

The NICU is also around the corner from the main triage desk and is indicated by a large pink heart decoration with the title, “NICU”. There is a large window beside the door with the blinds closed. There is no way to see inside the unit and the only access into the unit is by admittance from a clerk. It is clear from this that this unit is not for the general public but for those with specific access passes or patients with exceptional circumstances.

Passing through the main door is the first step to admittance. The general entrance room is a small-enclosed room much like a waiting room. There are posters on the walls with rules and regulations for the unit. The posters communicate that all jewellery must be removed; cell phones switched off or onto silent mode and hands must be thoroughly washed or disinfected. There are benches and coat hangers available for individuals to leave their outdoor wear. While the majority of the communications in the waiting room are regarding hospital policy and patient safety, there are many materials available to offer support to families as well. There is a board with notices for parent support groups, breastfeeding information and one poster with a housing suggestion. Once the clerk admits you, you are able to enter the unit.

Once through the waiting room door and into the NICU, there is a long hallway and three large patient rooms dedicated to the infants. Within the hallway there is a large white board that indicates who is on staff for that day. From here you get a sense of the chain of command that exists within the unit. At the top is the neonatologist on staff for that day, the fellow and then nurses that are responsible for which infant there. There's also additional information regarding

the pharmacist, dietitian and resuscitation nurses for the NICU. This information is placed in a hierarchical template with the neonatologist at the top, nurses at the bottom. Figure 5 is a template of this board.

As indicated by the white board, infants are organized into three different rooms - A, B, and C, depending on acuity and space available. Generally, higher acuity infants are placed in room A because this room is closest to the labour and delivery unit and also is the largest. More critical infants generally require more space due to the equipment surrounding them. Room C has healthier babies and contains additional space for infants requiring observation. However, if a baby in room C deteriorates, it does not always mean they will move back into room A or B. Appendix 1 illustrates the map for beds within the unit. From communications with the parents, staff and neonatologists, this gradient from A to C is neither concrete nor communicated as a policy to families. It is something that parents seem to understand from experience in the unit.

*“Some said it had no, no link with the care, with the nothing, except the fact that A and B had a lot of babies with ventilators and C-PAP<sup>1</sup> and in room C normally we would find babies who don't have that much machines and we would have the staff that is not as experienced with the CPAPs and the ventilators because they're working their way up. Interviewer: Okay, you learned that in the visit? F: No, throughout the time here, in general, I don't remember who told me that. It might have been a nurse from the room A. so we kind of graduated so fast to the room C and to me the room C was like the room where you take charge, the C for charge, you know”- Mother 6*

This unspoken rule had significant meaning for some participants. For example, Mother 5, describes how moving from Room A to C was an indication that her infant was doing well and getting close to discharge.

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<sup>1</sup> C-PAP is a method to facilitate better breather, it is an acronym for continuous positive airway pressure

*“Cause you're going home or to Montfort [nearby hospital] where it's not level three care, it's level two care.”- Mother 5*

This demonstrates that the room the infant is assigned to can create a false sense of potential discharge or better infant health.

*“But to me, it seems like he moved so fast from room A to room C, I was like, okay, so we kind of graduated so fast to the room C and to me the room C was like the room where you take charge, the C for charge, you know, you take charge because you're going home soon.”- Mother 6*

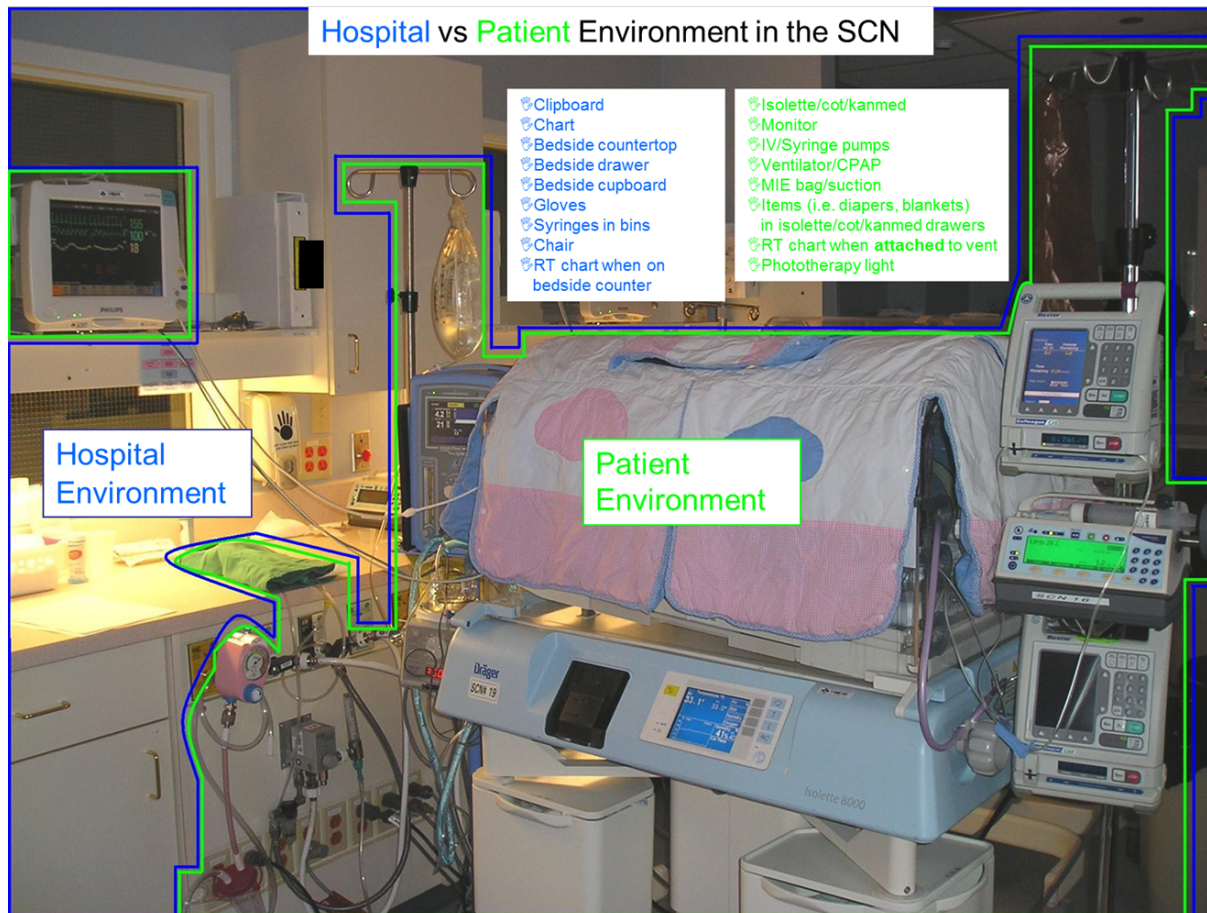
In addition to the three patient rooms, there are two family rooms available for resting or breastfeeding, one in room B and another in room C. Having these spaces available to families created an environment that was comfortable and did not feel like a typical hospital according to participants. One participant compared this space to the NICU at the Civic hospital to emphasize that a separate space is valuable.

*“It makes such a huge difference. I went to the Civic for an appointment and I brought my pumping stuff with me and I went to the NICU there and I asked if I could pump so I wouldn't rush to either go home or come here-we are pretty spoiled here. Cause at the Civic, I mean, it's an older hospital, but at the Civic they have one room and it's two chairs and curtains.”- Mother 4*

Another element that was meaningful to participants was a board that includes photos of previous patients, cards, and thank you notes for the NICU staff. This poster provides families with a reminder that their situation in the NICU is temporary and that even the sickest infants can improve their health and lead happy, healthy lives. One mother reinforced this by saying:

*“I love the board out in the hallway that shows how well the babies are doing now and I just love hearing stories about how there have been other kids they know of or whatever that were born premature and now are totally fine and, you know, where they're supposed to be” – Mother 6*

Lastly, through the observation process it was noticed that there was posters scattered throughout the unit and within the residents' room that indicate proper hand hygiene rules. The poster illustrates that there is a “hospital environment” and a “patient environment” and when entering the patient unit, hands must be appropriately clean. This can mean using hand sanitizer, proper hand washing techniques or using gloves. Through observation it was very apparent that nurses, staff and parents are aware of using these precautions prior to anything that may come into contact with the infant. Below is a copy of one of the posters within the unit.

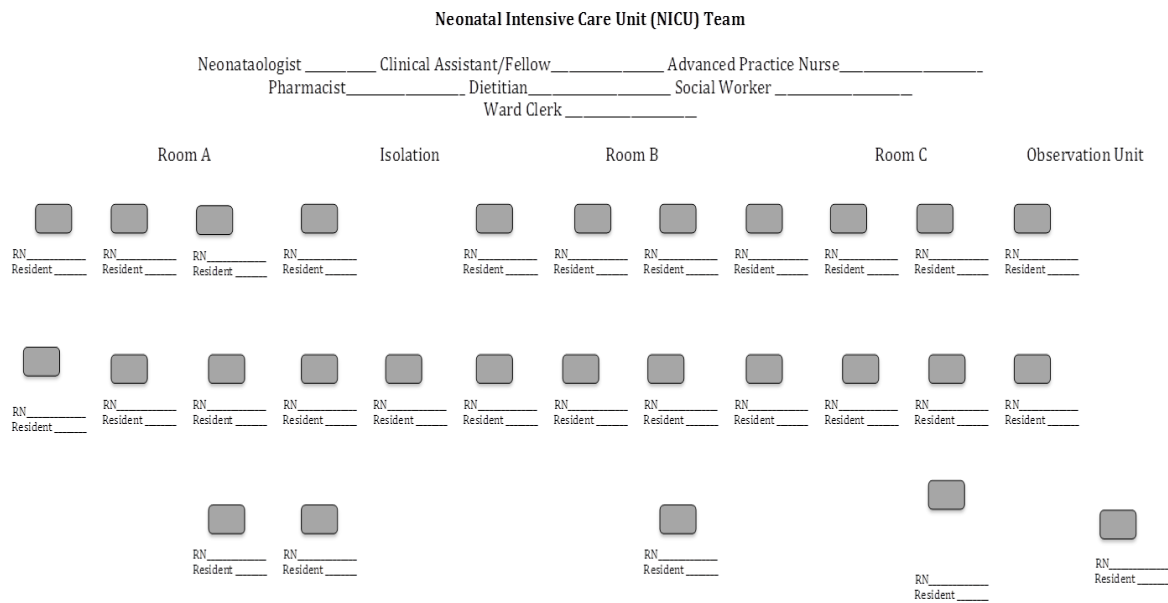


This poster also communicates another message that there is a space and equipment belonging to patients and the remainder is belonging to the hospital. Communicates such as this one reinforces the ruling relations that institutions can have.

## People

The social context that exists between the people on the unit was a significant influence on mothers' experience. Only a select group of staff have access cards that can gain them entrance into the NICU. These people include the neonatologists, clinical managers, residents and fellows, respiratory technicians, nurses, pharmacists, dietitians and NICU researchers. Along with the patients and families, all these individuals have relationships, which create the social culture that exists within the unit. These are generally the same individuals labeled on the board in the hallway that illustrates what staff member is assigned to which patient. It also provides a visual understanding of the hierarchy of staff in this unit. Figure 5-NICU Staff/Patient Board is an illustration of what this board looks like.

**Figure 5- NICU Staff/Patient Board**



This section will describe the social culture, which was observed and discussed through patient interviews in an effort to understand how this has impacted the experience for mothers in the NICU.

First, it was clear from initial observations in the NICU that there are many individuals involved in the care for these infants. Rotations and shift changes contribute to the overwhelming number of staff involved. New groups of residents are coming in, neonatologists and nursing staff are rotating, simultaneously as patients are being admitted, getting transferred or preparing for discharge. The amount of staff coming and going can make it difficult for mothers to tell who is in charge and to build relationships. This finding was observed by the amount of

introductions made throughout each day. Patients who had been there for several weeks or months appeared to know who to ask for or remember the names of particular nurses. Parents and families still adjusting to the NICU were consistently being re-introduced to staff and vice versa. Mothers commented on the amount of people involved and difficulty remembering names, even if the infant has been cared for by a particular staff in the past.

*“There's too many names, like faces I recognize, and I know (baby's name) has had them before. There've been very few where I remember their actual names.”*

*“We've had multiple nurses. I mean a few of them we've met more than once. Like the nurse he has right now, we've seen her before. But then there's been other nurses where they've been like once and we haven't seen them before”*

These comments reinforce that the number of staff involved can make it seem less intimate and somewhat detached.

Two participants discussed the impact of having the nurses rotate and the issues it can create. They both comment on not understanding why there is a rotation and the issues around these frequent shift changes.

*“I trusted most of them. I mean the thing is, I never understood why they keep rotating different ones in all the time when I see the other ones here. I'd dealt with them before. I know they work different shifts but when they're here why not keep them with the same baby? - Mother 3*

Alternatively, in labour and delivery, mothers' had one nurse with them through the experience to provide support, information and care for her. One participant reported this being very helpful regardless of the overwhelming amount of activity occurring during the delivery. In the NICU, there is not one designated nurse or provider but rather many nurses.

*“And she was constantly with me, telling us everything that was going on and stuff, but it was just still, just so much at one time.”- Mother 6*

Another participant commented on the reputation of the NICU staff as a whole comparing them to other units in the hospital. This participant discusses how other units in the hospital respond to learning about a mother with an infant in the NICU. This emphasizes the emotion that is associated with having an ill child.

*“Right, they, they, I guess as soon as you say NICU it's a little bit more, they feel more compassion, you know”. Mother 2*

Through the observations, I was able to develop an understanding of the social rules that govern the behaviour of the staff in the unit. Similar to other medical units, there is a hierarchy that exists among doctors, nurses and other staff. The way in which the unit is designed and the processes involved, emphasize the differences among the different groups of providers. Firstly, the most obvious and strongest social “rule” is associated with the residents. The NICU residents have their own office located off of Room A. There are unspoken rules associated with this room. For example, no one except residents, fellows or neonatologists enter that room. Nurses often knock and pass information or a request through a half opened door.

When asked about the relationships with residents in the interview, the participants described the experience as positive. The mothers describe their confidence in the residents and the appreciation for their communication and leadership efforts.

*“I told (physicians’ name) because I think she was under her, the resident. I was too occupied to keep apologizing and saying, no, no, no, after my water broke, but my husband was so impressed with how she took charge and pretty much told everyone, like their position and what they need to do, and, she took charge and she was phenomenal. Like we saw her, I think, we saw her a couple of times after, coming to the NICU and we*

*just literally we couldn't thank her enough, because she did a really great job, she was on the ball, she was amazing."*

*"Yah, she was very, giving everyone directions what to do. She was very, focused and she knew what she needed to be done, so, that was great."- Mother 5*

*"Oh, often, really great. I'd say that's even better, they're really good at explaining stuff and listening to you and I mean, you're not with them as much, but any experience we've had with them, it's been really great."-Mother 1*

Another mother commented on being told that she could make an appointment with the doctor for a one on one discussion to have all their questions and concerns resolved.

*"Totally fine, but you know they made sure that we knew that we can come and talk to her doctor any time and so we booked an appointment. And that helped, because, I mean we were told, in case they have an emergency they have to go somewhere, it might not work, so we'll have to reschedule. But nothing happened so we were able to sit down with the doctor and it was later than that, it was probably a week into it. But still we were able to be assured that, you know, that it was actually better to meet one on one"-Mother 5*

### ***Sharing early Mothering in the NICU system***

A specific component in the people element of the microsystem was the relationship mothers had with nurses. The results indicate that the actions and behaviours of nurses had a significant influence on mothers. This can include how the nurses include the mothers in the care, communicate with the mothers or treat the infants that they have been assigned to.

Most mothers spoke about the features that made for a positive experience with nurses. Several participants' mention having "favourite nurses" and why they are preferred. Some of the qualities that mothers reported appreciating included open, frequent communication, being asked to help with the care as well as the nurses who demonstrate that they enjoy their role and want to be caring for the infants in the unit. This last quality was observable in the unit as well. There were some nurses who would speak quietly to the infants, respond to monitors as soon as they went off and were quick to make the infant more comfortable.

*"The love that they give to these babies that, you know, they just take care of for whatever amount of time and a lot of them are not even moms. The nurses here and the team here, this is what they love to do." -Mother 4*

*"Nurse 1 is my, another of my favourite nurses, I guess, we get attached to some people more than others, they're all very good, but Julie has this extra touch or they're so nice with, everything they do, like the bed is always clean. There's always extra step, extra touch, extra everything. They're really gentle with the baby, so, when I saw he was having Julie was relieving because I could go home and not be stressed. Some nurses have other strengths but maybe they're not as soft or they're not as, the bed is not as neat and tidy. He doesn't seem as comfortable. You arrive and his face is not as clean, you know, like his lips are dry." Mother 2*

From the interviews, participants tended to describe wanting nurses to take more of a leadership role and bring parents up to speed in the infants' status right away. They wanted the nurses to take initiative to inform parents of what they need to know and help set them up for success.

*"Yah, I find some nurses are more talkative, you don't have to ask as much. They'll just, tell you. And then I find some nurses you have to talk a lot to get them to actually tell you about your baby, which is kind of frustrating." - Mother 3*

*“I like the nurses that are more, that tell you what's going on with your baby without you needing to know all the questions, cause sometimes you don't know the questions you have to ask, so it's got to be pro-active if you don't know what to ask about your baby, cause you don't know what's going on. So it's kind of frustrating that they expect you to ask questions, if you don't even know what's happening. So it's nice when you kind of just walk in and they kind of just like start a conversation with you.”- Mother 3*

Alternatively, there were some mothers who felt negative emotions such as guilt by letting the nurses provide all the care. It made them feel like less of a parent as mentioned by Mother 5:

*“I feel like a mom that's always on the go, that does everything else but take care of the child, because I let the nurses do it most of the time, you know.” –Mother 5*

Two mothers mentioned that speaking up and being more assertive felt like it could be a risk and result in less quality care for their infants. As a result they did not speak up and went along with the status quo regardless of their discomfort.

*“Because if you don't have a good experience with the nurses and stuff, um, I imagine it would have made it a lot worse.” Mother 4*

*“So yah, so I mean I found most of them great but some of them you could tell they were just having a bad day or wanted like full control or whatever, I don't know, but yah, it was, and I'm the type of person, I'm not, you know, I don't think they would treat them differently if I went in and made a big fuss about stuff but at the same time I don't want to risk it, right.”-Mother 1*

*“I try to take charge, you know, I didn't want to at first, cause it's intimidating. I don't want to have the medical staff, opposite to me, because if I go and I say, this is what I*

*want, this is how it's going to happen, blah, blah, blah, then I'm afraid that it would affect the care of the baby. “ –Mother 5*

This section encapsulates the interview data regarding what the mothers report as influential about the nurses and staff in the unit. They mention that what makes a nurse a “favourite” is one who shows the infants extra care by chatting with the babies, responding to alarms quickly and proactively answering questions for mothers. The results from this section emphasize the role nurses play and how much their actions can influence these mothers. Particularly when it comes to communication and working with mothers to care for the infant. The following section will explore the results that focus on the processes within the unit.

### **Process**

There are several processes specific to the NICU that illustrate having an influence on the mothers. Processes included the structured delivery of care or procedures in the unit. This section will describe the results that speak to these processes in the NICU microsystem. The description of processes will begin with the intake package as this makes sense chronologically. Results about clinical rounds and nurse turnover will then be described.

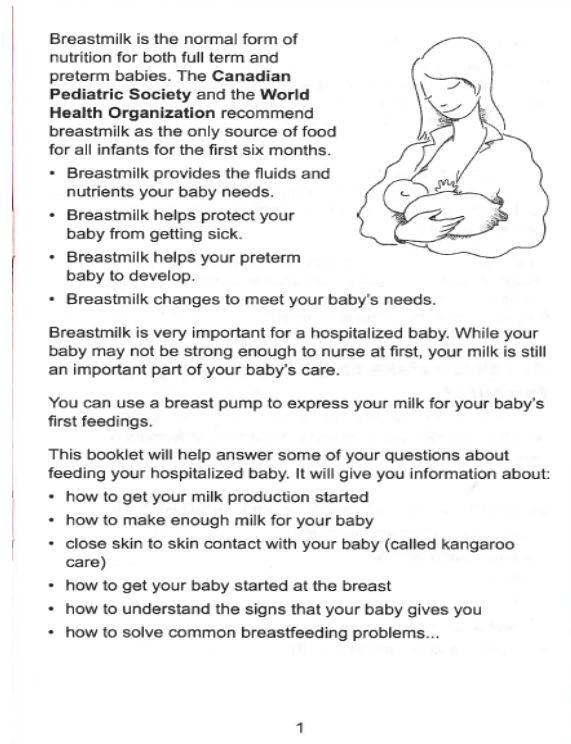
### ***Intake Package***

At intake parents are provided an information package meant to introduce them to the unit.

This package includes 6 different items including:

- 1) *Guide to Breastfeeding your preterm and/or hospitalized baby*
- 2) *Daily Pumping Recording sheet*
- 3) *A letter regarding purchase or rental of a double electric breast pump*
- 4) *Letter with instructions about breastfeeding for an infant in the NICU at The Ottawa Hospital*
- 5) *NICU Information for Parents booklet*
- 6) *A notice regarding making donations to the NICU*

Simply from the titles listed above it is clear that there is a large emphasis on breastfeeding in the NICU. A photo of the first page in the Guide for Breastfeeding your preterm and/or hospitalized baby is provided below:



The first sentence in this guidebook refers to breastfeeding as normal which can imply that not breastfeeding may be abnormal. Some of the participants included in this study were unable to breastfeed or struggled with it, which will be discussed toward the end of this section. The first page of the guide explains all the benefits to breastfeeding. While these statements are valid and important, they can also create a great sense of pressure for mothers who are already under a great deal of stress. One participant describes feeling upset when she did not have enough milk production:

*“Someone mentioned to me that I wasn't getting enough milk, well, I was so upset and that screwed things up for me and, I didn't really talk to other people about it until later on,”-Mother 5*

The letter from the World Health Organization describes breast milk as the “perfect food” and provides instructions on how to properly label pumped breast milk. The letter from The Ottawa Hospital also describes breast milk as being the “preferred feeding” for all infants and then provides information on how to rent a pump. Not only are mothers receiving messages that breastfeeding is the “perfect” and “preferred” source of nutrition in the textual information they receive but the nurses also reinforce this message. Mother 6 describes an attempt at avoiding nurses who might give her a hard time about returning the pump early and then commenting on the impacts of nurses’ comments regarding these issues.

*“I had a hard time, like even I returned the pump, the rental, three days ago and I had a very hard time. I was thinking that I'm going to run into those nurses and they're going to make me feel bad..., it gets into your head something that you can't really get out, but it is what it is. I wanted, it didn't work out. I have to move on. And yah, of course, I wish I could have breast fed her more, but again it would have been just my decision” -  
Mother 6*

Wanting to breastfeed but not being able to, was a commonality among mothers. It seemed as though they understood the benefits and wanted to provide breast milk but some of the challenges of having an infant in the NICU interfered with this. Such as this mother who references how the separation from the infant interfered with her ability to pump.

*“I chose to breast feed her, it was unfortunate that my milk production decreased, but, I couldn't keep up with her, like we even used like the frozen stuff. I would have liked to breast feed more, but just waking up at night, I mean, it's not like having her at home for sure, because you just wake up, pump and clean yourself and go back to bed”-Mother 5*

From the observations, breastfeeding was a challenge for mothers in the NICU. One observation of the breastfeeding process included three nurses assisting a mother to breastfeeding. The process was uncomfortable as an observer. The intimacy between mother

and infant is removed and made much more clinical. If breastfeeding is a success it is celebrated, if not it creates a feeling of disappointment and there is dialogue about “trying again” and “next time.”

The package provided at intake lacked informing families of what to expect and how to navigate the NICU system but rather, emphasized breastfeeding. This created challenges and distress for some mothers who were not able to breastfeed. The next section will explore how nursing schedules influence mothers in the NICU.

### ***Rounds***

There were conflicting messages given regarding parental presence during rounds. One parent mentioned being at rounds was an opportunity to learn what was happening with their infant and ask questions. Other parents were told not to be there during rounds to protect the privacy of the other families. One participant reported hearing information regarding the health of her infant during rounds, information she otherwise not have been privy to if she had not attended rounds:

*“I think they knew for like a few days but they probably ask me if I knew but I didn't know and then I heard that in the rounds and I was surprised. ” –Mother 3*

While rounds are scheduled from 10am – 12pm, there is no set time for each patient, which can make it difficult for parents to know when to be present. Rounds are scheduled loosely to allow for resident questions and feedback to be offered. It also allows flexibility for more time to be spent with each infant.

*“Um, no, the rounds, it's just too bad they're not at a set time”- Mother 1*

Rounds are an opportunity for staff to engage with the parents to share information and also update parents. If there was a consistent method for completing the daily rounds, parents can make travel arrangements and attend.

The first process observed was daily rounds by the residents, fellow and neonatologist. Daily rounds began at 10am and often ended around noon. There was no set format as to how rounds were carried out. The question was asked, "Where do we want to start" indicating no confirmed organization was followed for rounds. Three different neonatologists leading rounds were observed throughout the data collection. Each had their own style of teaching and asking questions to the residents but most followed the same format:

The neonatologist would stand with a binder on medical tray to take notes; residents would be standing and make a circle around the infant. Nurses often sat in the feeding chairs around the circle. The nurse assigned to the infant being discussed would often stand to provide the summary and details of the infants' health current status and behaviour. Also present was the nurse manager, pharmacist and sometimes the dietitian. If parents were present, they would be on the peripheral of the circle, or sometimes be included into the circle to stand among the residents. In one observation, the neonatologist asked if the parents had questions and when the response was no, they moved on. This could be a point of concern, as some parents do not know what to ask:

*"Getting more information and not having to ask so many questions, cause that's hard. So even with my care too, there were certain questions that I didn't know like what to ask. Cause I just don't know so it would have been nice, especially if I was in this alone, I would have just been bedridden, without anybody and then I wouldn't have had any information at all, and I would have been frustrated." Mother 4*

Additionally, on one occasion, the dietitian remained behind as rounds continued to translate what had been discussed in non-medical terms. The parents did not understand what the next treatment would be so needed some additional time spent with them to feel confident they understood.

### ***Nurse Rotations***

As mentioned previously in the section on 'People', nursing rotation processes can create an issue for mothers as well. This is related to an interruption in decision-making power and how this influences mothers' experiences. Specifically, for one participant this meant waiting on information regarding discharge for her infant:

*"I mean it would be nice if their weekend team was able to make harder decisions, cause they did say he was going to be discharged on Saturday and then it was a weekend team and they didn't want to make a decision, so now we had to make until Monday because their main team is in now. That was kind of frustrating too. It seems like, oh, it's just the weekend team. They don't make decisions, and I'm like, oh, that's great!!- Mother 3*

This section discusses how the NICU processes such as daily rounds, intake materials and nurse rotations can influence the experience for mothers. These results demonstrate the overlap and linkage among the other system elements. The three themes that emerged illustrate how intake, rounds and nurse rotations can reinforce some of the issues mothers discussed about adjusting to being a mother in the NICU.

### **Power**

Cutting across the micro system elements of structure, people and processes is the presence of power the microsystem has. Previous results have made subtle hints to the struggle mothers feel in terms of feeling like the parent in the unit. Sharing the care between nurses and mothers can blur the boundaries of parenting and can be a point of contention for parents in that they feel nurses take too much control over the infant. Interestingly, this blurred parenting scenario was observable. One of the most significant observations made during my time in the NICU was that it is not easy to identify who is the mother during feedings. This is because when feeding the infants via bottles, nurses wear the gown, use a rocking chair and watch the infant. Mothers also wear the gowns, use a rocking chair and watch the infant. This demonstrates that the

nurses and mothers often perform the same tasks, but it depends on if the mother is present for all of the feedings.

Mothers' greatest issues with nurses were about control. Generally, this reflects a struggle between mothers and nurses about decision-making and care for the infant. Mothers wanted to have freedom to touch, hold and care for their infant at their discretion, however, due to policies and perhaps nurse personalities, this is not always possible.

*"One of the nurses the other day, actually, we didn't like her at all. Cause she wouldn't let us like touch the baby, and she was really, really to the book and strict on schedule, cause we were standing there and we saw that his diaper needed to be changed and she's like, not due for another hour and she didn't let us change him. So that was really frustrating and disturbing, to not let us change our son."-Mother 3*

*"I got to hold him for two hours, once three hours and I felt like it was just random and it was just the nurse that day and how she felt, kind of as to how long I could hold him." – Mother 1*

*"No, she was the type of nurse that's like, it's my baby, you can't touch him. You know, like she was treating him like it was hers and she didn't let me know that I was allowed to touch him. She didn't let me know that I can eventually do his care. You know, she didn't let me know nothing".-Mother 6*

*"Most of them I found really great, some of them not. But it was more personality differences. Some of them you could tell were on a power trip and wanted full control of everything that was happening, which was extremely annoying."*

*-Mother 1*

This power struggle often resulted in mother feelings powerless. If they had received information or an explanation for decisions they may have felt differently. This withholding or lack of communication resulted in feeling helpless. Additionally, the separation discussed previously can add to this feeling of powerlessness:

*“There [were] a lot of things that I wish I would have known that I didn't find out until afterwards. It's probably different, cause you know that, those forty-eight hours that he was on the respirator and he was so uncomfortable wanting to pull out the wires and he was crying and we were both crying. We were both crying watching him in the isolette and we both knew we couldn't do anything”- Mother 5*

Other mothers discuss understanding the reasons behind the policies and appreciate that they are in place to protect the infant. They also discuss how perspectives can shift when they are allowed to begin routine care such as bathing and changing but only to the extent that it does not interfere with the nurses' work.

*“They need their sleep and stuff but you just don't feel like you're in control of anything.”- Mother 4*

*“Oh, it's totally different. I mean you feel more like a parent now versus just an observer because before it was like no, you can't touch the baby and now we're going to do this. And you know you could only do what you were permitted to do, because of what they needed to do, which I understand. – Mother 2*

Lastly, mothers discuss feelings about the hospital having ownership over her infant rather than herself. This caused her to feel frustrated and not like the parent.

*“But, I mean, I’ll be really pissed if it’s not, cause we’re just getting to that point because even when I was still in the hospital before I was discharged, they’d be like, oh, he’s getting better.”- Mother 4*

*“His temperature was fine. Everything was fine, so it’s kind of like, we can do it. Just let us have him!”-Mother 3*

Power proved to be a critical theme that emerged from the literature. It reinforces why mothers struggle with feeling like a parent and conflicted with decisions made in the NICU.

### **Mediating Factors**

Factors which mediating power and some of the other microsystem elements included communication and inclusion. These two factors affected how the separation from the baby as well as the relationship with the nurses was experienced. The experiences seemed to change depending on the use of communication and inclusion. This section will explore the results related to these mediating factors.

### **Communication**

Communication included a range of issues in the exchange of information: if the information was provided at the right time and communicated clearly. This was an issue that was identified by participants as influencing their experience. Lack of communication was the greatest issue and resulted in mothers feeling like they had to advocate for themselves. Communication also influenced the relationship with mothers reported having with the nurses. Mothers indicated that the more informative the nurses were, the more positive the experience.

*“Getting more information and not having to ask so many questions, cause that’s hard. Even with my care too, there were certain questions that I didn’t know what to ask. Cause I just don’t know it would have been nice, especially if I was in this alone, I would have just been bedridden, without anybody and then I wouldn’t have had any information at all, and I would have been frustrated. I mean I guess I could have called,*

*but that's, I guess strange in a way if I'm just down the hall. I'd prefer somebody come in and actually take the time to show that they care about telling you what's on about my baby and I didn't really get that.”- Mother 2*

*“I, I don't know. I mean, the waiting was tough, obviously. Especially cause (baby) wasn't moving, right, so I didn't know what was going on, so waiting was the worst part, I would say, cause I didn't know what was happening.- Mother 5*

*“Yah, I find some nurses are more like talkative, you don't have to ask as much. They'll just, they'll tell you. And then I find some nurses you have to kind of talk a lot to get them to actually tell you about your baby, which is kind of frustrating.” - Mother 3*

Two participants comment that while they were being taken care of as a patient, they were not receiving information about their infant. This influenced them because their main concern was for their infant.

*“That's something that did frustrate me. They weren't giving me updates; all the nurses that were coming in were for me. They made sure I was okay and stuff, but I wanted to hear about my baby. The only updates I was getting was my partner coming here and then talking to him and then him telling me what they said. Just frustrating.” - Mother 3*

*“It's, I mean, I kind of think about it, but then I also don't really know what's going on, so it's, in a way, it's kind of like hard to feel something, because you don't know what's happening with the baby, you don't know how bad they are.” -Mother 2*

Another participant commented on the need for nurses to tailor information to people differently. She described how they could be very helpful for those not familiar with medical terminology but that sometimes their mood could interfere with their communication efforts.

*“It's just a little bit more medical, I find the nurses know a bit better how to explain things, to non-medical people. But they would always answer our questions. You know there [were] a few days where you got nurses who were pretty grumpy and didn't want to answer the questions but the majority of the time they were really good.”- Mother 1*

Lastly, two mothers described areas of communication that could be improved upon. The first is the feeling of frustration of not being heard some of which was attributed to the nurses not listening to her. Further, another participant mentions the inconsistencies when it comes to providing explanations about rules.

*“I mean there was a whole frustrating part of this whole experience that makes me not really happy. I mean overall it was positive but then there is that part that, there's a lot of things that you guys can improve on. Like just listening more.” -Mother 3*

*“That's what I started to ask myself. Why can I only take him once a day? And, from different nurses that explained to me, well it's different points of views of different nurses. It's also the fact that they're used to having smaller babies than thirty weekers who can cope really well with the, with the taking out of the isolette, bringing them in, back. You know, he was sleeping so well we could just transfer him back and he would sleep some more.” -Mother 5*

Specific information that was lacking in the communication of the NICU with mothers was regarding processes such as housing and other governmental programs. As mentioned, the information packages at intake included information about breastfeeding and some general info about what to expect in the NICU. There is very little information about where to seek housing resources, financial support or any other issues families may face when requiring treatment in the NICU. Below is an image from the Resource page (pg 27) in the NICU Information for Parents Booklet:

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### **CPR and Follow-Up Appointments**

Although it is unlikely you will ever need to use CPR (cardiopulmonary resuscitation) on your baby, we recommend that all parents attend a CPR course. The nursing staff can give you information about the course. There is a small fee. We suggest you book your course as soon as your baby is admitted to NICU/SCN as there are waiting lists.

Follow-up appointments may be needed on an outpatient basis to continue to monitor baby's progress. If a follow-up appointment is required for your baby, you will be given an appointment card with date, time and location.

### **Follow-up Clinic at CHEO**

For certain families, when your baby is discharged, the medical team would like to follow your baby's growth and development through the Neonatal Follow-Up Program. They will ask to see you and your baby at 4, 10, 18 months and 4 years of age.

We will make your first appointment for you before your baby goes home. Ask your nurse for more information about the follow-up program.

### **Services and Resources in the Community**

- **Parking Passes** are available on a weekly or monthly basis from the parking garages.
- **Electric breast pumps** are available to rent in the hospital and other locations citywide. Speak to your baby's nurse for further information.
- **The cafeteria** is located on the main floor of each campus.
- **Bank machines** are located on the main level of each campus.
- **Overnight accommodation** is available close to each campus at reasonable rates. Your baby's nurse or the social worker can give you more information.
- **Public Health Information Line (Ontario)** ..... 613-580-6744
  - Post Partum Concerns
  - Breastfeeding
  - Mother Risk
  - Healthy Baby, Healthy Children
  - Telehealth
- **Tele Health Ontario** ..... 1-800-797-0000
- **Multiple Births Canada** ..... 1-866-228-8824 (toll free)
- **Multiple Births Families Association (Ottawa)** ..... 613-860-6565
- **C.L.S.C. of your area (Québec)**
- **Canadian Premature Babies Foundation** ..... <http://cpbf-fbpc.org>

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The next sections will describe how the lack of communication about resources influenced mothers. Housing and financial services were two of the resources mothers could have benefitted from learning more about early in their NICU stay.

## **Housing**

Three of the participants in the study were not from the Ottawa area. This created housing issues for these participants living farther from the hospital. Mothers discussed having to find their own accommodations and also the challenges of their spouse or families being able to visit. Mothers also discuss the challenges returning home:

*“What I do, when I go back I stay there for like three, four days or, two, three days and then I come back and I stay here for a while and alternate like that”-Mother 2*

*“I'm staying with friends here in Ottawa, so I've been only been back to [hometown] twice, once to close the deal on a house and the second time it was just unpacking stuff in the house.”- Mother 1*

Referring back to the photo of the Guidebook above, communicates that there is very little information about housing provided; all participants found housing on their own through their own social network. There was no mention about having a discussion with nurses or staff about housing resources. This issue of a lack of communication regarding resources is continued in the next section.

### **Financial resources**

The resources page in the information booklet also neglects mentioning resources for mothers who are qualified for maternity leave or can receive employment insurance. The Government of Canada offers programs in which parents of critically ill children can receive subsidy to care for their child or delay their maternity leave to commence on the day the infant is discharged rather than on his birthday (Service Canada, 2014).

One participant discusses the discovery of this program by a close friend and not anyone in the unit. Mother 5 discusses following up on the details of this program with a staff member in the unit.

*“There's a new thing for critically ill children, you can go get the forms from Government Canada that way you don't touch your parental leave, because the baby's in the hospital and this and that. My friend, told me about this. When I asked (a member of the NICU staff), she told me, 'look at him, he's so cute, he's not critically ill'. And at that point, I guess I didn't realize that, hey he can't be out of the hospital right now.”- Mother 5*

One NICU staff member deflected the request and the mother accepted it until she realized that her infant could not leave the hospital. In the end, she followed up with the neonatologist who signed the forms for her to apply for the program.

*"I said, I don't know the criteria for this program, but if I would have listened to her, and not applied I would not have got the papers signed for December 31<sup>st</sup>. So that means we're not touching our parental leave until December 31<sup>st</sup>. That's awesome."-Mother 5*

In addition to these programs not being communicated verbally or via text to mothers, other staff are not aware of these programs that could greatly benefit mothers. Mother 4 discusses inquiring about a serious question that the application for the program requires with a resident who was not familiar with a program but sought out the individual who signed it. This situation raises an important issue about communication. Firstly, that staff coming into the unit are not all aware of the resources parents might need and/or that they are not being communicated consistently at intake. Secondly, that when the application is completed by a member of the care team there is no communication about the process or requirements.

*Exactly. And then the resident, who is French, she looked at it and then I told her, there's one question, that they're asking, if the baby is going to die soon, things like that. She's like, I'm not too sure about this, I'm a resident so I'm going to go ask the staff doctor or whoever signed it, you know. I'm not even sure who signed it cause I don't recognize the name."- Mother 6*

This section on communication identifies the need for consistent, constant communication from the staff to the mothers but also among the staff. The results indicate an opportunity for communication efforts to be improved in the NICU. The next section will discuss the mediating effects of including mothers in the infants' care.

### **Inclusion in the infants' care**

Inclusion for this study is centred on the mothers' feeling that she is a part of the care team for her infant. It encapsulates mothers feeling like they are a part of the discussions, decisions and care delivery regarding their baby. Being included mediates the experiences that mothers lack control over their infant or are struggling to feel like the primary care giver discussed earlier. Inclusion was a significant theme within the interview data but is also related to the

microsystem's structure, people and processes. The people, being the staff, have a role to play in including mothers in the care and the structure and processes need be designed to support this inclusion.

The nursing relationship as discussed above was heavily influenced by how the nurse included the mother in the care and helped her feel like a parent.

*“And the night nurse here, well one of the night nurses here, she was really, really friendly and she let us, parent”- Mother 3*

*“It was amazing knowing that actually I can care for my own child and not just the nurses here. Like at ten she showed me the first, the diapering and all that, so then at noon I got to do it.” Mother 6*

There was also mention of being included in processes within the NICU such as rounds. One participant described the positive experience of being included in the rounds and referred to as the parent. Her comment demonstrates that being included in the care team and having a say made her feel trusted and like she was being listened to.

*“ I like how the nurses refer to you as mom and dad and how they'll take into consideration some of the things we say, like in rounds this morning when she said, oh dad said he's not usually fussy and he's been really fussy lately, it's nice that they listen to us”- Mother 1*

Lastly, one participant expanded on how she appreciated a nurse encouraging her to provide the care, in this case a bath. This mother was nervous about handling her infant and wanted to observe the nurse again but the nurse reassured her she would be fine.

*“But then two days after, when she was due for another bath, I said do you mind, this is my only second time, do you mind if I just watch you, and she’s like, I’m going to be right here, she said, you know, I have, I’m very confident in you. I’m right here. It’s better if you do it hands on, cause that way you learn and it’s a great point”- Mother 3*

However, some mothers have a contradictory experience and experience guilt by not being included or feeling intimidated to take control.

*“I think that’s when I’ll realize it, because right now, if I’m a mom, I’m feeling like a really bad mom that’s getting the baby to be babysat most of the time.”- Mother 5*

This section describes how communication and inclusion were mediating factors that influenced the mothers’ overall experiences. Increased frequency and consistency of information and more efforts to include mothers in the care would have empowered mothers to make them feel more like a parent and less like an observer or controlled by the institution. The results section describes how the microsystem elements of the people, processes and structure also work in tandem to create an environment where mothers are considered separate and secondary to the infant. This was reinforced by the distress they experienced through the separation between themselves and their baby.

## **Chapter 6: Discussion**

The results of my research indicate that mothers are significantly influenced by the separation from their infant and the challenge of adjusting to mothering in the clinical environment of the NICU. The structure, processes and people of this microsystem can emphasize or exacerbate these two issues in different ways. What the results suggest is that feelings of powerlessness or control over their infant can be highly distressing. Increased, consistent communication and inclusion in the infants' care were factors identified as being mediators to this feeling of powerlessness.

While my results found that the mothers' experiences were similar to those described in other studies, the approach to this discovery was different. Other literature in this field focused more closely on maternal emotion or the relationships within this unit; not an emphasis on the contributions of the health system. Referring back to the literature synthesis in Table 2, there are various studies that allude to the process, people and even power, but not so much about the structure. In this chapter I will discuss the similarities and differences in the literature and provide a description of how knowledge gaps were filled and new insights were discovered.

First, this research blended a systems approach with an institutional ethnographic methodology. What this research scheme achieved was a study that put the mother in the very centre of the phenomenon being explored. The system elements each provided another layer that influenced the experience. It helps to tease apart what is the 'institutional' in institutional ethnography. Separation from the infant and learning to mother in the NICU are the experiential descriptions that the mothers reported and the system elements are woven through each of them. They are not linear, but overlapping and influencing these issues all the time.

### ***Separation***

The first most salient result explores how the separation from the infant affects mothers. From the triangulation of the data sources, this separation is emphasized through each system

element. This augments the literature about maternal wellness in the NICU, which is more focused specifically on the struggle of obtaining a maternal identity and developing attachment (Doering et al, 1999; Swartz, 2005). I suggest that separation could be a source of this difficulty adopting the maternal identity. If mothers feel separation from their infant, how can they be expected to develop a maternal identity? The literature also expands on the psychological and emotional consequences that occur when caring for an infant in the NICU (Lau & Morse, 2003). This thesis did not identify these psychological outcomes specifically but reflecting on interviews and the mothers' descriptions of lack of sleep I question if this could be a factor in this increased anxiety that other literature describes.

### ***Mothering in the NICU***

Adapting to motherhood and learning to parent in the NICU was a challenge for mothers in my thesis research. Pre-existing literature heavily focuses on the relationship between mothers and nurses (Reis et al, 2009). One of the most salient messages in the literature is about who has control over or who is in charge of care of the infant (Morey & Gregory, 2012; Hurst, 2001). This confusion regarding who is responsible for the infant while they are in the NICU was observable in my study. I often was unable to distinguish if it was a mother or a nurse, feeding the infant because they wear the same robes, sit in the same rocking chairs and can look very similar in their behaviour. Learning to parent was more commonly described in the literature in regards to power over the infant, communication and inclusion in the care. These two issues of separation and learning to mother are consistent with other studies in this field. The unique contribution of this study is the role of the system elements in how these are experienced.

### ***Structure***

As mentioned earlier, the literature discussed the role of the people, processes, structure and power as being influential in the mothers' experience. There was less literature, however, looking at the structural element of the NICU other than studies noting the physical/structural separation of the NICU within the hospital environment (Sim ,2000; Cohen, 2003). My research

suggests that the structure may actually have a more significant role than previously researched. The results suggest that the separation previously described by mothers may be exasperated by the structure of the NICU. Firstly, the NICU is an isolated unit, different from any other unit on the floor even requiring unique access procedures (bleeding into process elements). Already this suggests that this unit is not like the others, and is for different cases. Additionally, the structure also reinforces that mothers are going home without their infant by its location on the same floor as the labour and delivery unit. This means mothers in the NICU have to constantly encounter other mothers leaving with their new babies each time they visit their infant in the NICU.

Once in the unit, mothers are once again reminded of this separation from their infant by the posters indicating the hospital environment versus patient environment. While this is for clinical reasons, there are unintended consequences of this on mothers' experiences. This also prompted me to think about who the patient was in this poster. The patient is understood as being the infant, another reminder to the mother that she is independent and separate from this infant. This separation and isolation of infants is what appears to be at the core of what the mothers were describing. Even the discourse in the unit can promote this sense of isolation and separation from the infant. For example, we use the word "isolette" to describe the bed the infant is treated in. These structural factors have an influence on mothers that have not been as deeply explored in the literature.

The issues of structure described above can also be applied to the theme of adapting to motherhood in the NICU. If the structure emphasizes a separation mothers may feel increased discomfort parenting in the unit as they might have if the infant went home. The location and limited access to the unit also might suggest that mothers' situations are similar enough to be in close proximity to delivery and well-baby units, they are dissimilar enough to have their own unit and procedures for access. This speaks to the interaction between the microsystem and mesosystem. The structure of the unit and its location within the hospital is more significant than the current research suggests.

## *Processes*

Processes also played a significant role in the mothers' experience, although this was more subtle. The processes described in the literature were different from the processes included in my research (Heerman & Wilhelm, 2005). In this research I examined more closely the organizational processes, such as intake, clinical rounds and nurse rotations. What was found was that the intake package and processes were heavily focused on the benefits of breastfeeding and provided instructions on pumping and feeding in the NICU. Mothers reported feeling guilty and distress when they could not adhere to the breastfeeding guidelines communicated through text and verbally by the nurses. These two processes were unique to the processes included in the literature. Mothers also felt clinical rounds provided an opportunity to become informed about their infants and appreciated when they were included in the conversations about their baby. This finding relates to the research from Heerman & Wilhelm (2005) in that it is about how the process is used consistently that provides the benefits. When rounds are consistent and reliable, they can be very helpful for mothers.

The impact of nurse rotations, although, not discussed a great deal in the literature was aligned with other messages from NICU studies (Hurst, 2001; Argaard & Hall, 2008). Argaard & Hall (2008) explored issues regarding how nurses provide access to information and education to mothers in the NICU. These studies acknowledge the nurses as being gatekeepers to the information and resources. This research found that having different nurses care for the infant resulted in inconsistent communication and mothers who felt nurses withheld information. It may be that policy emanating from the mesosystem and possibly the macrosystem may influence the scheduling of nurses which in turn may affect the microsystem experience of mothers.

Additionally, in this research mothers described wanting information to be provided without having to ask for it. They mentioned wanting nurses to be more proactive in updating and discussing their infants' health. There was no mention of mothers requiring more education or

coaching although, they did express that the situation was overwhelming due to their unfamiliarity with infant prematurity or hospital systems in general.

The lack of familiarity among the mothers with prematurity and the hospital delivery experience is an issue that could be addressed with a primary health care provider during pregnancy. Health care providers can discuss with expectant mothers what to expect during delivery which can include issues around prematurity. Any information or education that could be offered prior to the delivery that could help familiarize mothers with premature childbirth might enable mothers to feel more prepared for this situation.

### ***People***

The results describing how the people in the unit influenced the experience mostly focused on the role of the nurses. One of the main issues identified in the literature is mothers' concerns about being perceived as "difficult" by the nursing team (Swarz, 2005; Heerman et al, 2005; Hurst 2001). The participants in this study described also feeling that it would be a risk to how they are perceived if they asserted themselves. One mother in this research also expressed concern that her infants' care would be negatively impacted if the nurses did not like her.

A more explicit analysis of the role of gender could embellish this discussion about people in the NICU. As mentioned in the review of the literature, there is a lack of research on how gender can influence how mothers experience the unit. Referring back to my example of struggling to identify if it is the mother or the nurse feeding the infant leverages a notion of blurred gender roles of mothers and nurses. The caring work accomplished by nurses in the unit make it difficult to know which one is mothering the infant. This prompts question the formal or informal nature of caring and mothering and how this influences the power struggle between two women, one a mother and one a nurse.

## ***Power***

The issue of power appears to be the most salient theme cutting through all the results. While the nurses appear to have the most power in the day-to-day operations of the NICU, similar to what has been found in other studies (e.g., Khokher, Bourgeault, Sainsalieu, 2009), it goes beyond that to power exerted from the meso and macrosystem. For example, when the nurses are “by the book” or “by the rules,” it is not known what the actual source is for those rules. Who makes them and how are they enforced are questions that could be asked.

The theme of power was similar to the literature in regards to the description of feeling like a mother in the unit described. This goes back to the idea of struggling with maternal identity discussed in the maternal wellness literature by Swartz (2005) and Hurst (2001). What was unique in what I found was that power was not just seen explicitly through conflict or NICU rules but rather implicit feelings of power and authority exerted by the institution. It seemed as though there are unwritten rules and policies that reinforce this feeling the mothers have of not fully being a mother. It was like they did not get to be a mother until their infant was well enough to be discharged. As opposed to the norm, of mothers who leave with their infants following delivery; mothers in the NICU “get” to be mothers when the hospital deems them being allowed to mother.

Power in this research is related to the institutional power or ruling relation that is central to institutional ethnography. The ruling relation in the NICU could come from broader departments of Neonatology, the overall hospital level, or the provincial health system. But it is a set of rules or social norms that are followed and ultimately have an influence on the people who live within them. The mediating factors, communication and inclusion, influence how mothers could feel powerless or empowered.

## ***Mediating Factors***

Communication was discussed a great deal in the literature and pointed to similar outcomes (Argaard & Hall, 2008). If there is increased, consistent communication between health

professionals and parents, the more informed and empowered they reported feeling. This research takes this idea a step further by considering communications within the system. From the results, there are opportunities for communications between staff to be improved as well as in the textual communications between staff and mothers. For example, ensuring staff are aware of available resources for families as well as having an agreed upon understanding of how to include mothers and others' in the infants' care. Inclusion was also discussed in the literature in regards to the nurses' roles in promoting a shared sense of responsibility for the care of the infant. This can go beyond the nurses into daily processes as well. Parents can be involved in rounds as well as decision-making regarding their infants.

### ***Consistency of Care***

After reflection on the results from this study, what emerged to be another important message is regarding consistency of care. Mothers describe a need for consistency regarding communications and inclusion. In each of the system elements there were issues regarding consistency of communications and inclusion. Permission to touch their infant was different depending on the nurse, communications regarding the health of their infant, and even scheduling of rounds were inconsistent. These unknowns and ever-changing "rules" seemed to have an affect on mothers. But there was not only changing rules, there were changing staff which exacerbated the lack of consistency. These issues of consistency of care are notable and similar to the continuity of care issue widely discussed in midwifery literature. The continuity of care approach (and argument) encourages more one-on-one care or a small team for the care of women while they are pregnant. As the argument goes, small midwifery teams offer mothers opportunities to develop stronger relationships with their care providers and feel more at ease. (Farquhar, Camilleri-Ferrante & Todd, 2000). If there is evidence of the efficacy of this approach for care of pregnant and birthing women, surely this would translate into the care of neonates (and their mothers) in the NICU.

In sum, the results of my study demonstrate that mothers' experiences are closely tied to their ability to develop the maternal identity. This can be impeded by their feelings of separation and

not being able to mother. Table 6 provides an overview of the literature review and how the results from my thesis research suggest alternative perspectives to considering the issues and addressing knowledge gaps.

**Table 6- Synthesis of Literature and Results**

<b>What we know from the literature</b>	<b>Critical knowledge gaps</b>	<b>Results from this study</b>
<ul style="list-style-type: none"> <li>- <i>There are inconsistencies in communication flow as care delivery.</i></li> </ul>	<ul style="list-style-type: none"> <li>- <i>Why there are inconsistencies</i> <ul style="list-style-type: none"> <li>o <i>Is it a process issue or are health providers not offering the accurate information?</i></li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>- <i>This research identifies communication gaps among people as well as in textual discourse in the NICU, for example, in the intake package</i></li> </ul>
<ul style="list-style-type: none"> <li>- <i>Positive relationships with providers have the most significant impact on NICU parental NICU satisfaction</i></li> </ul>	<ul style="list-style-type: none"> <li>- <i>What is needed for “positive relationships” with providers?</i></li> </ul>	<ul style="list-style-type: none"> <li>- <i>This research proposes that positive relationships with nurses were based on consistent, proactive communication and inclusion in care delivery and decision-making.</i></li> </ul>
<ul style="list-style-type: none"> <li>- <i>Mothers feel a loss of authority in the NICU</i></li> </ul>	<ul style="list-style-type: none"> <li>- <i>What is needed for mothers to feel empowered?</i></li> <li>- <i>How can processes or patient-provider relationships be improved to facilitate power balance?</i></li> </ul>	<ul style="list-style-type: none"> <li>- <i>To feel empowered mothers needed to feel included in the care for their infants. They reported wanting to be included in discussions and be notified of changes or opportunities for involvement in advance.</i></li> <li>-</li> </ul>
<ul style="list-style-type: none"> <li>- <i>Mothers experience increases in stress, depression and anxiety when they have an infant in the NICU</i></li> </ul>	<ul style="list-style-type: none"> <li>- <i>What roles do the elements of the system play in exacerbating or improve these symptoms?</i> <ul style="list-style-type: none"> <li>o <i>Processes</i></li> <li>o <i>People</i></li> <li>o <i>Structure</i></li> </ul> </li> <li>- <i>How can the microsystem be improved to meet the needs of mothers in the NICU</i></li> </ul>	<ul style="list-style-type: none"> <li>- <i>Separation from the infant was identified in the data as a significant source of maternal distress</i></li> <li>- <i>Providing more access to resources through verbal and non-verbal communications can help to mediate these feelings.</i></li> </ul>
<ul style="list-style-type: none"> <li>- <i>Mothers experience greater stress than fathers-specifically due to the perceived feelings of threat of the NICU</i></li> </ul>	<ul style="list-style-type: none"> <li>- <i>How can the NICU be less threatening?</i></li> </ul>	<ul style="list-style-type: none"> <li>- <i>Early communications and inclusion in care could help mothers feel more comfortable.</i></li> </ul>
<ul style="list-style-type: none"> <li>- <i>Mothers are significantly impacted by a power struggle with nurses in regards to caring for their infant in the NICU</i></li> </ul>	<ul style="list-style-type: none"> <li>- <i>There is a major lack of research on the influence of gender in this research.</i></li> </ul>	<ul style="list-style-type: none"> <li>- <i>There are blurred boundaries among who is responsible for the care of the infant between mothers and nurses.</i></li> </ul>

## **Contribution to the Field**

This research contributes to health systems research in the field of maternal and child health. It has suggested the need for system-level interventions to be considered to improve the experiences for mothers in this unit. It sheds a light on how staff, policies and the culture of unit can influence the patients being treated. Specifically, it demonstrates that communication and inclusion are factors that can have significant effects on mothers. The implications for this research could provide hospitals with evidence that mothers want to be consistently informed and included in the dialogue about their infants. This inclusion could lead to increased empowerment and positive experiences for mothers.

## ***Recommendations***

One of the key benefits of a microsystem analysis is the ease with which recommendations for ameliorating actions emerge. Some of the most notable recommendations that can be implemented at a systems-level, which could improve this experience for mothers, can be adopting a team approach led by one person. The first 'people' focused recommendation would be to designate one point of contact such as a case manager or social worker for the mother. This would provide mothers with a constant, consistent source for information, resources and also be an advocate for the mother's needs. From the participant interviews communication, consistency and support were mentioned as their needs and might improve the experience.

A second people-focused recommendation would be to assign the same team of nurses to a family could provide another sense of consistency and some continuity of care for mothers. The accounts of the mothers here spoke volumes about having multiple nurses to one infant provoked feelings of frustration for mothers. Assigning the same nurses to the infants can also promote a sense of intimacy and trust between the mothers and nurses, which could positively influence their relationship. Having one point of contact and then a consistent care team could provide mothers with feelings of familiarity, support and inclusion.

A process oriented recommendation would be to offer mothers an opportunity to capture the experience in the NICU might help to make the experience feel more personal and connected to their infant. There are blank pages provided in the NICU Information packet but having a separate journal can make the experience more intimate. Having a journal at the bedside can also encourage nurses to complete this for parents to inform them of changes in their infant. This might also facilitate communication between the nurses and the parents.

In regards to structure, recommendations should target reducing physical separation. As previously mentioned adopting a structure that offers individual rooms or increased privacy than an open-bay concept could provide mothers with more privacy. These individual rooms can often be personalized as well, which could help mothers create a sense of comfort for themselves and their infant. It may also assist in one-on-one interaction with nurses by making the space more intimate (White, 2003).

Another process related recommendation would be to include parents in rounds as this may increase feelings of inclusion and empowerment. If approximate round times were assigned to infants the day before, parents could prepare to be present. This could also improve communication, familiarity with staff and inclusion in decision-making. These recommendations are general and more research would be required for implementation of these recommendations. They are a starting point for addressing system-level issues. The next section will present the limitations for the study, areas for future research and some examples of how this study contributes to health systems research.

### **Limitations of Study**

As with all research there are some limitations, largely related to scope but also to method. A primary limitation to this study can be seen to be regarding the generalizability because of limited sampling. The sample only includes mothers in one, level 3 NICU in the Ottawa area. Therefore, results may not be transferable to other NICUs. Further, the sample only included

English-speaking mothers with infants that had positive prognoses. Participants in the study were able to leave the unit with their children and lead healthy lives; however some infants do not survive and the experience of mothers might have been different. Therefore only the experiences of mothers whose children were improving were captured in this research. Further, this research did not address issues of social support, which could have had a major influence on the maternal experience. The interview protocol did not ask questions regarding spousal or family support while the infant is in the NICU.

Secondly, due to constraints from ethics, demographic information could not be collected and considered for this research. Demographic information may have provided significant information about the mothers' readiness for children or adapting to the NICU. This information also would have offered more contextual cues as to how macrosystem factors interact with the microsystem. For example, if mothers experienced poverty or low socioeconomic status, this may lead to increases in stress if there were lost wages due to spending more time in the NICU.

Saturation could have been stronger with the involvement of more participants. Issues that affected the sample size and recruitment included patient health status, transfer and discharge. Approximately 20 mothers were approached for this study and ten gave verbal consent however if the infants' health worsened it was agreed that they would be excluded from the study to respect the parents. Other participants were lost due to transfers to higher-level treatment units such as the Children's Hospital of Eastern Ontario or to a lower level such as the Civic campus. Due to ethics not including other units, and being specifically for research at the General campus the participants transferred were lost. This impacted the sample size and ultimately the breadth of experiences.

Lastly, a limitation to this research was the role of support and spousal involvement in the mothers' experience. Social support may have been a factor that mediates the negative

experiences. This research also did not include paternal perspectives, which could have added new perspectives about parenting and gender in the NICU.

### **Areas for Future Research**

Areas for future research should include understanding the paternal experiences and what it is like to be the father of an infant in the NICU. It was already stated that the experiences for mothers and fathers are different, thus a study to deeper understand these differences would be beneficial for hospital systems. This also prompts a greater need for gender differences to be studied in health-systems research. There is a lack of gender analysis for patient-provider relationships of the same gender. This research would offer an additional lens to analyze health care issues. Lastly, more research on increasing family engagement and empowerment in the health care system is needed in an effort for patients to have better experiences and navigate the system more easily.

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# Appendix A- Ethics Approval



Université d'Ottawa University of Ottawa

Bureau d'éthique et d'intégrité de la recherche Office of Research Ethics and Integrity

**Re: U of O Ethics file no. A07-14-04 – “Impacts of the NICU Microsystem on the Maternal Experience”**

Thank you for the protocol documents and Certificate of Approval from the OHSN-REB (REB # 20130893-01H) for your project named above.

This is to confirm that, in accordance with the agreement between the University of Ottawa and OHSN-REB, the University of Ottawa has authorized this board to act as Board of Record for the review and oversight of research involving human participants conducted at or through the hospital.

We remind you of your obligation to:

- Follow all procedures of the OHSN-REB including reporting and renewal procedures;
- Submit to the authority of the OHSN-REB and that you are subject to OHSN-REB requirements, including, without limitation, the requirement to modify or stop the research on demand of the OHSN-REB.

If you have any questions, please contact our ethics office at 562-5387.

Sincerely yours,

Director  
Office of Research Ethics and Integrity

550, rue Cumberland 550 Cumberland Street  
Ottawa (Ontario) K1N 6N5 Canada Ottawa, Ontario K1N 6N5 Canada

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<http://www.recherche.uottawa.ca/deontologie/>  
<http://www.research.uottawa.ca/ethics/>

## Appendix B- Interview Protocol

### Research Questions

Logistical Questions to open and get facts and contextual information:

1. *To get started, can you tell me a little bit about yourself and your family? (Children, spouse)*
2. *How long has your baby been in the NICU?*
3. *Can you talk to me about your pregnancy with that child?*
  - a. *Were you aware during your pregnancy that you may have to spend time in the NICU?*
4. *At what point were you informed that your infant needed some extra care? How did this make you feel?*
5. *Can you describe your delivery experience? (early, on time, complications, circumstances etc)*
6. *What kind of emotions did you feel regarding the delivery?*
7. *Can you tell me how you felt when you saw your child for the first time?*
8. *Were you able to interact with your child at that time? If so, how?*

### NICU-specific Questions

9. *Once your child arrived in the NICU, when were you first able to make physical contact? Has this changed in any way?*
10. *Was there a doctor or nurse that had a significant impact on your experience? (positive, negative)*
11. *Has there been a difference in your relationship with nurses or physicians that impacted your experience? How so?*
12. *What has made you feel supported in the NICU? What has made you feel unsupported? How could the staff make you feel more supported?*

13. *How has the technology or the equipment impact you?*
14. *Do the other patients/visitors in the NICU have any impact on your time there?*

#### Mother and Baby Questions

15. *At this time, how is your health? Physical, mental, emotional?*
16. *Aside from the hospital staff, have you felt supported by other individuals who are close to you? How so?*
17. *Can you talk to me about the current health status of your child?*
18. *How is this experience affecting how you attach and bond with your new infant?*
19. *Tell me about how you felt as a new mother during your stay?*
20. *From your first day in the NICU to today have your feelings changed? This could be about your perceptions of the unit, the health of yourself or your infant or also the care that is being provided by the staff at the hospital.*
21. *How do you feel this experience has shaped/is shaping you?*
22. *Do you think this experience is shaping your relationship with your child?*

#### Additional Impact Questions

23. *How is caring for a new infant in the NICU influencing your relationship with your spouse, partner?*
24. *Is this experience impacting your relationship with your other children? How so?*
25. *Is this impacting your financial situation or employment?*
26. *Before we wrap up, is there anything you would like to add?*
27. *If you had to do it again or to help future NICU families, what would you like to have been different? While having a baby in the NICU is never ideal, what would make the experience as positive as it can be?*

## Appendix C- Consent Forms



### PARTICIPANT INFORMED CONSENT FORM

Title of Study: Impacts of the NICU Microsystem on the Maternal Experience

Sponsor (or Funding Agency): Telfer School of Management, The University of Ottawa

Participation in this study is voluntary. Please read this Participant Informed Consent Form carefully before you decide if you would like to participate. Ask the principal investigator as many questions as you like. We encourage you to discuss your options with family, friends or your healthcare team.

Why am I being given this form?

You are being asked to participate in this research study because you and your child are currently receiving or have recently received care in the Neonatal Intensive Care Unit (NICU) at The Ottawa Hospital.

Why is this study being done?

This study is being done to understand how mothers are impacted by caring for a child in the NICU. Most of the current literature on the NICU focuses on staff satisfaction and not the parental experience.

One NICU site will be included in this study from the University of Ottawa.

How is the study designed?

This is a qualitative study to explore and understand what this experience means to mothers.

The study has 3 phases:

Phase I: *Non-participant observations* in which the principal investigator will be observing the NICU.

Phase II: *Interviews* in which the principal investigator will interview mothers who currently or recently have an infant in the NICU.

Phase III: *Collection of artifacts* in which the principal investigator will collect pamphlets, notices and memos within the unit to understand their influence on the experience.

What is expected of me?

For the observation phase, it is expected that you will continue with your day-to-day activities as normal. The principal investigator is there to experience the unit and observe what it is like daily.

You will be asked to participate in an interview that will take approximately 60 minutes to complete. The purpose of the interview is to explore your experience in the NICU and how it has impacted you. Questions will be asked about your emotions and well-being during this time. You may skip any questions that make you uncomfortable or that you do not wish to answer and can terminate the interview at any time.

Will my samples or research data be used in future research?

No, your research data will only be used for the purposes of Emily Rowland's Master of Science thesis research.

How long will I be involved in the study?

The entire study will last approximately 1 year. Your participation in the study will last approximately 1 month.

Your participation in the study may be stopped for any of the following reasons:

- *You have decided to withdraw your participation.*
- *The study doctor feels it is in your best interest.*
- *You need additional medication/treatment that would interfere with the study.*

What are the potential risks I may experience?

Observations:

You might find the observation process uncomfortable. You can terminate the observation at any time by letting the principal investigator know.

Interviews:

You might find the interviews upsetting or tiring if they are quite lengthy. You might not like all of the questions that you are asked. There are no correct or incorrect answers to interview questions. You do not have to answer any questions that make you uncomfortable and can terminate the interview at any point in time.

We will take all reasonable steps to keep your research information confidential. Should someone not involved in the research find out that you took part in this research study, or if

you choose to share your results (if they are provided to you), there is a possibility that this could affect your insurance or employment.

Can I expect to benefit from participating in this research study?

You will not receive any direct benefit from your participation in this study. Your participation may allow the researchers to gain insights into this experience. This may benefit future patients as research findings may indicate opportunities for care improvement.

Do I have to participate? What alternatives do I have?

Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now, and then change your mind later without affecting the medical care, education, or other services to which you are entitled or are presently receiving at this institution.

If I agree now, can I change my mind and withdraw later?

You may withdraw from the study at any time without any impact on your current or future care at this institution.

- *You may also choose to discontinue your participation in the study.*
- *If you withdraw your consent, the study team will no longer collect your personal health information for research purposes.*

How is my personal information being protected?

- *All personal health information (PHI) and your personal identifying information (PII), such as your name, address, date of birth, etc. will be kept confidential.*
- *Release of your PHI/PII information will only be allowed if it is legally required.*

- *As a participant, you will be assigned a coded study number that will be used throughout the study on all your study records.*
- *Documents or samples leaving The University of Ottawa will only contain the coded study number. All of the data will be stored and managed on a password protected computer belonging to the Principal Investigator.*
- *A Master List provides the link between your identifying information and the coded study number. This list will only be available to Emily Rowland and her thesis supervisors and will not leave this site.*
- *The Master List and coded study records will be stored securely.*
- *For audit purposes only, your original medical records may be reviewed under the supervision of Emily Rowland by representatives from:*
  - *the Ottawa Health Science Network Research Ethics Board (OHSN-REB), and The University of Ottawa*
  - *You will not be identified in any publications or presentations resulting from this study.*
- *Research records will be kept for 20 years, as required by the OHSN-REB/Health Canada.*
- *At the end of the storage time, all paper records will be shredded and all electronic records will be securely deleted.*

Do the investigators have any conflicts of interest?

There are no conflicts of interest to declare related to this study

What are my responsibilities as a study participant?

It is important to remember the following things during this study:

- *Ask the principal investigator if you have any questions or concerns.*

- *Tell the principal investigator if anything about your health has changed that may impact your ability to participate.*

Will I be informed about any new information that might affect my decision to continue participating?

You will be told in a timely fashion of any new findings during the study that could affect your willingness to continue in the study. You may be asked to sign a new consent form.

Who do I contact if I have any further questions?

If you have any questions about this study, or if you feel that you have experienced a study-related injury or illness, please contact Emily Rowland at (613) 883-8285.

The Ottawa Health Science Network Research Ethics Board (OHSN-REB) has reviewed this protocol. The Board considers the ethical aspects of all research studies involving human participants at the University of Ottawa. If you have any questions about your rights as a study participant, you may contact the Chairperson at 613-798-5555, extension 16719.



### Consent to Participate in Research

- *I understand that I am being asked to participate in a research study about my experience in the Neonatal Intensive Care Unit.*
- *This study was explained to me by \_\_\_\_\_.*
- *I have read, or have had it read to me, each page of this Participant Informed Consent Form.*
- *All of my questions have been answered to my satisfaction.*
- *If I decide later that I would like to withdraw my participation and/or consent from the study, I can do so at any time.*
- *I voluntarily agree to participate in this study.*
- *I will be given a copy of this signed Participant Informed Consent Form.*

### Investigator or Delegate Statement

I have carefully explained the study to the study participant. To the best of my knowledge, the participant understands the nature, demands, risks and benefits involved in taking part in this study.

\_\_\_\_\_

Investigator/Delegate's Printed Name

Investigator/Delegate's Signature

Date

### Assistance Declaration

Was the participant assisted during the consent process?  Yes  No

- The consent form was read to the participant/substitute decision-maker, and the person signing below attests that the study was accurately explained to, and apparently understood by, and consent was freely given by the participant/substitute decision-maker.
- The person signing below acted as a translator for the participant/substitute decision-maker during the consent process. He/she attests that they have accurately translated the information for the participant/substitute decision-maker, and believe that the participant/substitute decision-maker has understood the information translated.

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Name of Person Assisting (Print)

Signature

Date