

## ABSTRACT

Title of Document: THE POETICS OF BODILY BEING: THE LIVED EXPERIENCE OF BREASTFEEDING AN INFANT "OUT OF REACH" IN THE NICU

Christy A. Sampson-Kelly  
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Directed By: Professor Francine Hultgren, Department of Teaching and Learning, Policy and Leadership

Babies born preterm (<37 weeks gestation) and at very low birth weight (VLBW, <1500 grams, 3.3 pounds) reside "out of reach" from their mothers in a neonatal intensive care unit (NICU) during the very beginnings of life. As the evidence of breast milk versus formula for infants within this vulnerable population is well established, multiple initiatives call for the provision of breast milk, and NICU professionals are subsequently making efforts to increase numbers of breastfed infants. However, there is a gap in the scholarly literature that brings forth mothers' voices relative to this unique breastfeeding experience. These voices are imperative to making a greater understanding of this phenomenon.

This hermeneutic phenomenological study asks the question: **What is the lived experience of providing breast milk for one's child who lives in a NICU?** My exploration draws upon the writings of several philosophers including Levinas,

Heidegger, Merleau-Ponty, Gadamer, and Derrida that relate to the phenomenon and discover how the phenomenon is made visible through them. The wondrous writings of poets are interlaced throughout my journeying, reverberating the deep meaning that lies beneath the surface of things. Max van Manen's depiction of hermeneutic phenomenology provides the methodological structure for the study, which is uncovered through the multiple, individual conversations with and journal entries of ten mothers who share this human experience. As meaning unfolds, breastfeeding emerges centrally, as a remedy and offering a way to transcend the dis-eases of self-blame, dis-place-ment, and dis-member-ment underwent as part of mothering in the NICU. Reflecting on these dis-eases, calls for the offering of pedagogical insights of more welcoming and less judgment in supporting mothers in *doing* the work of mothering, taking on a view of breast milk as more than pure resource, and the importance of nurturing the nurses. Attending to these stories may help NICU professionals to imagine an envired NICU, were mothers, too, are cared for in their journey to self-forgiveness, em-place-ment, and re-member-ment, amid the strange and wondrous terrain of their beginnings.

THE POETICS OF BODILY BEING: THE LIVED EXPERIENCE OF  
BREASTFEEDING AN INFANT “OUT OF REACH” IN THE NICU

By

Christy A Sampson-Kelly

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Advisory Committee:  
Professor Francine Hultgren, Chair  
Professor Joan Lieber, Advisor  
Professor Paula Beckman  
Professor Emerita Susan Komives  
Associate Professor Brenda Hussey-Gardner

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## Dedication

To mothers everywhere, becoming who they are.

### Acknowledgements

You were born with potential.  
You were born with goodness and trust.  
You were born with ideals and dreams.  
You were born with greatness.  
You were born with wings.  
You are not meant for crawling, so don't.  
You have wings.  
Learn to use them and fly.

Jalāl ad-Dīn Muhammad Rūmī (1207-1273)

I offer heartfelt thanks to those who have contributed to my growth as a student, but more importantly as a person, and there are many. Some only crack the window of opportunity, enough to allow you to take in the freshness of the air. Perhaps this is a design to motivate you to take on the weight its pane bears down on your shoulders, as you struggle to push it wide enough to squeeze through. Others fling the window open wide and welcome you to begin your journey. They support your readiness, share what they know, and care for those very wings they dream will fly you to worlds even they have not seen (but through you will certainly touch). I have gained confidence in my voice, and learned to recognize the value it holds. I cannot give enough thanks to all who have listened. That is something I could not have done alone.

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## Preface

The subsequent chapters represent a hermeneutic phenomenological investigation of the lived experience of mothers providing breast milk to their babies born preterm and at very low birth weight (VLBW, <1500 grams), as they reside “out of reach” in a neonatal intensive care unit (NICU).

Although NICU professionals have made significant gains over the past two decades in the care of infants born preterm, the prevalence of this occurrence remains (Goldenberg, Culhane, Iams, & Romero, 2008). There is extensive research documenting the numerous benefits of breast milk feeding, especially in the low birth weight (LBW <2500 grams) preterm population (Hylander, Strobino, & Dhanireddy, 1998; Meinen-Derr et al., 2009; Sisk, Lovelady, Dillard, Gruber, & O’Shea, 2007; Schanler, Shulman, & Lau, 1999; Amin, Merle, Orlando, Dalzell, & Guillet, 2000). Breastfeeding has been found to contribute directly to the health of babies and these healthier infants develop into healthier children (U.S. Department of Health, Office on Women’s Health, 2008). The American Academy of Pediatrics (AAP) Section on Breastfeeding (2005) emphasizes the benefits for infants born preterm and the importance of maternal support and education in the hospital setting to promote breastfeeding and the use of expressed breast milk. Infants born preterm and at VLBW are at increased risk for neonatal and neurodevelopmental impairments and although medical professionals agree that the provision of breast milk has many important health and developmental benefits, children within this vulnerable population are also far less likely to receive it (Hill, Ledbetter, & Kavanaugh, 1997;

Killersreiter, Grimmer, Buhrer, Dudenhausen, & Obladen, 2001; Yip, Lee, & Sheehy, 1996).

In view of the protection breast milk provides in the face of this biologic risk, I wonder about mothers' experiences providing breast milk to these very children who are too sick or small to be with them. Where are their voices in this body of research and its ensuing initiatives? Through this hermeneutic phenomenological investigation, I attempt to bring forth mothers' voices relative to this unique breastfeeding experience, resulting in a greater understanding of this phenomenon available to mothers, their families, and NICU professionals.

Hermeneutic phenomenological inquiry is a human science rooted in philosophy and its conventions more closely correspond with the traditions of the humanities (van Manen, 1990/2007). Hermeneutic phenomenology is embedded within the interpretivist ontological perspective, which embraces the belief in multiple realities constructed and altered by the knower that are not more or less true, but instead are more or less informed (Lavery, 2003). Methodologically speaking, hermeneutic phenomenology, as coming from the interpretivist perspective, involves the researcher engaging in a process of interpretation and communication with the participants in an effort to understand their lived experience through the uncovering of meaning (Lavery, 2003). This stance, therefore, does not seek a definitive answer, solution to a problem, or ways to predict or direct the behavior of others. Rather, it helps "human beings to become increasingly thoughtful and thus better prepared to act tactfully in situations" (van Manen, 1990/2007, p. 21).

The language of phenomenology differs quite extensively from that of the social science tradition. Intrinsically, hermeneutic phenomenology is a writing activity, as the research and writing find themselves inextricably connected within this form of inquiry with “phenomenological descriptions, if done well” being “compelling and insightful” (van Manen, 1990/2007). The language used is vital because the goal of researchers using this methodology is movement away from abstractions toward a deeper understanding of lived experience. It is a “language that authentically speaks the world rather than abstractly speaking *of it*” by means of a “poetizing which harkens back to the silence from which the words emanate” (van Manen, 1990/2007, p. 13). Ultimately, a phenomenological researcher strives to “construct an animating, evocative description (text) of human actions, behaviors, intentions, and experiences as we meet them in the lifeworld” and it is “to this purpose the human scientist likes to make use of the works of poets, authors, artists...and it is in this work that the variety and possibility of human experience may be found in condensed and transcended form” (van Manen, 1990/2007, p. 19).

Throughout this research endeavor, I have drawn upon van Manen’s (1990/2007) depiction of hermeneutic phenomenological inquiry, discussed further in Chapter Three, “as a dynamic interplay between six research activities: turning to a phenomenon which seriously interests us and commits us to the world; investigating experience as we live it rather than as we conceptualize it; reflecting on essential themes which characterize the phenomenon; describing the phenomenon through the art of writing and rewriting; maintaining a strong and oriented pedagogical relation to the phenomenon; and balancing the research context by considering parts and whole”

(pp. 30-31). The following paragraphs address the structure of this hermeneutic phenomenological dissertation in order to help acquaint its readers with the conventions of hermeneutic phenomenological research, assist in understanding the nature of the way the phenomenon is being brought forward, and clarify how the methodology leads to the forming of each chapter.

In Chapter One, I turn to the phenomenon as I share my own experiences in breastfeeding, my chosen life as a special educator, preterm birth, and my lifelong interest in social-emotional health. Together, these induced my turning to this phenomenon, and this chapter serves as an introduction to my engagement in this pursuit. I show the way in which my experiences as a special educator, mother, and sister have led me to a concern for, concentration on, and commitment to my research question. In moving through this chapter, I open up the phenomenon, explicate my assumptions and pre-understandings, and formulate the phenomenological question. The purpose of this chapter is to draw the reader in to a lived account, in order to begin to understand what this experience might be like for women. As a way to draw the reader into the phenomenon, I also use relevant literature. Through my engagement with varied texts (poetry, essay, descriptive quotes, scholarly literature), I am able to get inside the phenomenon and work my way to naming it, through a gradual unpacking of its many features. In Chapter One, I begin with a poem I wrote in bringing the phenomenon forward, and then I begin to wonder about what it might be like for mothers who did not have my opportunity of breastfeeding a full-term and healthy infant. I begin with my own breastfeeding experience and breastfeeding in general and then narrow the focus to the NICU experience. I represent my own pre-

understandings of the phenomenon as they come into view, bringing myself forward. In this chapter, my-self, as researcher, is made manifest.

Chapter Two represents a preliminary investigation of experience as we live it, where I explore the phenomenon through various textual sources including the writings of philosophers, researchers, scholars, NICU professionals, and mothers who have lived this experience. This chapter does not engage a review of the literature, but rather a rendering of work that allows readers to see the phenomenon more deeply. Through this chapter, my goal is to more deeply question the nature of this lived experience. I consult the experiential descriptions of mothers who have lived this phenomenon. The beginnings of investigating experience as we live it, as demonstrated in this chapter as well as Chapter One, include using personal experience as a starting point and the tracing of etymological sources. I do this as I trace the etymological sources of the words we use to describe and associate with becoming a mother in the NICU and the experience of breastfeeding an infant at a distance. Phenomenological researchers trace the etymological source of words, related to their phenomenon of interest, in an attempt to bring forth original meanings that have been covered over, and which lend to the possibility of seeing new meanings. Doing this puts researcher and reader in closer contact with the lived meaning of those words, bringing us closer to a place “where the terms still have living ties to the lived experiences from which they originally sprang” (van Manen, 1990/2007, p. 59). I close the chapter by presenting some of the initial themes that emerge from my beginning investigation into the phenomenon.

In Chapter Three, I draw upon the ideas of various philosophers that relate to the phenomenon and discover how the phenomenon is made visible through them. This philosophic grounding serves to support the methodological scaffolding for carrying out the study, which I also provide in this chapter. It is in this chapter that I begin to balance the research context, which continues throughout my engagement in the research project. The description of my research design reflects a flexibility that allows for traveling in directions that may not be foreseeable in the planning stages.

Chapter Four makes known the lived experiences of mothers providing breast milk to their “out of reach” babies, by way of conversations and journal entries, as emerging themes are addressed and developed. The third and fourth activities described by van Manen are interwoven throughout the research process and serve to guide me toward emergent meanings presented in Chapter Four. Activities five and six serve as a foundation for my investigation of the phenomenon and involve thematic analysis. Through these activities, I will seek meaning by uncovering thematic aspects in textual sources, isolating statements, composing linguistic transformations, and determining incidental and essential themes. This is the process of phenomenological writing.

In the final chapter, I address the insights from the study that support professionals in the NICU, as well as educators and mothers, in living with this phenomenon in ways that overcome obstacles and provide new possibilities for the way in which this phenomenon can be addressed



**CHAPTER ONE**  
**TURNING TO THE PHENOMENON: BREASTFEEDING “OUT OF REACH”**

**Being Called to Our Humanness**

The pride I feel as others admire  
your round, full cheeks  
and shapely thighs.

I grew those thighs.

First, as they lay inside of me.  
    as I ate, you ate  
    as I breathed, you breathed.

Now, as you lay in my arms.  
Taking in a cocktail created especially for you.  
We look into one another's eyes,  
exchanging expressions and sounds.

We are one again,  
if only for a while.  
I think this a proper way to assist you  
in becoming yourself  
    progressively allowing,  
    gradually accepting.

One of my favorite parts  
is when something unexpected amuses you.  
The corner of your mouth turns up,  
leaking me down your cheek  
as you smile.

Knowing that even after my body has lost its breath  
and my spirit absconded,  
I live on in your flesh.  
Never  
will you entirely be  
without me.  
(Sampson-Kelly, 2009)

The idea of breastfeeding mostly conjures images of chubby, content infants,  
lying in the arms of their mothers. This poem describes the meaning of breastfeeding

for me. My children were healthy, full-term infants, who were never out of my reach. Breastfeeding came to my assistance as I established my new place in the worlds of my children after their births, and helped them find their new place in the world given to them. Breastfeeding eased our separation and made it less apparent. I have always felt that this act somehow contributed to the social-emotional development of my children; perhaps humanness is encouraged through the sustained bond breastfeeding affords us. This idea stays with me now in a different way, ready to be released and explored. It is aflutter with meaning and questions that go deeper than theoretical explanations, as I consider the experience of mothers whose infants are “out of reach” at the very beginnings of their individual lives.

Van Manen (1990/2007) brings forth the story of Diogenes, who is said to have wandered the streets in search of humanness. “Even with a lamp in broad daylight I cannot find a real human being” (p. 5). This statement reveals that even when we are able to see clearly, the conception of humanness eludes us. What does it mean to be human? Does being born of a human automatically make us human? Does it take more than that, and if so, then what? Before our births, we exist in the womb. We exist in complete darkness and without air. We are a part of an Other, a human being without whom (prior to a certain point) we would cease to subsist.

What does it mean to be human? What is it about breastfeeding that calls us to our humanness? Steeves (2006) explores the idea of humanness by posing this question: “What if a child needs to be treated and attended to as a human in order to be human?” (pp. 32-33) Could this earliest of *powerful and gracious acts* of attention play a part in laying the foundation for human intentionality? During breastfeeding, I

reconnected with my children. I was again apparently necessary to and needed by them. I was important and perhaps more significantly, irreplaceable. The physical act of breastfeeding brought me to a primal space, feeling in place and connected in the most basic of ways. It was one of the few times in life when I knew exactly why I was here in this place at this time. I was meditatively present, and I thank my children for that. What of mothers who provide breast milk to their infants while they reside apart from them in a neonatal intensive care unit (NICU)? Do mothers providing breast milk to their infants from afar share this feeling of necessity? Does pumping milk for their babies bring them to this primal space?

The experience of breastfeeding an infant, residing in the NICU and born at very low birth weight (VLBW), usually begins with the premature birth of that child. One's baby is born, much before her anticipated time and very small. A mother chooses to breastfeed. Perhaps this was her decision all along, or perhaps she encountered something or someone causing a re-vision of her original plan. Nevertheless, she is unable to hold her baby in her arms, unable to place her cheek against soft newborn skin, and unable to nurse her baby at her breast. Still, she has made this choice. As she urges her body onward, do you not wonder what this is like? What meaning does this experience hold for her?

### **Basking in What is You**

The pride I feel as others admire  
your round, full cheeks  
and shapely thighs.

I grew those thighs.

First, as they lay inside of me.  
as I ate, you ate

as I breathed, you breathed.

My children's birth stories are all different and my breastfeeding experiences with each of my children are different still. I definitely recall one constant though – immediately after birth, I put them to my breast. There was something about that moment with each of them that stays with me bodily, and perhaps that feeling is the embodiment of necessity. What is it like, though, for mothers to dwell in a place where they are providing milk, yet do not experience this bodily connection with their child? Instead, they are pumping milk from their breast for hopeful provision to their baby only when others deem the time as right.

Feeding has a primary role in the NICU environment and is more an endeavor than an act. It is vital to the growth, development, and recovery of the infants who reside there, as well as an essential criterion for discharge. Most infants born preterm and at VLBW begin with parental (via intravenous line) feedings with the goal of an early transition to enteral or gavage (via nasogastric tube) feedings, as there is a limit to the amount of time they can remain on total parental nutrition before complications occur (Linden, Paroli, & Doron, 2000). Initially, professionals in the NICU usually introduce continuous gavage feedings slowly with incremental amounts of breast milk or formula, only after the infant is medically stable and readiness for milk feedings has been determined through assessment. The next triumph along the trek to nipple feedings is twofold. Infants must demonstrate tolerance for bolus feedings (delivering a set quantity at intervals) by gavage and behavioral and developmental readiness (Vergara & Bigsby, 2004). At long last, one's infant can begin taking some portions of feeding by nipple!

This passage is not without its difficulties. Therapists in the NICU are consulted for feeding problems most often (Linden, Paroli, & Doron, 2000). Since it can be weeks or sometimes months before an infant born preterm and at VLBW is able to begin nipple feedings, breastfeeding mothers must continue pumping through this time. What do these mothers feel, as they pump and store milk for the possibility of their baby receiving it? What do mothers who are breastfeeding at a distance undergo, as successful feeding is a requirement to their baby's transition home? Is the goal for these mothers eventual feeding at the breast? Once the baby is able to receive breast milk, is feeding their babies a nurturing and social activity? What does the breast pump provide for these mothers? Do they consider this act a way of caring for their babies?

Heidegger writes about the concept of *Dasein*, as our way of being-in-the-world. According to Heidegger, the existential meaning of *Dasein* is *Sorge*, a German word translated to English, meaning *care* (Moran, 2000). It appears, on the surface to mean caring for others, but *Sorge* is the noun as recognized by its capitalization (the verb is *sorgen*), and diving deeper into the meaning of care as a noun reveals a broader concept. The noun, care, is defined as "suffering of mind, a disquieted state of mixed uncertainty, apprehension, and responsibility; a cause for such anxiety and a painstaking or watchful attention; a person or thing that is an object of attention, anxiety, or solicitude (Oxford University Press, 2013). This notion of care implies a great concern, and an immersed, almost uneasy, state. Perhaps mothers of infants born preterm and at VLBW find themselves dwelling

more fully in this broader concept of care, even though they are one of a seemingly endless number of professionals *caring* for their baby.

What meaning of the word care did Heidegger hold? Did he consider care to be intentionality, as the directing of our attention? Surely we can mechanically carry out acts of “care” without truly directing our attention to another, without truly being present in that moment with another. In *Being and Nothingness*, Sartre writes, “I exist my body” as being the first dimension of being (Sartre, 1989, p. 351). He exists his body as fatigue in response to physical pain. Sartre also writes, “I live my body” as he references being in danger and surrounded. Embodiment requires existence; it is a part of it. Existence, though, seems passive. As long as I am here I exist, yet to live is to *be*. Living seems an active endeavor, melding consciousness into body and leading to new and alluring discoveries. To *be* seems to require the presence of another.

### **I See You**

Now, as you lay in my arms.  
 Taking in a cocktail created especially for you.  
 We look into one another’s eyes,  
 exchanging expressions and sounds.

The Zulu greeting, *Sawubona* “I see you” is followed by the response *Ngikhona*, which means, “I am here to be seen.” Intrinsic in the Zulu greeting and response is the idea that until you saw me, I did not truly exist. In being recognized by an-Other our humanness is called forth and affirmed, almost as if magically bringing us into existence (Lessem & Nussbaum, 1996). A traditional African concept further clarifies this idea. The concept is *Ubuntu*. A person with *Ubuntu*

recognizes that a person is only a person through their relationship to others (Tutu, 1999).

I am because you are. I am because of others. Behind these words inherently lives great intention. Seeing another is an affirmation that they exist. What does it mean to belong? Does humanness lie in belonging? Is it possible to practice conscious intention without looking at an Other face-to-face?

When a human baby is born, he cannot focus on anything more than 18 inches from his newly opened eyes, but when a face comes close to him...The blank clearing of the newborn's face quickly becomes a mirror of the Other. (Steeves, 2006, p. 2)

During my breastfeeding experiences, my children and I were one again, as we were before. Looking down at my child seemed like looking down at me. I would marvel at what I had done. I was amazed that I had grown this person inside of me and from me. As I sat, I perceived him as my likeness. As he became the mirror of me, I had become the other, and in a way that was difficult to accept. My thoughts drift to my baby sister, Sydney. She came home after giving birth to twins by cesarean section with an aching incision and without her babies. How did she know herself then, without her reflection? Did she feel incomplete?

The face-to-face encounter is a remarkable occurrence. During the face-to-face encounter, according to Levinas (1961/1991), "The Other precisely reveals himself in his alterity not in a shock negating the I, but as the primordial phenomenon of gentleness" (p. 150). This face-to-face encounter calls forth a response by instilling responsibility to the Other. In tracing the etymology of the word *respond*, I find it is derived from the Latin word *respondere*, meaning to answer to or promise in return, with *re* meaning back and *spondere* meaning to pledge (Harper, 2001/2012).

According to Levinas (1961/1991), this encounter is the source of the ethical and occurs passively and sensibly, preceding active thought. It is as if the face of the Other claims us and holds us hostage, demanding a response, a pledge back and it is here that we enter into an ethical covenant. The presence of an Other causes me to contemplate my own desires and weigh them against the load the Other bears down upon me. Perhaps it is here, in the face-to-face encounter, that vulnerability arises in the form of care as concern, as Heidegger's *Dasein*. It is the face of the Other that demands this concern of me and my conceding is not decided, but rather reflexive.

My mother laughed as I cursed each time my son latched on and cursed some more if he managed to slip off, in piteous anticipation of having to begin again. It took him and me a while to choreograph our routine, and a longer while for our routine to become the seeming fluid effortlessness of ballroom dance partners. This now seems inconceivable without the relationship my mother and I shared, without the relationship my son and I were building. Her being-with gave me more strength to push forward. His staking his claim on me provided the necessary and constant encouragement that was revealed through his face. It seeped through his gaze time after time and recommitted me. What is it like for breastfeeding mothers in the NICU, without the face of their baby to call them forth, to encourage, and recommit them? How do they continue their sacrifice of self? What is it that calls their freedom of self to responsibility?

### **Missing You**

We are one again,  
if only for a while.  
I think this a proper way to assist you  
in becoming yourself



progressively allowing,  
gradually accepting.

Breastfeeding was, in a way, an extension of my pregnancy. I was at times, still connected to my children, even though they were no longer living inside of me. What is it like for mothers who breastfeed apart from their babies, without a continued physical connection to them? As these mothers pump their breast milk for their children, do they feel a continued connection? Perhaps these mothers and their children are neither together nor truly apart. Mahon-Daly and Andrews (2002) speak of mothers and their breastfeeding infants as being often in a state of liminality, neither in the old world nor the new. Might these mothers stand at a threshold, stepping neither forward nor backward, but lingering in an in-between space? How is it that mothers whose infants reside apart in the NICU regain this feeling of connectedness?

### **Smiling Back**

One of my favorite parts  
is when something unexpected amuses you.  
The corner of your mouth turns up,  
leaking me down your cheek  
as you smile.

That smile is what I lived for, and to know that everything at that moment was taken care of. While fulfilling the needs of my son, he reflected my own contentment back at me through his face. A greater feeling of joy is difficult to attain and I knew in my heart, even then, that those moments were fleeting. In time, he would grow and I would no longer be everything this child would need. He would outgrow what I only could provide. I do not think I realized this fully with my first child. By the time I had my daughter, I knew it within every inch of my body. It flowed through

me; I knew that this dance was time sensitive, that eventually it would become larger than just the two of us. As a result, I lived my time differently with each of my subsequent children. How is time lived by mothers of infants born preterm and at VLBW?

Van Manen (1990/2007) describes lived time as our subjective way of being in the world. Lived time is not measured in minutes, hours, or even circadian rhythms, but rather through our perception of it, as we live it. We perceive the passing of time differently at different times of our lives. Through her metasynthesis of qualitative studies looking at the maternal experience of breastfeeding from 1996-2006, Nelson (2006) uncovered the essential theme of breastfeeding as “an engrossing, personal journey” (p. e15). It seems the times when we are more fully immersed, in whatever it is we are engaged in, time passes more quickly. Yet, my experience in breastfeeding was somehow different. While I perceived time as fleeting, during those exclusive times with my children it was as if time were momentarily suspended. I was wholly present and apart from past or future, as if lingering above the two. Perhaps this is a reason we tend to baby our youngest children. Could our innate protectiveness be compounded by our recognition of this eventual and certain loss? What of mothers who must get to know their children in the NICU, who have hastily been forced to let go of their children? How do they choreograph their dance while living apart from them, and hurdling the obstacles of the NICU environment?

### **Forever Entangled**

Knowing that even after my body has lost its breath  
and my spirit absconded,

I live on in your flesh.  
 Never  
 will you entirely be  
 without me.

Breastfeeding solidified my presence in my children's lives. Does pumping breast milk for mothers of infants born preterm and at VLBW serve this same purpose for them? By the time my fourth child was born, I savored the experience even more. I was increasingly present, more aware that one day he would grow up. There were times I wept, smiling down at him, as he looked up at me. His small hand would reach up toward my face to touch a falling tear. I am with him, literally pouring myself into him. At that moment, I give him all that I have to give and all that he needs to receive. Is there any greater gift than the gift of self? Does the giving of self require the presence of an Other? Do women pumping breast milk for their babies view their gift in this way?

Mothers of infants born preterm and at VLBW almost certainly are unable to put their baby to their breast upon birth. If their choice is to breastfeed, in order to begin doing so and continue doing so, they most often must acquaint themselves with the technology of the hospital-grade electric breast pump with double-pump kit. What are the experiences of women who are the first in their circle to breastfeed using the technology of an electric breast pump? What is it like for women who have no bodily memory of providing breast milk in this way, no ancestral reminiscence? What is this experience like for them?

### **Poet as Creator**

What is it to be human? Language does not equal being human. Yet it is through language that I seek to understand humanness and seek to communicate my

discoveries of humanness. Nursing my children has made me more human. My newborn baby cannot describe with words anything about his pre-language world. Does this mean that he had no consciousness, no awareness, and no intellect? Perhaps being with the Other in silence allows us entry into what is real and true. As my youngest child learns to speak, somehow I begin to have lessened access to his experience. He is two and I misinterpret his attempts to commune with me verbally. It is only when I breathe that I can understand what he is going through. In my stillness, I remember that I knew everything about him long before he could speak. I read his facial expressions and observe the form of his body. I remember that once we shared the air. We still do. How did I get to know him? He is my poetry. He revealed himself through me from the very beginning, and when my writing seemed complete, he revealed himself to the world. How do the mothers of children residing in the NICU re-member themselves when preterm birth cuts their writing process short, their poetry revealed *too soon*?

Pregnant with possibility that is unseen to the outside world, the poet begins crafting her verse the day it is born. The word *craft* is a transitive verb meaning to make or produce with skill, care or ingenuity (Merriam-Webster, Incorporated, 2010). In the beginning, after the creation of life, life requires care. Each experience, beings met along the way, places visited – all contribute to the poem's conception. Thought, love, acceptance, rejection, belief, doubt, and more all make their way into each stanza from the inside out. The poet creates her verse and once born she crafts it by deliberately adding herself into it until, at once, it is recognizably outside of her self. Her poetry brings to light these formerly unseen prospects.

**Poetry.** We create our poetry. Many have attained the rank of creator. I am a creator; my mother is a creator, as was her mother before her. My sisters are all creators. Sometimes we create one, sometimes many; my baby sister can create two at a time. They are our children. We create our poetry from the inside out and then go on to craft it. Bachelard (1994) tells of Valéry's contemplation of the mollusk shell and the mollusk's motto: "One must live to build one's house, and not build one's house to live in" (p. 106). This idea of *slow, continuous formation* from the inside out is reminiscent of so many things. For me, it initially brings to mind the evolution of self. In contemplating my-self, I understand that I am a continuing process. Precisely when I feel I have truly evolved, I evolve some more. Others and I are continuously learning, continuously experiencing, and continuously becoming. We continuously become from the inside out. I smile when I think of the people I have been during my life. It is almost as if I have lived other lives. How did my evolution of self begin? How did it develop?

The idea that human infants have a need for a secure relationship with adult caregivers, without whom normal social and emotional development is negatively impacted, is widely accepted (Bretherton, 1992). Different caregiver-infant relationship experiences can lead to different developmental outcomes. Caregivers, who are available and responsive to their infant's needs, have been found to foster a sense of security within their child. As a result, the child learns that the caregiver is dependable and creates a secure base for the child to then explore the world (Ainsworth, Bell, & Stayton, 1974).

Our bodies are our children's shells. They stay true and protect them as they continuously become. As they change, they do so from the inside out (from our insides out) until finally, we reveal our poetry. For a time, we are ceaselessly engaged in the hard work of creating, and then it ends. Our children are born. Our poetry is revealed.

I believe that we exude through our bodies, our shells. How often have you experienced someone in passing and her inner self, her emotional being, seeps through to you? This person has an immediate impact on you. Is the impact fleeting? Is it lasting? If the experience of this person aligns with your beliefs, with your agreements, then is it more lasting? Might someone who is dramatically different also have a lasting effect? This concept buttresses the thought that contact with others feeds our own transient emotional states, and even our overall emotional well-being. These emotional states, if enduring may have the potential to seep through and affect our very selves and our interactions with others. Consider now, for a moment, a mother and her child. They literally share emotional states initially through their bodily connection. The child feels that which the mother perceives. After birth, does this connection simply disappear all at once? Is it possible that after their bodily separation mother and child continue, for a time, to exist as one through their nearness to one another? What is it like for mothers who often cannot share this body-to-body connection, due to long bouts of separation? Do women who provide breast milk to their premature infants experience such a continuation? Can the technology of the breast pump bridge their distance?

**Poets.** We are poets, our children are our poetry, and it is they who help us perfect our craft. They are our inspiration, and because of them, we write again. Their existence calls us to them. They demand us. We experience one another. They change us and we revise. We change them and they reflect this change back to us to perceive yet again. The variation is marvelous. Poetry is described as a “writing that formulates a concentrated imaginative awareness of experience in language chosen and arranged to create a specific emotional response through meaning” (Merriam-Webster, Incorporated, 2013). The word poet comes from the Greek *poetes*, which means *maker* (Harper 2001/2012). I like the thought of mothers as meaning-makers. What happens to mothers who are separated from their babies as they are sustained in the NICU? What are their ways of being as they reside apart from them? What is their experience crafting their poetry, caring for their baby? I wonder how it is to hand over one’s child to another, to care for, to foster, and to nourish.

### **Searching Behind the “Out of Reach” Experience**

I begin now, in a preliminary exploration, to uncover the significant meaning behind the experience of parenting in the NICU. Guided by the poetry of one mother and looking through the eyes of two additional extraordinary mothers, Sydney and Theresa, I illustrate this landscape and glimpse into the nature of mothering here, as a beginning revealing of what it means to breastfeed “out of reach.” Sydney was a single, teenage mother of twins born preterm six years ago. Theresa is a married, thirty-something mother of three children, who were each resultant of the miracle of in-vitro fertilization. Her youngest, born preterm and at VLBW, lived many weeks after birth at a distance. Through my conversations with these women, I glance upon

the strange and wondrous terrain that comprises the world where they began as mothers. I begin with one mother's evocative poem, entitled "Lost and Found," written after her own experience with premature birth.

### Lost and Found

She gazes down  
through the plastic box,  
unable to comprehend his  
tiny body.  
The monitor wires,  
IV lines and  
feeding tubes tangled over  
the gently rising chest  
expanding and contracting  
in mechanical rhythm,  
his mouth taped open--a gaping, silent cry  
that freezes cold  
her heart.

She is lost.  
Sinking into the madness  
of her grief, her guilt,  
an apology  
forever on her lips.

She lifts, so slowly, the door  
to his high-tech womb,  
her own aching,  
for its emptiness.  
His hands flutter and feet twitch,  
she cannot interpret his  
fetal dance,  
a foreign language spoken  
too soon.

She longs to touch him,  
to erase this space between them-  
her hand trembling,  
settling down on this other-worldly  
angelchild,  
her palm enveloping his entire  
torso.



She feels  
 fragile skin like soft tissue paper,  
 his back arches up, he squirms  
 at her touch,  
 and at the sound of her whispered voice  
 his eyelids slowly draw up,  
 dark eyes drawing her into  
 this mystery.

She is lost now in love,  
 and is forever found.  
 Too much ecstasy,  
 too much desire to sweep him  
 up into her arms  
 and she chokes on  
 the grief and the love,  
 surrendering to the joy that he lives, he lives,  
 her sunflower, her son!  
 (Peterson-DeGroff, 1999)

### **Ways of Being**

What are a mother's ways of being when she suddenly finds herself navigating the unfamiliar terrain of the NICU? How does she conceptualize herself as mother? How does she become a mother? The poem above vividly depicts one mother's experience with preterm birth and serves as a guide as I consider the meaning of mothering in this environment.

Poetry is a unique form of art. Its ability to express an experience through language and allow for an understanding of that experience can be remarkable. The word *art* is also the archaic second person, singular present and indicative form of the verb *to be* (Harper, 2001/2012). Could we imagine this second, present person being one's child? It is only after birth that our children exist as separate beings, as singular and present forms indicatively apart from their mothers. The work of art, the poetry, is now present.

The word *be* is the most irregular verb in modern English, as well as the most common. It is a verb of utmost importance, yet considered defective due to its incomplete conjugation (Oxford University Press, 2013). The child born preterm, too, seems an incomplete conjugation. Formed out of the pairing and joining of male and female, this child arrives outside of its mother still in progress.

The current meaning of *be* includes being equal in meaning and having an objective existence, yet tracing the etymology of the word suggests its roots lie in having or occupying a place (Oxford University Press, 2013). The online Oxford English Dictionary describes the primary sense of the word as having, “one’s personality, substance, or presence, to be present, so as to find oneself, or to be found” (Oxford University Press, 2013). Is it possible that being has more to do with belonging than existing? Could our idea of defined and distinct existence be dependent on that which surrounds us? Could it be dependent on our place among others?

In modern English, the conjugation of *to be* is a result of the unification of the surviving inflexions of three originally distinct and independent verbs. The modern verb represents the merger of these three once-distinct components, represented by *be* and the *am/was* verb, which was itself a conglomerate. Looking deeper still, the word conglomerate comes from the Latin *conglomerare*, with *com* meaning together and *glomerare* meaning to collect into a ball (Harper, 2001/2012). This depiction is reminiscent of the nature of baby making, the becoming from a ball of cells, winding and winding its way to life. I am my-self. I was my parents. What of be? What will I be? This appears dependent on what surrounds me, where I find myself, where I

find my place to be, and where I find belonging. This thought provoking word seems constantly changing in shape. It can be ambiguous, blurred, and often veiled beneath one of its eight different forms of expression: *being, is, was, were, am, been, are* and *be*.

**Being.** The word *being* is the progressive form, or present participle, of the verb *to be* (Oxford University Press, 2013). This is the continuous tense, a gerund or noun formed from a verb. *Being* represents existence or presence (Harper, 2001/2012) and this form can express present, future, or past time. A child's being is revealed.

She gazes down  
through the plastic box,  
unable to comprehend his  
tiny body.  
The monitor wires,  
IV lines and  
feeding tubes tangled over  
the gently rising chest  
expanding and contracting  
in mechanical rhythm,  
his mouth taped open--a gaping, silent cry  
that freezes cold  
her heart.

The world now sees his being, her poetry, formed of her actions, her care.

After birth, our children are clearly less apparently a part of us. How do mothers find their place in the daunting and highly technological environment of the NICU? Being a mother seems almost an evolutionary process stirred by the dance we do with our born children. What is *being* for mothers of infants living apart in the NICU who dance alone, waiting and preparing for their partner to return to them?

Mothers of children born preterm and at VLBW are displaced from their children, from their home. When coming to see their children, they can find temporary dwelling in the NICU, yet they are obviously visitors. Unfamiliar with the sights, sounds and rituals observed, they must learn the foreign language spoken and strange customs.

In a qualitative study, Jamsa and Jamsa (1998) interviewed seven mothers and described their experiences of nursing their sick, full-term newborns in the NICU. These researchers identified several factors that caused anxiety in parents, including the appearance of the equipment, wiring, tubing, and blinking lights; and especially the audible signals and alarms. For these parents, the fear of this equipment caused them to feel like outsiders, delayed their development of parental caretaking behaviors (including ability to learn to nurse the baby), and interfered with parental bonding. These parents also found the technological environment to be oppressive, as they described feeling shocked, frightened, and disturbed. The audible signals were particularly upsetting and reminded parents of movies where alarms carried the meaning of serious and impending danger.

Sydney speaks of her thoughts upon seeing her twins in the NICU:

...you're scared to do anything because there's monitors there...you know it's just monitors. It's not that something is going to happen. So, there's leads and...all types of them! But, you don't know... it's like, "Can you touch your own kid or not?" (Sydney)

Theresa also speaks of her memories seeing her son in the NICU. He was born at an implausible weight of one pound and, as in the poem, the size of her child was salient for her in addition to the technology, even though she had experienced the NICU environment with her daughter years earlier.

The first time I saw him, I think it was more - surreal. I couldn't believe that he was so small. I think that was the biggest thing. I don't even think it made sense to me yet that he was my child. I think I was just so overwhelmed at how small he was...I just couldn't believe it. He was so miniature. But at the same time, he was just so perfectly developed and so put together that I really was just like okay this can work...But I don't even know if I had that initial feeling of - Oh my God this is my baby. I don't think I could get over the whole thing just yet...of seeing him intubated. You know I think size. Size just did it for me...I remember even the nurse was changing him at one point and I think she had just finished putting his diaper on or was getting ready to...One of my thoughts was how big is a penis at one pound (laughing). I couldn't even think, if the rest of you is that small. I swear his penis was the size of a potato bug...I think I really was just overwhelmed at how small he really was.

I think also to see all of these things hooked up to him that were gigantic! You know that were small in the scheme of things, but even them putting tape on his face covered his whole darn face... to see that was overwhelming...I think initially it was like - wow, there's a lot going on there and I still look back at pictures and he just looked awful when he was born. I thought he was the most beautiful child, but he looked awful. And I expected that. I knew that with Maggie and I expected that would be the case with him. He just looked extra bad, extra bad. (Theresa)

The technological aspects of the NICU environment play an important role in the care of infants born preterm and at VLBW. While parents are often overwhelmed and alienated by technology in the NICU, it sustains life for their children. This technology is not only required for survival, but can also serve as a way to their child through breastfeeding and the use of the hospital-grade electric breast pump. What is the meaning of living with this technology of the breast pump to mothers who provide breast milk for their infants in the NICU?

Heidegger (1954/1993) writes of the essence of technology, the human relationship with it, and the idea that humanity's role of being with technology lies in our challenge to unconceal its essence.

...the essence of technology is by no means anything technological. Thus we shall never experience our relationship to the essence of technology so long as

we merely represent and pursue the technological, put up with it, or evade it. Everywhere we remain unfree and chained to technology, whether we passionately affirm or deny it. But we are delivered over to it in the worst possible way when we regard it as something neutral; for this conception of it, to which today we particularly like to pay homage, makes us utterly blind to the essence of technology. (Heidegger, 1954/1993, pp. 311-312)

Heidegger (1954/1993) presents technology as a way of revealing and traces the word technology to its source in the Greek word *technē*, which designates both the pursuits and talents of a crafter. These ideas seem to lead to the essence of technology dwelling, almost poetically, beside the truth of being. Perhaps the meaning for mothers providing breast milk by technological way of the hospital-grade electric breast pump with double pump kit lies here too. This may be their way of crafting their poetry, at a time when their poetry is out of reach. As opposed to considering modern technology as a way to control the natural, it is conceivable that these women have found a way in their relationship with the pump to find technology's true essence through their active, personal, and purposeful engagement with it, and therefore dis-covering its true power.

**Is.** The word *is* is the present tense, third person singular form of the verb *to be* (Oxford University Press, 2013). The present tense shows things that are happening now or around now. She is lost.

She is lost.  
Sinking into the madness  
of her grief, her guilt,  
an apology  
forever on her lips.

She is lost as she tries to make sense of the way she feels about the world around her. How do mothers remedy the arduous emotions of grief and guilt? The desire to compensate for preterm birth is one of five themes uncovered by Lee, Lee

and Kuo (2009) after conducting in depth interviews on two occasions with 31 mothers in Taiwan regarding their experience breastfeeding their VLBW babies. These mothers often blamed themselves for the preterm birth of their infants, and expressing breast milk for their children was a form of recompense. This relates to Flacking, Ewald and Starrin's (2007) finding through their interviews with 25 mothers of very preterm infants receiving care across seven NICUs in Sweden, that unresolved grief and experiences of shame represent barriers to the development of secure and reciprocal mother-infant relationships. While Theresa did not express self-blame, she did view providing her youngest son with breast milk as a way to counteract his rough start. Her youngest spent his first four months of life residing in the NICU, and she provided enough breast milk that it comprised his sole form of nutrition during his entire stay. She explains:

The pumping, I just did it because I felt it was the right thing to do. That was why I did it. I felt there were enough nurses there that spoke. One in particular, she was my favorite nurse and the lactation consultant. She always talked so highly of it that I thought - I don't know if it's the best thing in the world, but she felt it was and she convinced me...we are going to do the best we can to give him the best for as long as we can. Absolutely, absolutely.  
(Theresa)

The idea of being lost uncovers yet another theme of the experience of becoming a mother and breastfeeding in the NICU as a need for support. Through their research, Lee, Lee and Kuo (2009) also discovered that mothers viewed the support of their parents, spouses, and the nurses in the NICU as necessary to their confidence, persistence, and overcoming of breastfeeding problems. These mothers considered their own mothers and their partners to be the most significant sources of support. Mothers of infants born very preterm often perceived individuals who seem

pushy or critical, as opposed to considerate and optimistically encouraging, as offensive - regardless of the message they carry, and some of these same mothers even expressed experiencing rejection of themselves as mothers by the NICU staff (Flacking, Ewald, & Starrin, 2007).

How do mothers of infants who reside in the NICU balance the need to mother their child with their need for support? How do mothers gain and accept support from the very people who seem to be re-placing them as mothers? Theresa speaks of breastfeeding her youngest child as a need for support from her husband.

...With Maggie my biggest thing was I wanted to try. I wanted to do it, but with her being small, I wanted to focus on her gaining weight more than anything and I think that's why it didn't work that well. I was just like, "Ok, forget it. Let's just go to the bottle so she gains weight." With Chase, the same thing. I wanted to give it a go and Maggie was only 19 months old when Chase was born, so I felt overwhelmed...Chase didn't really do well with it. I would've had to work at it, so I stopped. Then with Mark, I said to Bob, "I'm gonna give it a try." And he was like oh, great. It was one of those, okay, here we go, because Bob thinks it is just more work than it's worth...the bottle is just so easy. If we're out you've always got to worry about whatever. So, I decided. I sat him down one night and I said, "Hey I just want to let you know that I'm gonna give the breastfeeding a try. If it doesn't work, it doesn't work. But I'm gonna try." So, he said to me, "Actually, I've given it some thought and I think our situation is very different this time. I think you should do it...whether I believe that it's better than formula or not...we're starting out with such a small baby that we need to do all of the things that even anyone says is better. Let's give it a chance." So, that's probably one reason it went well is because he was very supportive. I knew he was on board with it. He would tease me all the time because I was constantly pumping and he would constantly say, "Isn't breastfeeding just great!" (Theresa)

The experience of breastfeeding, while in today's world deemed so private, seems almost impossible to do alone. The experience has no prerequisites, no frame of reference. Mothers question what is happening. Is he getting any milk? Is he getting enough milk? Without the means to measure answers to these questions, all



mothers have to trust in their bodies, put faith in the unseen and the unknown. We have to believe that we are providing what our babies need, and believing in ourselves means pushing any doubt, pain, or discomfort aside. How do mothers whose infants reside in the NICU continue through uncertainties, especially given the fragility of their infants?

**Was.** The word *was* is the past tense, first and third person singular form of the verb *to be* (Oxford University Press, 20013). *Was* shows things that have happened in the past. I was. He was. She was.

She lifts, so slowly, the door  
to his high-tech womb,  
her own aching,  
for its emptiness.  
His hands flutter and feet twitch,  
she cannot interpret his  
fetal dance,  
a foreign language spoken  
too soon.

The birth-day of our children marks our presentation of them to the world. How will my baby receive me? How will the third person receive us, the others outside of ourselves? Of the five interrelated metaphors identified through a meta-synthesis of 14 qualitative research studies about the experiences of mothers having a preterm infant in the NICU, Aagaard and Hall (2008) identify the metaphor *from their baby to my baby*. This metaphor describes mothers' experiences as they move from feeling like an outsider and visitor to feeling comfortable getting to know their baby within the NICU environment. These researchers found that mothers often initially react to their preterm infant as a stranger or outsider, and at times this can lead to feelings of ambivalence or fear of attachment. How is it to feel you do not know your

own child, a baby who was once a part of you? How do mothers resolve such feelings? Sydney speaks about feeding her twins in the NICU and how this helped her get to know them again:

Well it was...hard. I guess because feeding your child, your baby, is one of the first ways you bond with your child. So it's kind of finally like, I am taking care of them. It is not somebody else giving them feeding through a tube...I am the one feeding them, taking care of them. It was nice. They have rocking chairs...finally...these are my kids, not somebody else's. Especially being young and not being able to take them home...it's away from you. You know, there is still - a distance, like it didn't really happen yet - Did I have them? But, then once I was able to feel like I was actually giving them something, it's real. (Sydney)

Parent-infant synchrony is a term used to describes the interplay between a mother and her infant. Feldman (2007) describes this interplay as one that helps infants form expectations for future experiences and as a process that is thought to embrace the continuous interchanges of sensory, hormonal, and physiological stimuli between parents and children during social interactions. This interchange then offers input essential to child growth and development across the period of early gestation through weaning. Once a child is weaned, maintenance of the parent-child relationship is communicated through the emergence of complex social connections, as opposed to particular behaviors on the part of the parent (Feldman, 2007). It seems the concept parent-infant synchrony describes the dance engaged in by mothers and their children, their attunement. How do mothers get to know their children in the NICU environment with limited access and rules governing their behavior? How do they move through their child being a distinct part of them (what their child was) to getting to know this child from a distance?

Aagard and Hall (2008) also present the two additional metaphors of *striving to be a real, normal mother* and *from silent vigilance to advocacy*. As mothers of infants born preterm work to be what they consider a real, normal mother they face separation from their baby and a mix of emotions. Moving *from silent vigilance to advocacy* describes mothering in the NICU as measured and progressing from passive to active. Mothers were found to reclaim their role as mothers by employing a variety of strategies including, seeking physical interaction with their child, negotiating with healthcare providers, gaining the support of others, learning about their child's medical condition and equipment, and providing breast milk.

Theresa describes her struggles to mother her son in the NICU even after she feels they have achieved attunement and she has moved to nursing him at her breast during visits:

So every time I'd go in, the second I'd talk to him, touch him, he became this madman. When I picked him up, he no longer wanted me (to just hold him), he wanted to nurse immediately, and it was cool...One day we were in the IMC, the intermediate, step down unit at this point. They thought he was getting sick again because he was slightly lethargic. There was only one nurse who told me I couldn't hold him one day when I was there. Well, I had her again and this was weeks or months later, but she said, "I don't think you should hold him today. I know you've been holding him, but I don't know how he's feeling. He needs to rest."...I was sad because it was when I was getting ready to go back to work for the first time. So, for whatever reason he was sleeping and she had to do his cares...well all of a sudden he knows, okay, she's here. He becomes this *spaz* and is crying and jumping all around the bed, practically trying to jump out of the incubator. I finally get him settled where I'm kind of just patting him and the nurse comes over and decides that he needs to be on his belly...I just actually got him calmed down...she says she thinks his saturation will be better if we turn him over. I say, "Okay." So, they turned him over. Now he's extra mad! He's trying to lift his head up and I actually have to laugh that (talking to baby) you can't lift your head up now at nine pounds but you did it at two! I mean he is beside himself! She finally comes over and she says, "Did he calm down?" and I said, "No, he's mad...he wants me to take him out. Every time I come in, I nurse him and he knows this. We don't give him credit that he's older and yes

he's still small, but he's all about getting what he wants now." So, she says, "Actually I think you are right. I think we are upsetting him more than letting him rest." So, I was happy with that. Thank goodness! I went and changed, came back in and instantly I took him out and he was fine. He was instantly fine. (Theresa)

I wonder, too, about inexperienced teenage mothers experiencing preterm birth. Are they even more intimidated by mothering in the NICU environment? Is it a more oppressive space for them? How do they negotiate their place here? Sydney speaks to this a bit and seems to attribute a nurse's lack of expectation to her age:

...even at Good Sam getting away from feeding a little bit...I was young and I was 18, but I looked...younger. I told her (a nurse) I just graduated and she said, "From junior high school (laughing)?" I was just like - no, from high school. They thought I was like 14, so really when I went in there they were very...you don't know what you can or can't do...Some nurses just waited for you to say, or you to jump in, otherwise they would just kind of do their thing. I felt like they discounted me. But, now I think that was part of just experience on the nurses' part. You know what I mean, because when you know the importance of it [tending to the babies' needs], you want the mother or the father to do that. (Sydney)

**Were.** The word *were* is the past tense second person singular, past tense plural, and past tense subjunctive form of the verb *to be* (Oxford University Press, 2013). The mood of this verb shows hopes, doubts, and wishes. We were one. What if I were? What if he were?

She longs to touch him,  
to erase this space between them-  
her hand trembling,  
settling down on this other-worldly  
angelchild,  
her palm enveloping his entire  
torso.

The fact that mother and child were one and shared one body is no longer apparent. How easily they got along when they were inseparable. Now in their individual forms, they must consciously commune and re-collect their pieces in order

to re-member themselves. For mothers of children born preterm and at VLBW, their infants are not only outside of themselves, but for a time are often completely out of reach. How do mothers re-collect their pieces as they sojourn in their child's world of the NICU?

Mothers whose children reside in the NICU seem to exist in the space in-between, a state of liminality. Out of the action required to become a breastfeeding mother in the NICU, comes this state of in-between. Breastfeeding an infant at a distance, born preterm and at VLBW is a relatively new phenomenon. NICU professionals have made significant gains only over the past two decades in the increased survival and care of infants born preterm (Goldenberg, Culhane, Iams, & Romero, 2008). Mothers who choose to breastfeed children born preterm and at VLBW, most often must do so in a manner dependent on the technology of the breast pump. These mothers exist for a time in a state of liminality, as providers of breast milk to children who cannot yet eat. Sydney discusses her time existing in this in-between space of providing breast milk to her babies indirectly. She illuminates the additional barriers of temporary contraindications to breastfeeding, and the idea that what she was providing was not enough:

When I was in Westchester I did start pumping. They brought me the pump in the room. I started pumping. Then when I left, I had to leave them there in Westchester for the week. I left before them. I was there for about 4 nights, I think. Four nights or so, which is the normal for a c-section. I left and they were only there maybe...a few more days and then they were doing well enough to be transferred to Good Sam, which is a Level 2 NICU. But, their issue was still weight and just feeding because they still had the NG (nasogastric) tube at Good Sam and they were starting to suck but, it wasn't enough so they had to supplement and I pumped. I would pump at home and bring it, you know, what I could. But, it still wasn't enough...then I went on antibiotics because my c-section wouldn't heal. I went on antibiotics for...a

week or so, so I couldn't give them anything and then I just wasn't producing and then ...it was just easier to do the formula. (Sydney)

I wonder if the breast pump serves as access to children residing in the NICU, *erasing the space between them*. Theresa was able to persist in the in-between space for two months, long enough for her child to gain the strength to breastfeed at her breast. Her baby had received her breast milk via a feeding tube from the time he was able to feed. She describes that experience:

He was intubated for three or four weeks. So they definitely did not start [feeding him] until after that. It took a while. It was very slow with the feeding tube and [they] were giving this teeny amount. It was a very slow process...I remember that there was one day at three weeks old that I could hold him for the first time. He was still intubated, then once he was extubated and went on the nasal cannula he would just lay on my chest and just do nothing and by probably mid to late February he was off all breathing support. Literally, he would just lay on my chest and just do nothing and he was so content and just would lay there. One day all of the sudden, he was just a madman. Obviously, he was like this teeny (gesturing) and he was moving all around like he lost something. And I'm like - what is his problem! Okay, the baby who is so content and just lays quiet is not quiet and my Mom's like - I bet he's rooting. I mean honestly he's never done this why all the sudden now. So then at some point she comes by and I'm like - what do you think and she's like - I think he is. I think we should give it a try...he's probably not gonna do much. He's probably just gonna latch on once then he'll stop. So, I'm like, sounds good and believe it or not he latched on and it was well into minutes and she's like. "Well he's made a liar out of all of us." I just thought it was so funny that this tiny little guy was just into this. So, from that moment the second he heard my voice he flipped out in the incubator. He would start crying. I think he honestly knew like, "Look. She's here, get me out, stop stalling. I want out of this incubator!" (Theresa)

How do mothers view this act of providing breast milk and what does this mean to them? What place does existing in the in-between disclose for these mothers? Is it a place of exile on the periphery of their children's lives, a proving ground, or a safe haven? Do the NICU walls shelter and support mothers? Are they limiting? What do they create? The NICU, though, is only a temporary dwelling for

all who reside there. It is a stopping place. They are in transition from the home they knew within their mothers' wombs to the home they will come to know. The NICU is a necessary in-between space that serves to prepare these children for life outside of their mothers. Casey (2009) writes about moving between places:

On every kind of journey, one moves between heterogeneous places. A beginning-place and an end-place may stand out as the most conspicuous parts of a journey – they delimit the diurnal aspect, the daily duration, the *dies*, of the journey – but the in-between places are just as interesting, and sometimes more so. (Casey, 2009, p. 275)

**Am.** The word *am* is the present indicative, first person singular form of the verb *to be* (Oxford University Press, 2013). This indicative form of the verb is used when making a strong statement. The first person present is I. I am. Who am I?

She feels  
fragile skin like soft tissue paper,  
his back arches up, he squirms  
at her touch

How does it feel when your child seems not to recognize you, to writhe at your very touch? The skin is the principle mode of interaction between caregivers and newborns, so it is not surprising that the tactile system is one of the first systems to develop and is the most mature sensory system at birth (Vergara & Bigsby, 2004). As a mother reaches out to touch her child, the mother, too, is sensing that touch. She is receiving the tactile sensation of being touched by her child. Heron (1970) writes of encounters between human beings and explains that there are only two cases, one of them being bodily contact, when “simultaneous, reciprocal interaction between qualitatively similar processes occur” (p. 243).

How must mothers of children in the NICU, who are whisked away soon after birth and often cannot be readily touched initially, interact with their children? How

do they re-attach? How do they gain the affirmation that their child knows who they had been?

Full-term newborn infants display primitive reflexes, motor responses to sensory stimuli that originate in the lower brain stem and are not present in neurologically typical adults. Two primitive tactile reflexes that are fully functioning in infants born at full term are the rooting reflex and Palmar grasp reflex. As they lay their trail of typical development, though, children begin to inhibit these reflexes through higher order brain functioning. When rooting, a touch at a corner of the mouth or cheek causes newborns to turn their heads and open their mouths in search of a perceived source of food. The Palmar grasp reflex demonstrates tactile sensitivity in a newborn's hand. When the hand is stroked newborns instinctively close their hands and grasp (Vergara & Bigsby, 2004). Both of these tactile reflexes suggest a reaching toward something, a desire to approach, yet in the womb, avoidant tactile responses are most prevalent. When infants are born premature, they have also not fully developed these, as most primitive reflexes begin to appear around 28 weeks. They are less likely to display these approach reactions. Both the rooting and Palmar grasp reflexes are dormant at 24 weeks gestation and are not considered perfected until 35 weeks (Vergara & Bigsby, 2004). How do mothers feel when they reach out to their children and are met with perceived rejection? Do these women question themselves as mothers? Do they ask the question, "Who am I?" How do mothers remedy this seeming un-re-cognition by their children? How do they re-construct themselves as mothers? How do they become re-cognizable again to their children? What keeps them going until they feel they are?



Levin (2003) portrays the idea of identity construction as something that occurs when one finds they have no history, no shared cultural experience, and no bodily memory:

The carpenter of today repeats the gestures of skill which have always constituted his handicraft; and it is only by the grace of that ancient gesture that he belongs to the tradition of the craft as it has been handed down from generation to generation across thousands of years. Analogously, the mother nurses her child, repeating thereby one of the oldest of human gestures. In these ways, and in countless others, *Dasein* is held open to its history and tradition, and is granted the chance to find in this beholden-ness the deepest dimensionality of its fulfillment as an historical and tradition-bound being. (pp. 174-175)

Where are new mothers of infants born preterm and at VLBW left? Where do they find themselves dwelling with no history or tradition, and in a strange and alien land? How do they belong to the tradition of motherhood without the grace of nurturing, an ancient gesture of motherhood? They cannot nurse their babies and often cannot even hold them, so what is being a mother in this land called the NICU, with its incomprehensible landscape seemingly so disconnected from the natural earth?

**Been.** The word *been* is the perfect form or past participle of the verb *to be* (Oxford University Press, 2013) and indicates completed action. Does he remember who we had been?

and at the sound of her whispered voice  
his eyelids slowly draw up,  
dark eyes drawing her into  
this mystery.

It seems that being able to look into her son's eyes, face-to-face, served as an acknowledgement that he knew her, as a sign of re-cognition. Eye contact is the second type of concurrent and mutually shared encounter between human beings

described by Heron (1970) as each receiving what the other is giving. When two people look into one another's eyes, making eye contact, they acknowledge one another's presence and affirm the place of each. I suddenly become we. The mother's silent *I see you* is met with her child's *I am here to be seen*. Mothers of infants born preterm often are unable to experience this connection with their children because their child's senses and behavior are not yet ripe for the occasion.

Linden, Paroli and Doron (2000) describe vision as perfectly focused from eight to 12 inches after full term birth, the distance to a mother's face when feeding at the breast. In the womb, once the eyelids are formed they subsequently close over the eye and remain fused shut until 26-27 weeks of gestation. Although vision is our most predominant sense after birth, it develops gradually during gestation and is the last to activate. It is not until 30-33 weeks of gestation that newborns seem to discriminate between different visual images and show special preference for the human face. Theresa's son was born at 24 weeks, so early that his eyes were still fused shut. She remembers this and associates it with having difficulty viewing her son as being the child she gave birth to.

It was just so...so funny. His eyes were still fused shut at that point. He never opened his eyes. I didn't know that (they were fused) until a couple days into it. I was like, is he gonna open his eyes? I would touch him or whatever, but I think it took me at least two days, three days to really wrap my head around that this was my baby. (Theresa)

**Are.** The word *are* is the present tense first, second, or third person plural, as well as the present second person singular form of the verb *to be* (Oxford University Press, 2013). This present tense shows things that are happening now or around now. They are. You are. We are.

She is lost now in love,  
and is forever found.  
Too much ecstasy,  
too much desire to sweep him  
up into her arms  
and she chokes on  
the grief and the love,  
surrendering to the joy that he lives, he lives,  
her sunflower, her son!

You, my child, are a work of art, my poetry. You are, thou art, and giving birth marks the presentation of my creation, our being. Does this presentation mark the ending? Is it the beginning? Is it both? Upon giving birth, our poetry crosses a threshold. We push them out of the home that they know and into the world that we know. They are homeless and must find their place. It is at this point that care must begin because without proper sustenance our masterpiece will not live on. Love for this mother presents itself more deliberately as a process. Perhaps facing her son's fragility and appreciating the basic truth that he lives assists her in her own evolution as mother. How do mothers of children born preterm and at VLBW come to this appreciation of who their children are? What part could the provision of breast milk play here?

The ten months of pregnancy begin and end with the revelation of our poetry to the world. At this point, for most, a new crafting can begin. Upon giving birth, our bodies instinctively create a responsive and ever evolving cocktail especially designed to assist as we craft our poetry. Our milk meets the demands of our children. Even the milk of mothers who deliver preterm is an idyllic match for their unique nutritional needs, a testimony to their central place in the lives of their children. We pour ourselves into our poetry from the outside in. We continuously

receive input and change to meet those demands. In the beginning, the production of breast milk just happens. We experience it unwillingly, although some mothers cannot provide breast milk to their babies due to contraindications. Breast milk used to be the only option and today there are others. These alternatives are widely accepted and at times quite necessary. Most often, they are at least considered. Many mothers of infants born preterm and at VLBW cannot nurse their babies at their breasts because they are too small or too sick to do so, and because of this are living at a distance in a NICU. All of us choose to continue crafting our poetry. We nurture and raise our children. Mothering infants born preterm and VLBW in the NICU begins at a distance and, for some, through the provision of breast milk they can find themselves of use to their children.

**Be.** The word *be* has three forms, the infinitive, the subjunctive, and the imperative (Harper, 2001/2012). The infinitive is the basic form of the verb. It merely names the action and usually follows the word *to*. The verb is in the subjunctive when it shows that the content of an expression is doubted, hoped for, or feared true, rather than being directly stated; while the imperative form of the verb strongly gives instructions or commands, and is the base form of the verb.

What does it mean to be? Thinking of *be* as that third part of the conglomerate, I see the *am/was* verb as the parents. I imagine the child's perspective in the womb: I was my father and now I am my mother. Yet, even with those two essentials only time can tell what I will be. What then, comprises the *be*? Could it be it time, place, spirit, will, care, love?

Breastfeeding seems a way for mothers to be with their children, while simultaneously allowing them to be. What is it like for those women who cannot breastfeed directly? Does the act of pumping and providing breast milk, their baby's specialized and unique cocktail, make their once lost connection to their child reappear? It is as if providing breast milk, although indirectly and through the wonders of technology, may blur the lines of separation defining two now separate bodies. Does breastfeeding at a distance assist in breaking down the barriers between mother and child presented in the lay of the NICU environment? Do these mothers consider this act a physical reconnection, as that which is them flows into their child? Does the experience of the breast pump make this act more of a duty, or a sharing?

#### **Tender Verse: Being Called by the Question**

Breastfeeding is the poetic craft of women. This act is something that we alone can do. It is a choice that only women have to make. Men are not afforded this opportunity, although I have known some to partake in a variety of ways.

Women breastfeed the first time they do it and no sooner. There is no practicing its aspects, no honing of skill. It seems an artistic endeavor, requiring such things as presence, willingness, attention, action, thoughtfulness, and responsiveness. Does breastfeeding somehow contribute to the social-emotional development of our infants? Is it possible that the act of breastfeeding contributes to laying a foundation for human intentionality? What occurs for mothers who provide breast milk to their children living apart from them? Is this breastfeeding? I wonder what this experience is like for them.

I wonder what breastfeeding was like for others, for my mother, for my sisters, and for my friends. In this study, I show what it means to be a mother providing breast milk for her infant born preterm and at VLBW living in the NICU of a hospital. The question driving my study is: **What is the lived experience of providing breast milk for one's child who lives in a NICU?** What is breastfeeding like for mothers whose infants hold onto life, as they reside separately and at a distance from them? I ask this question, lantern in hand, in giddy anticipation of enlightenment. I wander through the darkness and wonder what will be revealed as I direct my glow toward my Others. I am excited and thirsty.

### **Clearing Pathways**

Although there are many ways to explore the experiences of mothers providing breast milk to their infants who live in the NICU, being granted access to these experiences through conversation offers the opportunity to allow mothers to *inform*, thus reawakening the obsolete meaning of this word being “into form” (Harper, 2001/2012). I bring the experiences of mothers into form, in the shape of textual accounts and interpretation of those experiences. My motivation for choosing hermeneutic phenomenology as my research method lies in the way it can lead to the dis-covery of truths that lie beneath the surface. Van Manen (1990/2007) discusses phenomenology as a human science that studies persons in all of their uniqueness:

...Phenomenology is, in a broad sense, a philosophy or theory of the unique; it is interested in what is essentially not replaceable. We need to be reminded that in our desire to find out what is effective systematic intervention (from an experimental research point of view), we tend to forget that the change we aim for may have different significance for different persons. (p. 7)

Hermeneutic phenomenology allows for an uncovering of what is hidden beneath, and it empowers me with the use of language and poetic expressiveness to acquaint others with a human experience they most likely will not live through themselves. Through this type of research, I have the opportunity to reflect, that which is illuminated by the glow of my lantern, in a way that allows it to be seen by others. The human phenomenon of providing breast milk to an infant born preterm and at VLBW and residing in a NICU is an experience lived by few women. Due to its interpretive nature, which holds the potential to generate new understandings of complex and multidimensional human phenomena, I view hermeneutic phenomenology as most suitable for this research project. The reflection upon and interpretation of the lived experiences as shared by mothers in an open and natural approach through conversations, can potentially lead to a more complete understanding of how professionals can best support families in this endeavor.

Van Manen (1990/2007) also provides us with six research activities that compose the methodological structure of hermeneutic phenomenology. These six activities provide me with overlapping pathways as guides.

- (1) turning to a phenomenon which seriously interests us and commits us to the world;
  - (2) investigating experience as we live it rather than as we conceptualize it;
  - (3) reflecting on the essential themes which characterize the phenomenon;
  - (4) describing the phenomenon through the art of writing and rewriting;
  - (5) maintaining a strong and oriented pedagogical relation to the phenomenon;
  - (6) balancing the research context by considering parts and whole.
- (pp. 30-31)

I have traveled along, through, and between these pathways as I research the lived experience of providing breast milk to one's infant born preterm and at very low birth weight and residing in a NICU. In Chapter One, I turned to this phenomenon as

I re-turned to my own experiences with breastfeeding. Looking into my ideas about the personal meaning of breastfeeding opens me to consider the experience of breastfeeding one's infant, but apart and at a distance from them. I exposed my preunderstandings of the experience of breastfeeding, and in uncovering these pre-understandings, I am able to look deeper and discover further questions about the experience. I continue turning, peering in the direction of mothering in the NICU through the eyes of two remarkable mothers in my life, focusing my lens using the poem of a third.

In Chapter Two, I consider literature and other textual sources exploring the lived experiences of mothers who provide breast milk for their fragile children, residing separate and apart from them. In doing this, I continue to move beneath my ideas to a place where I am able to receive new meanings through my conversations with other mothers. Through existential investigation, I more deeply explore some of the questions discovered in Chapter Two by researchers and others who have examined this experience.

In Chapter Three, I clarify my understandings of how hermeneutic phenomenology can help reveal the meanings of the experience of breastfeeding for mothers whose babies since birth have resided apart from them. I elucidate the methods and philosophical grounding upon which my research stands through the formation of a landscape of views provided by Max van Manen, Martin Heidegger, and Hans-Georg Gadamer.

In Chapter Four, I unearth themes found within the conversational texts and written participant reflections I gathered. In a final chapter, I offer insights to



professionals working within NICUs and for mothers who experience this phenomenon.

## **CHAPTER TWO**

### **EXPLORING THE PHENOMENON: ENVISIONING THE RE-VISION IN-BETWEEN**

#### **A Diverging Lens**

During my pregnancy, I dreamed of my son's traits. He would be beautiful. He would be brilliant. He would be perfect. Ten fingers, 10 toes, a killer smile, a keen intellect. When my water broke prematurely at 30 weeks, I had to come to grips with the fact that those dreams might not come true. I didn't like it one bit. (Sukel, 2007, para. 12-14)

Breastfeeding in the NICU, where mothers are unable to suckle their newborn children creates tensions, as an intimate experience happens in a non-intimate sort of way. Mothers exist in in-between spaces. Their months spent dreaming a dream of motherhood, pregnant with possibility, are over and they find themselves abruptly awakened, unsure of just how to continue their becoming. They provide breast milk to their children indirectly, by use of pumps and tubes and within the NICU, a place not their own. Here, mothers are unable to hold their children in their arms, unable to place their cheeks against soft newborn skin, and unable to nurse their babies at their breast. Still, they follow through with a re-vision of their motherhood dream. As they urge their bodies onward, what compels them physically and emotionally? What is their lived experience of breastfeeding at a distance from their babies?

Many researchers have studied the developmental, cognitive, and social-emotional outcomes of children born preterm and at VLBW. As a special educator directing my awareness toward the beginnings of life for the many children I have known and have yet to know, these outcomes capture and hold my attention. In this chapter, I look more deeply into the nature of mothering in the NICU and more vividly illustrate this landscape in order to expose to view the meaning of

breastfeeding at a distance. I gaze upon the strange and wondrous terrain that comprises this world where some women begin as mothers. In searching scholarly literature regarding the provision of breast milk to children born preterm and at VLBW, I find an inextricable connection to the expedition of becoming a mother in the public and watchful place of the NICU. Feeding emerges at the heart of mothering. I explore this unique circumstance, where mothers who choose to breastfeed find themselves while doing so at a distance and without the encouragement of their baby gazing upward, urging them on. This exploration traverses through and between a rich variety of sources, including the writings of researchers, philosophers, poets and mothers who have lived this phenomenon.

With increasing rates of children born preterm, and survival at greater degrees of prematurity ever increasing with technology, the development of children born preterm and at VLBW has been a widely researched area. Looking through the lens of risk, research to date clearly and unequivocally demonstrates that being born preterm and at VLBW is linked to poorer school age outcomes as compared to full term, normal birth weight (NBW) peers (Anderson & Doyle, 2003; Hack et al., 2005; Bhutta, Cleves, Casey, Cradock & Anand, 2002; Nadeau, Tessier, Boivin, Lefebvre & Robaey, 2003; Reijneveld, et al., 2006; Samara, Marlow, & Wolke, 2008). The lens of resilience, though, is a diverging one that brings about the extension of rays of light into different directions, although originating from a shared point. Directing our gaze through this lens, reveals breastfeeding as a maternal behavior that significantly affects children's cognitive and social-emotional functioning (Currie, 2005) and breast milk itself as a protective factor related to the development of children born

preterm (Anderson & Doyle, 2003; Drane & Logemann, 2000; Schack-Nielsen & Michaelsen, 2006). Furthermore, infants born preterm and at VLBW represent a vulnerable population at increased risk for neonatal and neurodevelopmental impairments who are far less likely to receive breast milk as compared with healthy term infants (Hill, Ledbetter, & Kavanaugh, 1997; Killersreiter, Grimmer, Buhrer, Dudenhausen, & Obladen, 2001; Yip, Lee, & Sheehy, 1996). The experience of having an infant in a NICU is something most of us will not endure. While the provision of breast milk under such circumstances is increasingly beneficial and recommended, what does the experience of doing so demand?

### **Saguaros and Palo Verdes**

I can still conjure the photographs of the desert I marveled at as a young child in the National Geographic magazines that created a horizon of golden spines on the top ledge of our bookshelf. I felt as if the terrain was otherworldly, intriguing, and mystifying. I was amazed at the people and the animals, but most of all at the earth and flora. The landscape was beautifully barren, yet unexpectedly full of unusual life, like the spindly Palo Verde and mighty Saguaros towering above them amid the rocks of the foothills.

As an intern under the NICU Developmental Specialist of a large Northeastern urban hospital center, I spent time in the Level IIIC NICU (capable of caring for the most unwell of babies born preterm) there. My first visit to the NICU was surreal, and I felt as if I myself were in a daydream. All I could see were Saguaro seedlings and Palo Verde trees. The seedlings were the tiny children born too soon and vulnerable, existing within their microenvironments. Their nurses were

the looming Palo Verde, either standing above or perched on high stools. As I went through the door, the Palo Verde turned toward me and I felt an immediate need to explain, to justify my presence in their world. I was clearly an outsider, and if I did not think so before, I now knew and grasped at my quirky knowledge of desert flora to make sense of it all.

The preceding Palo Verde trees care for the tiny Saguaro seedlings and protect them from the hazards of life outside of the home they once knew, as a kernel inside of the bright red fleshy fruit of their parent. Like these seedlings, babies born before their due time and very small will only grow and develop within a specialized environment and under the specialized care of their nurses, who themselves are under the advisement of neonatologists, nutritionists, and various specialists and therapists. What happens to their mothers? What do they feel they can contribute under these circumstances?

Walking into the VLBW pod in the NICU, I noticed the nurses first and foremost. It was clear they acted as protectors of those who survive beneath them amid what seems a tangled maze of technology. Only upon approaching an individual nurse could I perceive the life existing within a plastic isolette and interwoven among the tubes and wires leading to massive towers of machinery. The complex apparatus attached to each baby seemed almost an extension of the nurses. They check it, respond to it, and consult it as they cared for their seedlings. Do mothers feel that the technology and nurses are replacing them? Do they perceive themselves as being necessary here? How do mothers mother their babies under these circumstances?

## **Mother-Nurse**

Although history credits Florence Nightingale as the founder of nursing as a profession, nursing actually predates medicine with the mother-nurse preceding the medicine man or woman, where “the seeds of medical knowledge were sown by the natural remedies of the mother” (Donahue, 1996, p. 4). The change the word nurse has undergone over the centuries represents a split, into separate beings, of those once united. The mother-nurse role divides into the indistinct roles of mother and nurse, each one still carrying a bit of the other. In the NICU, they are apparently reunited and tensions exist, perhaps not only because their orientations today are so different, but maybe also because each sees them-self in the other, with mother enduring most of the discomfort as she struggles to determine where her place is in her baby’s new life.

Donahue (1996) maps the evolution of the word nurse and in doing so, she finds that the history of nursing is closely related to the gradual changes the definition of the word nurse has undergone, from the primitive suckling of an infant to the refined and erudite profession of today. During the 13<sup>th</sup> century, the word was first used in the English language (arising from Latin and French roots) as a term for a nursing mother, especially a wet nurse. The use of the word in the 16<sup>th</sup> century identified someone, usually a woman, who looks after those who are ill. It was during the 18<sup>th</sup> century that the word stopped naming women within its definition, and it was not until the 19<sup>th</sup> century that the ideas of education, training, and performing tasks while being overseen by a physician make an appearance.

### Accessing Remote Aquifers

In tracing the etymological roots of the word nurse, I find that it dates back to the 12th century. The word finds its beginnings in the feminine form of the Latin word *nutricius*, meaning that which suckles or nourishes (Harper, 2001/2012). The words nurse and nourish both share their beginnings in *nutricius*, as variants of the now obsolete word *nourice*, meaning a woman who takes care of a child, a wet nurse, nursemaid, or foster-mother (Oxford University Press, 2013). Mothers seem like natural nurses, and it seems the very definition of the word nurse describes one attribute of mothering an infant that readily comes to mind, providing nourishment through feeding.

For mothers giving birth to children born preterm and at VLBW, the ancestral impulse of the mother-nurse is arrested, as their children must begin life outside of their reach in the NICU. With feeding presenting itself as central to the idea of mothering and nursing, it is no wonder that mothers in the NICU can feel alienated and experience difficulty re-cognizing their place within the new lives of their babies. I wonder how it is to have one's child handed over to another, to look after, to care for, to foster, and even to nourish. I imagine these mothers as blossoming willows waking in the desert, trying to spread their arms and grow to motherly heights, yet confined by the parched walls of the NICU, and far from their homes along the wet soil of stream banks. The desert life force, though, is long-suffering and tolerant, hallmarked by its slow rhythms and extreme fragility, much like the becoming of a mother in the NICU. The NICU, too, seems a domineering bionetwork, yet

demonstrates a complicated interdependency of the delicately fragile, their mothers, and their nurses. Central to this parched environment of the NICU are the tiny warriors, the Saguaro, children born preterm and at VLBW and their mothers, some of whom hold on to their dreams of motherhood by tapping the remote aquifers of the original meaning beneath the word nurse. Could providing breast milk at a distance be a way for these mothers to answer the ancestral nurse-mother impulse?

### **Palo Verdes and Willows: Distancing the Distant**

A mother's experience of breastfeeding her baby born at VLBW and residing in a NICU, occurs at a distance. The very lives of their children are dependent on the care of others, making traditional mothering difficult at best. Mothers often feel like outsiders in this world, where others are their children's caretakers, and they seem to have difficulty knowing just where they fit. In researching the interactions of mothers and nurses under these circumstances, the ideas of watching and being watched surface in their sometimes shared and often differing notions of care and good mothering.

### **Watching**

In the *Phenomenology of Perception*, Merleau-Ponty (1962/2002) writes, "We must conceive the perspectives and the point of view as our insertion into the world-as-individual, and perception, no longer as a constitution of the true object, but as our inherence in things" (p. 408). The idea behind this is that things can only present themselves to us within certain limits, with those limits resultant from our vantage point. We are only able to declare such attributes to a subject that we are able to *see* based on who we have become to that point as individuals. The word inherence is



derived from the Latin *in plus haerere* meaning to stick (Harper, 2001/2012). We can only perceive those aspects of the object that attach themselves to us in a way that makes particularized sense. I wonder how a baby presents itself to his mother after preterm birth and how nurses present themselves to mothers. The possibilities seem endless, yet individual stories show much commonality.

Of the professionals, nurses were almost exclusively the only ones mentioned within my conversations with Sydney and Theresa, whom I first introduced in Chapter One. Theresa expresses her love for the nurses, yet also that her gaining access to her child was dependent on their approval. They first had to judge her worthy. It was only then that they allowed her to be with her baby at times when they previously would not.

They loved me and I loved them. They were very good, you know. I watched him being extubated and all the procedures that they had to do. They sent me out in the beginning a couple times. And then, once they saw I was a sure thing and I was there on a regular basis, they were like, “Do you mind if we do this?” I’d say, “No, I want to be here.” So, then I got to watch a lot.  
(Theresa)

Theresa reveals the idea of watching and describes it almost as a privilege. How is it to dream of motherhood only to awaken a mere spectator?

Another mother of a son born preterm, who is also a freelance writer, expresses her feelings of watching her baby being mothered during his stay in the NICU, an endeavor undreamt by her prior to then. She, too, awaits permission to attempt re-connection with her son.

I never thought I would be strictly an observer in the first weeks of my son’s life. I imagined that I would be up all hours, complaining about too many night feedings. I saw myself tightly gripping his slippery body and singing silly songs as I bathed him each night. I pictured myself holding him, always

holding him, rubbing my cheek against the silky down of his head, deeply inhaling his sweet scent.

And love. Oh, love. My Mommy friends told me about how I would fall in love with my son at first sight. They told me that life, work, even my husband would all fall away next to the all-encompassing love I would have for my child. It would hit me like a thunderbolt, and I'd never be the same.

Seldom does life unfold exactly how we expect.

Instead, I am the consummate onlooker. I am permitted to be at my son's side for eight hours each day: three in the morning and five in the afternoon. In those hours, I watch my son intently. I observe the nurses tending to him. I stare at his chest, rising and falling in time with the monitors. I wait for permission to open the small doors on the side of his isolette and hold his tiny hand. (Sukel, 2007, para. 7-10).

As mothers watch their babies who were once a physical part of them cared for by those other than themselves, they seem further distanced from their babies. The dream these mothers dreamt during the months of their pregnancy ends, and they wake caught somewhere in-between their dream and their reality. In their dream, upon their babies' birth, they would re-connect with their poetry outside of themselves, get to know them, fall in love with them, and fully become mothers. Instead, they lay in wait. Their becoming is temporarily suspended. How are relationships with others built and rebuilt? How do women become mothers and renew their relationship with their babies in a place where they are disconnected from their children?

According to Abram (1997), "Humans are tuned for relationship. The eyes, the skin, the tongue, ears, and nostrils – are all gates where our body receives the nourishment of otherness" (p. ix). The physical proximity mothers once intimately knew before their baby's birth is no longer available to them. That she is no longer able to feel her baby with her, reduces her shared embodiment to a memory. Mothers

of children born preterm and residing in the NICU, often did not initially experience the expected bond with their child upon giving birth, and this is further complicated in that they are unable to interact with or touch their babies once born (Lupton & Fenwick, 2001).

One mother in particular clearly expresses this feeling of distance, and feeding again makes an appearance.

I wasn't mentally prepared – the fact that you don't get to see them very much and when you do you're not feeding them, it's very distancing. I felt very odd about the whole thing. It didn't feel real 'cause it happened so quickly. I didn't feel like they were my babies. You're not looking after them and you can't sort of do anything. (Lupton & Fenwick, 2001, pp. 1014-1015)

She explains that her babies' birth did not feel real and the babies didn't feel like they were hers because she was not carrying out the actions associated with mothering.

Because she was not able to participate in the care of her babies, she felt further distanced and experienced difficulty attaching to them and feeling as though they were her own. Being reduced to watching seems to place mothers on the outskirts of motherhood.

### **Being Watched**

Merleau-Ponty distinguishes between the two ideas of *geographical behavior* and behavior in its true sense. He describes geographical behavior as “the sum of the movements actually executed by the animal in their objective relation with the physical world,” while behavior in truth is a term that regards these movements “in their internal articulation and as a kinetic melody gifted with a meaning” (Merleau-Ponty, 1963/2004, pp. 50-51). As opposed to a mere sequence of events, our

movements through the world are imbued with meaning. How are a mother's movements in the NICU interpreted by nurses as they watch her?

Sydney speaks here of her feeling of attachment to her twins and the idea of being watched emerges, as somewhat impeding that endeavor. For her, it was not until she was at home with her children, though, that she considered them hers. She contrasts the comfort she felt being herself, once home with the uncomfortable understanding she possesses of the nurses' role in the NICU, hallmarked by their evaluative gaze. Sydney attributes this watchfulness to further distancing her from her babies.

No, it was there in the hospital. I mean of course when you take them home they're yours. You are more comfortable, because (in the NICU) you know there are people there watching you. And they have to watch you because that is their responsibility for the day or whatever. But (at home), you feel a little more free to just be. (Sydney)

As Sydney expresses, when mothers do begin to participate in the care of their babies, they are watched. The mother has been a bystander watching her baby and then moves to the position of being watched. The evaluative gaze of her baby's nurses is ever present.

Through their research examining how women with infants hospitalized in neonatal nurseries due to prematurity or other medical conditions construct and practice motherhood, Lupton and Fenwick (2001) found that nurses view their role as teacher and protector. The nurses have distinct beliefs regarding how mothers should conduct themselves in the NICU, with many nurses either placing mothers in the category of a good mother or considering them difficult. Imagine being judged as to whether or not you are a good mother based on your behavior at a time and within a

situation that seems insurmountable, the weeks following the preterm birth of your baby. Do mothers *conduct* themselves in the same way at all times?

These same researchers found that nurses describe good mothers as happy and friendly, easy to talk to and grateful for the work the nurses do. Does this have anything to do with mothering? Is the baby even a presence in this evaluation of the *good mother*? The nurses were also found to consider those mothers who make their baby their top priority to be good mothers and often judge women on this based on the amount of time spent in the NICU. What do women who have other children do in such a case, or women who are the financial stronghold of their families? What do women do who have no means of personal transportation, whose babies need the most acute care and have been transferred to a Level III NICU in a far and unfamiliar location? On the other hand, mothers who nurses considered as spending *too much* time in the nursery also gained a negative reputation. It seems such nurses do not see the lived experience of the mothers who so desperately need them.

In nurses' overwhelming belief that they are responsible for the education of mothers in *proper* parenting and *correct* infant care, Lupton and Fenwick (2001) found that they consider attempts at traditional mothering practices by mothers to be *rebellious and disobedient*, and expect mothers to care for the infant in the way *they* teach them. The nurses' view of themselves as protectors of the infants, justifies their positioning of mothers as potentially harmful to their babies. Nurses enact this by discouraging mothers from handling infants, hovering over mothers and constantly advising them how to handle the infant, and preventing touching. As these mothers

are objectified by their babies' nurses, they are distanced even more from their babies.

I can feel myself under the gaze of someone whose eyes I do not even see, not even discern. All that is necessary is for something to signify to me that there may be others here... From the moment this gaze exists, I am already something other, in that I feel myself becoming an object for the gaze of others. (Lacan, 1991, p. 215)

In the above excerpt, Jacques Lacan demonstrates that the gaze actually belongs to the object of the gaze as opposed to the subject. Although nurses often feel justified in watching mothers in the NICU, do they realize how this affects the objects of their gaze?

Mothers who have infants residing in the NICU not only have to navigate through their new environment, but they also must forge relationships with the nurses, which is in addition to getting to know their new child, to re-member and re-new their relationship. Sometimes mothers and their babies' nurses stand side by side in agreement, and sometimes in stark disagreement, about what is best for the baby. Either way this is a delicate relationship, where nurse can stand between mother and child, with the nurse feeling that she is the protector and teacher, and the mother viewing the nurse as a hurdle she must become strong enough to clear.

### **Converging Ideals**

Lupton and Fenwick (2001) also found that both nurses and mothers share some ideas of good mothering in the NICU. These ideas include being physically present, showing interest and concern for their babies, inquiring about information related to their babies' condition and care, learning the language of the NICU, and taking part in the physical care of their babies once medically stable. These ideas, in

themselves, do not convey much meaning. Just because one feels doing something is a good idea, does not mean mothers can carry these practices out without difficulty. Within the complexities of the mother-nurse relationship, how are mothers supported in carrying out these agreements related to good mothering? How do mothers and nurses view the same situations?

An interesting set of two articles published together are entitled “Reflections in the NICU” (Jed, 1999; Morris, 1999). In the first article, a mother describes her experience of the preterm birth of her daughter and her time in the NICU, while one of her daughter’s nurses writes the second article describing her experience in the NICU.

The mother writes here about her view of the nurse, and once again feeding emerges at the center of mothering, as she considers her baby’s weight gain a triumph in the days after NICU discharge.

Not for a minute did she forget what we were going through, or overlook that we were nearly as frail as our daughter...Alyssa came home right on her due date, thanks to the miracle workers in the NICU. Now our exhaustion is the kind that comes from the demands of a feisty baby. She’s over 18 inches long and weighs 5 pounds, 7 ounces; she’s in the 25<sup>th</sup> percentile of other newborns. Will she become a star athlete or an Ivy League scholar some day? For now, we’re happy just to see a double chin and dimples. (Jed, 1999, p. 22)

In comparison, one of Alyssa’s nurses writes about her own experience in the NICU. She views her job as a quest to get babies home to their parents, positing holding and breastfeeding as triumphs, and emphasizes the other extreme of infant death.

The daily span of emotions in the NICU is long and varied: unspeakable sadness when parents have to make the soul-destroying decision to take their baby off life support – a decision that deserves respect – and the inescapable feeling of having little control over the unexpected death of an infant thought

to be doing well. But balancing the sadness is the elation we all feel when a baby no longer needs to be intubated, when a mother and father hold their baby for the first time, or when an infant finally breastfeeds months after birth. My greatest satisfaction, though, comes from seeing a child, born with the odds against him, discharged home to a loving family. (Morris, 1999, p. 23)

The mother, in this case seems to view the nurse in terms of her relationship to her. She respects the work the nurses do, describing them as the *miracle workers*, but she emphasizes the nurse in her *being-with*, rather than focusing on technical knowledge or expertise. The nurse conveys a feeling of discomfort with her inability to anticipate and control the outcomes of illness. After all, this is what she is trained to do. She views her goals as keeping babies healthy and getting babies home. Although the relationship with the nurse was most salient to the mother, there is no emphasis by the nurse on goals to foster this relationship or to be a source of empowerment for mothers in the NICU. Even when mothers and nurses mutually consider their relationship to be a good one, there are still priorities and strong foundational beliefs on the part of each that differ from one another.

### **Resistant Convictions**

To be situated within a certain point of view necessarily involves not seeing that point of view itself. (Merleau-Ponty, as cited in Leder, 1990 p. 33)

There are more instances than not when mothers' and nurses' differing priorities and agendas position them in conflict with one another. Lupton and Fenwick (2001) found that mothers strive to reclaim their role through establishing a connection with their babies, and that this results from feelings of distance and detachment due their babies' circumstances. The major difference between mother and nurse views on being a good mother is that mothers place priority on being there



bodily for their infant. Engagement with their infants through affectionate touching and care for the infant, as well as developing close emotional bonds, is of utmost importance to mothers. Nurses often restrict such interactions, and this is a source of stress for mothers, as they feel unable to develop a bond with their babies. Focusing more on mothers showing concern for their infant's welfare and learning about their infant's condition and care, nurses were not found to place a high priority on loving touch and bonding. Mothers express the importance of breastfeeding as a part of good mothering, but the nurses rarely mention this act as a part of what they consider good mothering (Lupton & Fenwick, 2001). Could this be because nurses see breastfeeding as something they themselves cannot directly *teach* through demonstration? Are nurses viewing breastfeeding in this case only from a medical standpoint, focusing on the provision of the breast milk itself as opposed to the meaning of doing so for the mother? Do the nurses only feel the mothers should learn what they are able to teach them? Can pumping and storing breast milk in the early weeks after the preterm birth of an infant born at VLBW be a mother's only way to feel as if she is contributing to the baby's wellbeing? Is this a way for mothers to continue their becoming? Could this be a way for mothers to make themselves once again a tangible presence in their babies' new world with-out them?

### **Desert Willows: Becoming a Mother in the NICU**

The moment a child is born, the mother is also born. She never existed before. The woman existed, but the mother, never. A mother is something absolutely new. (Rajneesh, as cited in Malloy, 2011, p.8)

Desert willows are delicate, small, deciduous trees able to adapt to arid conditions, whose leaning, artfully entwined trunk opens into a spreading coronet.

Their long and narrow leaves only resemble those of a willow's (Texas A & M University, 2013). I imagine mothers enter the NICU as willows, ready to become the mothers their mothers were, ready to nurture, touch, and be with their children as they hold, cuddle, love, and take care of them. Instead, their attempts at this historical mothering are out of tune with what the NICU demands, making it necessary for them to shape a re-vision of their motherhood dream and become in a different way. How does this becoming unfold? Born on the day of their child's birth, as their babies' mothers, they instead must discover new ways of mothering as they face the differing demands of the NICU. From the outside, they must adapt to a NICU environment that does not seem to nourish them, looking like the good mother to nurses (thankfully willing to watch and learn), while on the inside the mother they *intended* to become lies dormant in silent struggle.

### **Mothering**

Although the research to date examining the experience of providing breast milk to children born preterm and at VLBW conducted in the United States is scarce, the provision of breast milk falls under feeding; this presents itself as a central component to becoming a mother. In my exploration of becoming a mother in the NICU, I begin with the findings of a meta-synthesis focusing on "typical" transitions to motherhood and conclude with research conducted among mothers whose initial becoming takes place within the NICU. How is becoming a mother during the period after the birth of one's baby under more typical circumstances similar to becoming a mother in the NICU after preterm birth? How do these experiences differ? Necessary to becoming a mother is engagement in the work of sustaining the life she

has created, and becoming a mother is a time dependent process, characterized in the NICU by postponement (Hyunjeong & White-Traut, 2007). What part do mothers play in the NICU?

The nature and pattern of human mothering is laid out in the womb. Prior to birth, both fetus and mother are subject to a nurturing process that occurs spontaneously after conception...The mother continues to accommodate to and to function for her baby in many of the same areas as she did prior to birth. She provides sustenance, temperature control, protection from danger, and immunity to certain diseases through antibodies in her milk. The mother also offers continuity to the infant in that her heartbeat and movements are sensations with which the infant is familiar. Through physical closeness and by holding and carrying her infant, she provides tactile, kinesthetic, and sensory stimulation and aids the baby in adjusting from a weightless world to the pull of gravity. Through her presence to her infant, the mother eases the transition from life inside her body to life outside her body. Although our culture does not recognize it as such, gestation does not end with birth. For the human mammal, it continues for many years after birth. (Kimmel, 1997, para. 7-8)

What is mothering? What exactly is it that mothers *do*? Mothering brings to mind so many things, but mostly it seems caring for another in the infinite ways that an individual other may need care. Like the word care, the word mother also exists in noun and verb form. The noun form primarily indicates the female parent of a human being, with the verb form of the word indicating becoming the mother of, to act or behave like a mother, to take care of, and to protect (Oxford University Press, 2013). Tracing the etymology of the word, I find the verb is at the core of its meaning; the verb form meaning to "take care of" is first recorded in 1863 (Harper, 2001/2012). It is out of her *action* that she becomes.

Mothering an infant is a dynamic and unpredictable process that fosters development because of the relationship formed. Yet, normal infant development requires more than care; it requires attachment, commitment, *and* caring (Kimmel,

1997). In light of this, mothers of infants born preterm and at VLBW have unique experiences related to attachment and care in the NICU. Does the meaning of breastfeeding at a distance lie here? Is providing breast milk to their “out of reach” infants representative of the commitment component of mothering for them? Could this particular act be a mother’s action at a time when other actions, too, are out of reach? In terms of attachment, they cannot touch, hold, or gaze into their babies’ eyes. They have difficulty experiencing the presence of their child and cannot actively participate in caring for their babies, as Others are doing that. Perhaps they really are being displaced from mothering.

### **Becoming**

A large body of research exists related to the transition to motherhood under what are considered typical circumstances, and in the following section I discuss a recent meta-synthesis of studies exploring this. I also discuss research related to the less studied area of becoming a mother in the NICU.

**In known places.** Through a meta-synthesis of studies exploring the transition to motherhood, Nelson (2003) exposes active engagement as a primary and essential social process, leading to the secondary social process of growth and transformation. This meta-synthesis is a result of the findings of nine qualitative studies limited to women participants of North America or Australia, as mothering practices differ dependent upon culture and societal expectations. The researcher excluded studies where women experienced this transition in the circumstance of preterm birth (among others) in order to interpret a more typical experience. She states, “Only through making a commitment to mothering, experiencing the presence

of the child, and being actively involved in caring for her child does a mother open herself to the opportunity to grow and be transformed” (Nelson, 2003, p. 475). Yet again, the three ideas of commitment, attachment, and caring emerge.

In tracing the etymology of the word commitment, I find its use dates back to the 1610s, and carries the meaning of the committing of oneself, a pledge, or a promise (Harper, 2001/2012). Breaking the word into its two parts of commit and *ment* provides further insight. The word commit finds its beginnings in the late 14<sup>th</sup> century, carrying the meaning “to give in charge, or entrust” and from the Latin *committere* meaning “to unite, connect, combine: to bring together” (Harper, 2001/2012). Does a mother’s commitment to her baby through breastfeeding lie here, in an attempt to re-unite, re-connect and re-combine? Peering deeper still, we can see the word commit as *com* meaning together and *mittere* meaning to put, or send (Harper, 2001/2012). Is breastfeeding in all forms a commitment in the sense that mothers are sending a part of themselves to their children so as to bring the two back together?

My sister sends me a multimedia message, as I sit here writing. It is a photograph of my newest nephew (born three weeks ago at a robust eight pounds) stretched out on his back with his hands behind his neck. The caption reads, “Rhys is living the life!” I text her back and tell her how proud I am of her and what a great job she is doing with the nursing. She replies, “Lol...thanks...it is a true test of will...” (Aislin).

**In the NICU.** In examining the work of researchers investigating the experience of becoming a mother in the NICU environment, I identify the common

theme of this as a time dependent process (Heerman, Wilson, & Wilhelm, 2005; Jackson, Ternstedt, & Schollin, 2003; Lupton & Fenwick, 2001). Mothering requires action, yet mothers are often unable to participate in the active care of their babies in the first weeks and sometimes months after preterm birth. One mother clearly expresses that she did not feel like a mother due to such inaction.

Invariably, the first question that friends and family ask me is, “How does it feel to be a Mommy?”

I understand that this particular game of pretend is for my benefit, so I try to answer graciously. In truth, I do not know how it feels to be a mother. Not yet. For now, my child is being mothered by the tubes and wires snaked around his minute body. My child is being mothered by those same alarms that seem to make my own heart stop. My child is being mothered by a different woman every eight hours: the nurse from whom I must ask permission to touch my own son. It would seem that I have little to do with any of it. (Sukel, 2007, para. 5-6)

Not only do mothers in this circumstance lose their infants to the technology of the NICU and the medical professionals, but she, too, seems lost. Steeves (2006) explains, “When something or someone is lost, we feel the loss as a present absence” (p. 56). These mothers have lost their babies to the necessary circumstances that follow preterm birth, but more than losing someone (the baby), the loss these mothers undergo may simultaneously represent a loss of self in the part of them that was their baby. After all, they were not finished crafting their work of art.

But when one is lost one’s self, the phenomenology is different. My Here becomes nameless, anchored only to my bodily presence. The nexus of Theres that surrounds me becomes unfamiliar, inhabited by unfamiliar Others. I do not lose my communitarian nature, but I feel so different, differently constituted by these Others, and this place. To distant Others I may be presented as absent. To myself, I am present in the unknown. (Steeves, 2006, p. 56)

Do mothers of children born preterm and at VLBW experience a simultaneous loss of self and someone else? How do these mothers become in a place where they feel so *differently constituted*? Leder (1990) uses the etymology of the word absence to consider the relationship of presence and absence.

An absence is the being-away of something. The lived body, as ecstatic in nature, is that which is away from itself. Yet this absence is not equivalent to a simple void, a mere lack of being. The notion of being is after all present in the very word absence. (Leder, 1990, p. 22)

How is it that mothers, even when visiting with their babies in the NICU, exist as a present absence? What is it that is being-away? Perhaps motherhood itself is away from these mothers, the part of them that was still becoming. After all, it is only through one's child that one is a mother. With their babies out of reach, motherhood is as well. As these mothers wait, in this in-between place, to engage in mothering, does the pumping and storing of breast milk help to move them forward in the re-vision of their motherhood dream and in their experience of mothering?

Two months after her baby is discharged from a NICU, one mother shares her emotional state and the shame in being a present absence while her baby resided there, unable to truly bond with her infant.

...everyone said: "But Sara, doesn't it feel good? Isn't it glorious to be a mom!?" I think that's criminal! Because that's not how you feel. In fact, it's only now in the last month that I can feel the real thing...that it's us two and how fond I am of her. It has taken a really long time. You hardly dare to say it. (Flacking, Ewald, & Starrin, 2007, p. 2408)

How do these mothers know that they are a presence in the new life of their babies? One month after her baby's discharge, another mother describes her longing for recognition of her relationship from her child.

I've given so much...and these months have been so hard...so you start to feel that you want something back. Then I would get my strength and pleasure back again. I want to feel that he knows who I am, that I'm a mother to him. It has taken me such a long time to understand that he's mine. I will feel it 100% when he's happy to hear me. (Flacking, Ewald, & Starrin, 2007, p. 2410)

Across five studies exploring the process of becoming a mother in the NICU, four states that mothers often find themselves in throughout their becoming are woven throughout. They are *mixed feelings, existing on the periphery, giving care as impulse and from this to that*.

***Mixed feelings.*** Many mothers experience ambivalence related to the unexpected birth of their babies, as they are processing happiness about their baby's arrival along with the grief associated with preterm birth. Often, the important turning point comes when mothers are able to take their baby out of the incubator, which leads to them viewing the situation as more real and positive (Jackson, Ternstedt, & Schollin, 2003).

The delivery was bittersweet: My husband caught a glimpse of Alyssa as they whisked her away. We didn't know if we should be thrilled to be parents of a tiny girl who weighed little more than a loaf of bread, or brace ourselves for the real potential for tragedy. (Jed, 1999, p. 22)

Another mother shares that she did not exactly know how or what to feel.

I just thought I was going to have a small baby...It just didn't occur to me that this was going to be so stressful; this was going to be an unhappy time. The doctors came in and said things to me, but you're excited about having a baby and just want your baby to be okay. When I first saw her I had mixed feelings. I was like, "Is something wrong with my baby and they didn't tell me? Are they keeping something from me that I don't know?" That's what I was thinking at first and I had mixed emotions. I didn't know whether to laugh or smile or cry or be happy. (Holditch-Davis & Miles, 2000, p. 16)



Mothers' views of their relationship with their baby are fraught with mixed feelings as well, as often they see their baby as belonging to the nurses, due to the technology of the NICU and the baby appearing tiny and fragile.

I didn't really feel like a parent at first. Especially the first couple of weeks when she was in the isolette and she had all these tubes and wires and oxygen and vent tubes and NG tubes and central lines. And even though I have a medical background, I still always felt like I needed the permission of the nurses. This was more their baby than it was my baby. (Heerman, Wilson, & Wilhelm, 2005, p. 178)

This idea of temporary ownership of the baby serves as a barrier to a mother's sense of possessing her baby or having the rights or privileges that come along with the baby being hers (Heerman, Wilson, & Wilhelm, 2005).

***Existing on the periphery.*** What is it to exist on the periphery?

It is through my bodily surface that I first engage the world. Only because my eyes and ears lie on the surface of my body are they capable of disclosing the events taking place around me. My hands, in order to explore and work upon the world must extend outward from my corporeal "extremities." My expressive face can form a medium of communication only because it is available to the Other's gaze. No organ concealed in the hidden depths of my body could actualize intersubjectivity in this way. It is thus necessary that our perceptual, motor, and communicative powers cluster at or near the body surface. The surface is where self meets what is other than self. (Leder, 1990, p. 11)

The word periphery finds its roots in Latin from *peri* meaning "round about" and *pherein* meaning "to carry" (Harper, 2001/2012). In the NICU, mothers find themselves outside of the inner workings of the NICU professionals. They are not yet part of this inner circle of which their baby is the center. How do mothers become as they pace the circumference of their baby's sphere of influence, carrying with them all things motherly? One mother describes her feelings existing on the outskirts, as an observer.

My son's appearance is morbidly comic, and I find myself thinking that if all the world is a stage and men mere players, then by cosmic accident my son has been temporarily cast as some sort of sideshow freak, locked in this transparent case. And me - I do not feel like a mother. Instead, I am the naïve, eager spectator, always pressing her face too close to the glass, waiting for something amazing to happen...Desperately hoping that my son will be normal. (Sukel, 2007, para. 12-13)

This mother, like others, found herself hovering around the edge of motherhood, and as a result, felt a diminished maternal role (Hyunjeong & White-Traut, 2007). What is it that holds women to their babies in these circumstances?

The hardest part was not holding him. I guess when the doctor told me there was a chance that he might not make it, and I had not held him, that was horrible! The best part was holding him...And then having to leave every day and leave him there. Someone else was caring for him, feeding him, holding him. Those were the hardest. As a result, during the NICU I did not feel like I was the one parenting him. I wasn't able to care for him the best way possible. There were others who knew how to take care of him better than I did. And that was tough. (Holditch-Davis & Miles, 2000, p. 18)

One concern, which mothers share with fathers, is the fear that their baby will die, making it both difficult to visit *and* to leave (Jackson, Ternestedt, & Schollin, 2003). A mother shares her experience, with this concern becoming a barrier to time spent with her baby.

It's been so up and down. It's still hard to believe. Seeing the baby was such a strain in the beginning. During the first few days after the birth I made short visits here (the NICU), maybe twice. I don't really want to think about the future, not now, but maybe in a month. I don't dare. (Jackson, Ternestedt, & Schollin, 2003, p. 123)

This concern affects another mother differently, as she found difficulty leaving her baby. "It was hard to go home, because I really wanted to stay with her in case anything happened" (Jackson, Ternestedt, & Schollin, 2003, p. 124).

***Giving care as impulse.*** Jackson, Ternestedt, and Schollin (2003) also found that mothers in the NICU possess a unique need for participation in care that is quite

the opposite of fathers, as fathers routinely delegate care to nursing staff. Could this need for active caring expressed by mothers find its roots in the ancestral impulse of the nurse-mother? Could this be an attempt to regain the life they once shared with their baby?

The maternal/fetal relation is another chiasmatic identity-in-difference giving rise to me. While separate, we are enfolded together, sharing one pulsing blood stream. Even after birth, through the act of breast-feeding, one body is nourished directly from the visceral production of the other. (Leder, 1990, p. 67)

At this intersection, the baby comes to be known by the mother in terms of the parts of him that are not her. She must now get to know him as his self outside of her, even though once they existed as one. How does she do this when her baby is “out of reach”?

I think also, when you have a c-section, it is a very detached weird thing that happens. You don't feel like you had a baby and then you don't get to see them right after and spend any time with them. It is a weird sense. (Theresa)

Theresa initially seems to associate her feeling of detachment from her baby with having a c-section, but reading on reveals that it has more to do with the nature of the procedure, with her baby being taken away.

Mothers often describe nurses as facilitators, acting on their care-giving impulse, as the following two mothers do. As described, *both* action and inaction on the nurses' part can be supportive.

We came here right after I was discharged (from the post-partum unit) because I wanted to see her. The nurse that was on duty was really good about it, “Come on, let's get you settled and then we'll get her out.” She was so sick and on the ventilator. I thought, “No, no, leave her alone.” The nurse said, “No you're mom and you need to hold her and she needs to be held by you.” She made it real easy and made me feel really good about doing that. (Heerman, Wilson, & Wilhelm, 2005, p. 179)

(My daughter) got out of the oxygen and off all the monitors. And when I could start holding her and not be told, “Would you like to hold her?” or “Would you like a cuddle?”...like being able to come in and pick her up myself and sort of start managing it myself, making more decisions rather than waiting for the nurses. I think that’s when I started feeling more like a mother. (Lupton & Fenwick, 2001, p. 1015)

*From this to that.* Heerman, Wilson, and Wilhelm (2005) identify three processes that mothers move through in the NICU: their focus – from NICU to baby, their voice – from silent advocacy to claiming responsibility for infant care, and their caregiving – from passive to active. Mothers initially focused on the NICU, with their babies existing in the background of an overwhelming NICU environment. Mothers kept the NICU in the foreground as they focused on technology, the expertise of nurses, and the language and culture of health care providers. These researchers also found that some mothers, for whom the NICU remains in the foreground, begin to take on the language and culture of the NICU, and in speaking about their babies, do so in a less personal way.

Even when he is on the vent, I know whenever he’s getting low enough on his sats that I need to get someone. Yesterday he desatted a couple really bad instances where he had to be bagged up. (p. 177)

Just as the nurse objectifies the mother through her surveillance, the mother, too, can objectify her baby. Perhaps this is also a result of distance. By virtue of the notion that one’s baby is out of reach, his mother cannot get to know him without interaction with him. It is only when the baby becomes his mother’s focal point that the NICU can fade into the background as simply being a service provided to her infant. Another mother demonstrates this, as she shares thoughts about her son, “Paul doesn’t do what the book says. If you read the book right next to Paul, you can watch him and he’s doing the opposite. There is the book of Paul and very few people know

that book” (Heerman, Wilson, & Wilhelm, 2005, p. 177). This mother seems to be looking at her baby as he presents himself to be, rather than through the lens of the NICU. What facilitates this transition for mothers?

The metaphors from silence to advocacy and from passive to active indicate a mother’s claiming of responsibility for her baby’s care and the subsequent giving of that care (Heerman, Wilson, & Wilhelm, 2005). How do mothers become sure enough to care for their fragile babies? Theresa shares her experience in moving from silent advocacy to claiming responsibility for the care of her baby with regard to feeding.

We would always do it [feeding] through the tube over a certain amount of time, like an hour, because his blood sugar was always kind of hit or miss. So, they [nurses] were very nervous to take him off. Sometimes we were on 24 hour feeds. We were on that a lot. Then we would get off for maybe an hour, but then we’d go back on again. We would do three and one, but that wouldn’t work...They [nurses] did a good job, in my opinion, of trouble shooting. But, my thought was always - okay, he’s getting bigger, why aren’t we just allowing him to take what he wants to take by mouth and see if he can maintain his sugar because we weren’t really changing the quantity. We were staying with very low amounts and over such a span of time! I’m like who eats over 24 hours! So, it was very strange.

By mid-March probably I was at my end. I was like look, “You need to switch something up here. I mean he’s such a good breastfeeder”. He would breastfeed for 20 minutes on one side and ten minutes on the other or 20 and 20. Why is he doing so awful at the bottle?...So finally, they [nurses at hospital where surgery took place] took the feeding tube out for surgery. For whatever reason, they didn’t address the blood sugar issue...I was kind of freaked out a little bit, but at the same time not. They just said, “He’s fine. He’s doing fine.” So even after the surgery when we went in...he didn’t have his feeding tube in...and she [the nurse] was like yeah he’s taking all bottles...we’re having no issues...the blood sugar is staying good.

*So...*when we were getting transferred back...that was my big thing. Don’t put that feeding tube back in, because they [the nurses] were not so sure as to what we were gonna do...but they [the nurses] did in the end decide to switch it to all bottle and sure enough...he did fine. You know, he came home nine days later.

They [the nurses] would bottle-feed him like once a day and gavage everything else. So, I kept saying, “If he needs practice with the bottle why are we not practicing every feeding?” But, they were quick to say, “Well, he gets tired. He gets worn out, you know.” That’s when I just finally said enough excuses! So, to the one nurse I said that I was going to fight with her about it. You know, nicely. We had a nice relationship. She said to me, “Okay we’ll talk about it when you get back after surgery.” But, we never had a talk about it because he was starting to do bottles. (Theresa)

Theresa moves from thinking about the needs of her baby in silent advocacy to claiming responsibility for his care. Using her voice to express her opinions and desires, instead of simply accepting the nurses’ answers, was a process.

Sydney shares more of her NICU experience, focusing on the giving of care.

But, they were good; you know when we went in. It depended on the nurse also. Some nurses wanted you to do [the cares]; if you were there, you did everything. Some nurses if you were there and it was time for a bath, you did the bath...Some nurses just, you know, waited for you to say, or for you to jump in, otherwise they would just kind of do their thing. I think that was part of just experience on the nurses’ part. You know what I mean, because when you know the importance of it (participation in care), you want the mother or the father to do that. (Sydney)

Sydney wanted encouragement from her daughters’ nurses in order to participate in the care of her twin daughters. She clearly understood the importance of a mother caring for her baby and attributes a nurse’s lack of encouragement to inexperience. Do NICU nurses realize that mothers feel unsure about what part they are to play in the care of children born preterm and at VLBW? Do they understand that a lack of voice and action on the part of mothers could be a consequence of their own behavior, as opposed to purely a shortcoming on the mother’s part?

### **Rendezvous with a Dream**

I wonder if mothers in the NICU feel that they are awaiting a rendezvous and pump breast milk as a way of remaining committed to motherhood, while preparing

for the day when they are once again together and re-connected with their children. Perhaps they reminisce about times spent with their child during pregnancy, feeling as though they are missing out on something indefinable now that they are apart. Mothers describe the preterm birth of their babies as surreal; it is as if they were in a dream. The NICU *visits* seem like a rendezvous with a dream, as they wait for the day when they will rendezvous with *their* baby. Could this, in part, explain why when mothers are able to take their baby out of the isolette, mothering takes on a drastic change for the better?

I wait for my son to open his eyes. I hope he will recognize me from all my long hours here at his side. I dream that he will hear my voice, and then his eyes, unaccustomed to the light, will blink a few times before seeking mine. I daydream about it often.

When it finally does happen, I am surprised. I smile at my baby, call him by name, and reach for his hand through the small plastic door of the isolette. His gaze is unwavering, and, in response, my heart opens wider than I ever thought possible.

As promised, it comes...The thunderbolt. (Sukel, 2007, para. 33-36)

When mothers are away from their newborn babies born preterm and at VLBW, their thoughts remain with them and during their dream-like visits, the mothers are for a brief time together again, knowing that time is fleeting. They wait for the day they consider themselves *true mothers* and that includes their baby, being touched, being held, being fed, and being taken care of by them. Perhaps they prepare, awaiting a rendezvous with a dream. Could the initial pumping and storing of breast milk be the only aspect of mothering mothers here can demonstrate? Does this act help to actualize their commitment to motherhood when attachment and active care giving cannot? Could this be a chance for mothers to present themselves

to their babies, at a time when they are unable to *be* in the presence of their babies?  
Do they engage in this act as an assertion and confirmation of their being, as they are temporarily with-out such mutual presence reciprocated through touch and eye gaze?

From the 1590's the verb rendezvous presents itself from *rendez*, the imperative of *render*, meaning "present" and *vous* meaning "you", carrying the general sense of a an "appointed place of meeting", and looking deeper still, the meaning of the word as conveying "to give as a gift" is first recorded during the mid 13<sup>th</sup> century (Harper, 2001/2012). A baby's presence is finally realized as a gift to his mother.

When the moon begins to beam  
I'll have a rendezvous, a rendezvous with a dream  
Down beside a rippling stream  
My heart will lead me to a rendezvous with a dream  
Then you will say that you love me and hold me so tight  
But like the stars up above me  
You'll fade away in the night.  
But when at last my dreams come true  
I'll have a rendezvous, a rendezvous with you.  
(Robin, Rainger, Rose, Poulton & Green, 1936)

As mothers await this rendezvous, they are envisioning the re-vision of their motherhood dream. Some choose to pump breast milk for their infants during this time in-between. In the next chapter, I lay out the philosophical foundations of my questioning and the methodology used in my research. I explain how I use hermeneutic phenomenological methodology in order to listen to the voices of mothers who live the phenomenon of providing breast milk to their "out of reach" babies.



## CHAPTER THREE

### PHILOSOPHIC AND METHODOLOGICAL FOUNDATIONS

The human phenomenon of mothers providing breast milk to their babies born preterm and at VLBW while residing “out of reach” in a NICU is an experience lived by few women. Due to its interpretive nature, which holds the potential to generate new understandings of complex multidimensional human phenomena, hermeneutic phenomenology is most suitable for this research project. The reflection upon and interpretation of this lived experience, as shared by mothers in an open and natural approach through conversation, leads to a greater understanding of the meaning within this phenomenon. This understanding, when made available to mothers, their families, and NICU professionals, can serve as a foundation to personal growth and relevant supports for mothers and babies.

The phenomenological question that I am attempting to answer through my research project is: **What is the lived experience of providing breast milk for one’s child who lives in a NICU?** Additional questions related to this overarching one include the following: What aspect of mothering does this serve for these women? Does a commitment aspect of mothering play a part in the pumping of breast milk, as differing from the attachment and giving care aspects of mothering usually associated with breastfeeding a newborn at the breast?

There is a dearth of studies that address this unique breastfeeding experience, while giving voice to the mothers who have lived it. The focus of such research to date has been the effects of breast milk on infant health and development and the specific qualities of the breast milk itself. Researchers designing interventions aimed

at increasing the amounts and duration of breast milk provided to infants born preterm and at VLBW, often have not considered mothers' voices. These voices are an element without which the goals of such efforts most likely will not be realized.

As the purpose of this study is to understand and interpret this unique breastfeeding experience, it is important to note that the evidence of breast milk versus formula for infants within this vulnerable population is well established. The AAP, Healthy People 2010, and the Baby Friendly Hospital (BFH) Initiative all call for the provision of breast milk to this population (American Academy of Pediatrics, 2005; U. S. Department of Health and Human Services, 2011; World Health Organization & UNICEF, 2009). The AAP Section on Breastfeeding not only emphasizes the benefits of human milk feeding for infants born preterm, but also the importance of maternal support and education in the hospital setting to promote breastfeeding and the use of expressed breast milk (American Academy of Pediatrics, 2005). How are hospitals striving to support mothers, without first considering the meaning of this experience for them? Why is it important to discover the meaning, as a mother, of providing breast milk to one's infant born at preterm and at VLBW and who resides "out of reach" within the NICU? This study represents an approach to the exploration of this phenomenon in a way that does not objectify mothers or their breast milk. Without such studies, we are continuing to stage interventions designed to increase the number of infants receiving expressed breast milk (EBM), without an understanding of what this effort demands of mothers.

The intended goal of my research is to gain a rich understanding of the emotional and bodily context for this time hallmarked by early bonding, discerning

whether a commitment aspect of mothering can be found here. Where does the provision of breast milk in this way fit within mothering in the NICU? What purpose does it serve for the mother? As the survival of infants born preterm and at VLBW, along with the formation of NICUs, is a relatively new phenomenon, the gathering of knowledge related to this lived experience seems important in the building of a collective awareness. My hope is to provide essential insight into the lived experience of this phenomenon for these mothers, their families, others who may find themselves in similar circumstances, and the professionals who work with them. Such insights can prove essential to relevant practice and policy development.

In this chapter, as I continue my travels along the phenomenological path, I explain my choice of hermeneutic phenomenology as a methodology best suited to uncover the meaning of this lived experience. A discussion unfolds as I consider how the nature of the research phenomenon itself has led me to a deepened understanding of hermeneutic phenomenology. I then lay out my navigational plan for this terrain through my methodological approach, using the six research activities of van Manen (2007).

### **Phenomenology: Being Drawn In**

I found myself not jumping into phenomenology, not boastfully announcing the liberation it had bestowed my thought. Instead, it quietly took me in, compelled me by what it offered, and I will not ever be as I was before. Today, I am walking a foggy path and welcoming the clouds that have met my earth. They allow me greater latitude, a movement of body that without them would be exposed, but not necessarily thoughtfully considered. This movement steals me away.

Phenomenology is about saying ‘No!’ to the meaning system bequeathed to us. It is about setting that meaning system aside. Far from inviting us to explore our everyday meanings as they stand, it calls upon us to put them in abeyance and open ourselves to the phenomena in their stark immediacy to see what emerges for us. True enough, the phenomena in their stark immediacy – the ‘things themselves’ – will prove elusive. In describing what comes into view within immediate experience (or even in thinking about what comes into view), we necessarily draw on language, on culture. For that reason, we end, not with a presuppositionless description of phenomena, but with a reinterpretation – as new meaning, or fuller meaning, or renewed meaning – it is precisely what we as phenomenologists are after (Crotty, 2003, p. 82).

Phenomenology provides an approach that allows me to dis-cover a phenomenon for which I have many ideas and some connection. I am a woman who has given birth. Making the decisions to breastfeed each of my children was apparent, eminent, and obligatory. I gave birth to full term, healthy babies and my body responded by producing milk to nourish them. My children were not born smaller than usual or before the usual time. They were with me, not residing in the NICU of a hospital at the time of enacting my decisions.

My intent to access mothers’ meanings of providing breast milk to their babies residing “out of reach” in a NICU, as opposed to explaining or predicting their behavior, comes out of my chosen field of Special Education. This field that I have poured myself into is based on the idea of the individual differences and needs of the minority, of the outliers. Those living lives hallmarked by one or more disabling conditions, very likely to have occurred by chance, are the very persons with whom we are concerned. Mothers give birth to children with special needs every day. They have a beginning, and through my proposed research, I am choosing to direct my gaze towards what is this beginning, for some.

While natural scientific methods of inquiry tell part of the story of providing breast milk to infants born preterm and at VLBW (they have been crucial in comprehending breast milk's protective qualities for infants belonging to this vulnerable population), human science methods of inquiry, such as phenomenology, can tell other parts. Van Manen (1990/2007) clarifies the differing orientations of the natural and human sciences.

...at the risk of oversimplification one might say that the differences between natural science and human science resides in what it studies: natural science studies "objects of nature," "things," "natural events," and "the way objects behave." Human science, in contrast, studies "persons," or beings that have "consciousness" and that "act purposefully" in and on the world by creating objects of "meaning" that are "expressions" of how human beings exist in the world. (pp. 3-4)

Phenomenological research begins in the life-world, the commonplace and often taken-for-granted world where human beings live out their lives every day. It is a study of lived experience and the exposition of phenomena in the way they present themselves to human consciousness, resulting in an offering of insight into what it means to be human (van Manen, 1990/2007).

Phenomenology asks, "What is this or that kind of experience like"? It differs from almost every other science in that it attempts to gain insightful descriptions of the way we experience the world pre-reflectively, without taxonomizing, classifying, or abstracting it. So phenomenology does not offer us the possibility of effective theory with which we can now explain and/or control the world, but rather it offers us the possibility of plausible insights that bring us in more direct contact with the world. (van Manen, 1990/2007, p. 9)

Phenomenology provides us with a widening as opposed to a narrowing view. It opens us to "lay aside, as best we can, the prevailing understandings of those phenomena and revisit our immediate experience of them," and in doing this

“possibilities of new meaning emerge for us or we witness at least an authentication and enhancement of former meaning” (Crotty, 2003, p. 78).

### **Hermeneutic Phenomenology**

Hermeneutics is the art or science of interpretation, and use of the term originally referenced scripture before expanding to encompass both written and spoken language (Oxford University Press, 2013). Hermeneutic phenomenology is a descriptive or phenomenological methodology in that it focuses on the way conscious human beings perceive and understand their lived experiences. It is also an interpretive or hermeneutic methodology, as it maintains the orientation that the particulars of lived experience are meaningful experiences captured in language, rendering it impossible to describe phenomena without interpretation (van Manen, 1990/2007). Lived human experiences are the data collected in the human sciences, and these data, whether they be written accounts, transcribed interviews, anecdotal information from close observation, literature, journals, or works of art, all comprise the text of human science research (van Manen, 1990/2007). The process of understanding such texts hermeneutically can be explained within the context of the hermeneutic circle.

### **Hermeneutic Circle: Language, Questioning and Human Conversation**

A discussion of Heidegger’s (1927/2008) concept of the hermeneutic circle describes the process of understanding a text hermeneutically. Within this circle, individual parts of the text are unknowable without considering the other parts and the whole. The reader moves between the whole of the texts and its parts until she

reaches an understanding and interpretation of the meaning contained in the text within its historicity or context.

McPhail (1995) describes the interpretive tradition as an invitation to special education researchers to inquire into their own consciousness through entering the hermeneutic circle, and as having the potential to imbue our field with a refreshing sense of sincerity. Heidegger's idea of the hermeneutic circle refers to a process of self-reflection in deriving textual meaning that is situated in our understanding of text and within our preunderstandings. Gadamer builds upon this and in his re-conceptualization of the hermeneutic circle, discusses the experience of interacting with a text as follows:

...a person trying to understand a text is prepared for it to tell him something. That is why a hermeneutically trained consciousness must be, from the start, sensitive to the text's alterity. But this kind of sensitivity involves neither "neutrality" with respect to content nor the extinction of one's own self, but the foregrounding and appropriation of one's own fore-meanings and prejudices. The important thing to be aware of is one's own bias, so that the text can present itself in all its otherness and thus assert its own truth against one's own fore-meanings. (Gadamer, 1975/2006, pp. 271-272)

This approach to text as possessing otherness or a *radical unfamiliarity* is something I see as unique to hermeneutic phenomenology, while at the same time fundamentally necessary to the meaning making process. Gadamer seems to elaborate on the concept of the hermeneutic circle with the idea that through conversations with others, we are able to delve into a new reality. The fusion of one's own *horizon*, or all that is seen from one's vantage point, with the text's *horizon* creates this reality, and in the end, the two can reach an agreement that signifies a new awareness. How is a new awareness revealed? Phenomenology offers authentic understanding through the merging of my horizon with others, as opposed to an

attempt at placing myself in another's shoes along a path, which I now perceive as wrought with the thorny bushes of arrogance and presumption.

### **Language**

For Heidegger, hermeneutics and phenomenology become one: "If 'hermeneutics' retains a nuance of its own, this is the connotation of language" (Richardson, as cited in Crotty, 2003, p. 97). Gadamer, too, depicts language as the medium of hermeneutic experience, and the acceptance of language as speech allows us to view all language as dialogue. This acceptance enables us to treat even text as a partner with which to interact. It enables us to view text not as a compilation of words in their unalterable permanence, but rather as alive and stirring with emergent meaning. A task of the hermeneutic phenomenologist, therefore, lies in breathing new life into the words on the page. This breathing of new life is an unveiling, a showing of seen things more fully. The hermeneutic phenomenologist uses language to unspeakably whisper what is often left unsaid. She does this through her engagement with her data, the various texts of life, and in her tireless effort of desiring understanding. Interpretation in this way goes beyond recreating the one meaning that is unchanging and verifiable. It reaches beyond and toward the new understanding of a reality and renders this understanding into a language that speaks anew.

### **Dasein: Being-in-the-World**

This phenomenological study represents my effort to expose-to-view the meaning of being, as revealed through the everyday events of mothers providing breast milk to their "out of reach" infants. My ontological focus is the exploration of



mothers who, too, are born preterm due to the preterm births of their children. These mothers are continuously becoming, and once born, find themselves having to continue this becoming in a different way. They must become *differently-abled* in order to practice mothering in a place where traditional mothering does not quite fit. Within this circumstance, mothers pump and provide their breast milk to their children at a distance. What is the nature of being a mother breastfeeding an infant who is “out of reach?” As a phenomenological researcher, I attempt to illuminate the meaning of being-in-the-world or *Dasein* for these mothers from the inside of their everyday worlds.

Everyone is the other, and no one is himself. The *they*, which supplies the answer to the *who* of everyday Da-sein, is the *nobody* to whom every Da-sein has always already surrendered itself, in its being-among-one-another. (Heidegger, 1927/1996, p. 120)

Heidegger writes that *Dasein* is more than just our individual existence. It has to do with the relationships we have with others. It has to do with the idea that being among one another is what helps us to become more fully. *Dasein*, our being-in-the-world, lies in our relation with others.

The point of phenomenological research is to borrow other people’s experiences and their reflections on their experiences in order to better be able to come to an understanding of the deeper meaning or significance of an aspect of human experience, in the context of the whole of human experience. (van Manen, 1990/2007, p. 62)

*Dasein* for my sister, her being-in-the-world, in her place, at her time, in the circumstances of her breastfeeding experience – is her meaning, as mine is mine. What must it have been like for her? I cannot place myself there, and instead, I choose to engage in the hermeneutic circle. In *Dasein*, we are constantly becoming – my sister herself today could not walk the same path she did six years ago even in the

face of the same circumstances, yet it is today that she and I together can come to a deep understanding of that very walk. Therefore, I ask what is it like for a mother to breastfeed her infant who is “out of reach,” as a facet of the possibilities of human being-in-the-world.

### **Navigating the Terrain while Mapping Meaning**

In navigating the terrain of breastfeeding one’s baby who is “out of reach,” in search of meaning, I will consult the map of six research activities described by van Manen (1990/2007). These activities are the very meandering and overlapping pathways that I will travel. Without imposing a rigid structure, these activities provide a prearranged and substantial scaffolding of material that is lithe enough to respond to the textual accounts gathered along the way.

Van Manen (1990/2007) presents a methodological structure of human science research as a relationship between the following six research activities, which I will use to guide my study:

1. turning to a phenomenon which seriously interests us and commits us to the world;
2. investigating experience as we live it rather than as we conceptualize it;
3. reflecting on essential themes which characterize the phenomenon;
4. describing the phenomenon through the art of writing and rewriting;
5. maintaining a strong and oriented pedagogical relation to the phenomenon;
6. and balancing the research context by considering parts and whole. (pp. 30-31)

Although I present these activities in a stepwise fashion, they are not linear as each influences the other throughout, and is intertwined within, the research process.

### **Turning to the Nature of Lived Experience**

To think is to confine yourself to a single thought that one day stands still like a star in the world’s sky. (Heidegger, 1971/2001, p. 4)

This hermeneutic phenomenological project begins with the directing of my gaze toward an “abiding concern” (van Manen, 1990/2007, p. 31), and as I pondered the experience of providing breast milk in Chapter One, my thoughtfulness related to this concern deepened. A component of turning to the nature of a lived experience involves realizing something that deeply interests you and then recognizing this concern as an experience that human beings live through (van Manen, 1990/2007). This turning includes bringing to light my understanding, presuppositions, assumptions, and biases related to the experience of the phenomenon, as well as formulating the phenomenological question. Van Manen (1990/2007) suggests that our knowing too much is a problem of phenomenological inquiry:

The problem of phenomenological inquiry is not always that we know too little about the phenomenon we wish to investigate, but that we know too much. Or, more accurately, the problem is that our “common sense” preunderstandings, our suppositions, assumptions, and the existing bodies of scientific knowledge, predispose us to interpret the nature of the phenomenon before we have even come to grips with the significance of the phenomenological question. (p. 46)

The purpose in explicating our assumptions and pre-understandings as part of this activity is not in an attempt to find a way to place these explications outside of our knowledge of the phenomenon, or even to ignore them. Rather, the point of this pursuit is to bring those ideas to the forefront of our consciousness, to confront them and deliberately put them aside as we investigate (van Manen, 1990/2007). In Chapter One, it was only through the discovery of the meanings I held within my own breastfeeding experience (as a way of continuing my bodily connection to my babies after birth) that I was led to formulate the phenomenological question of the meaning of providing breast milk to one’s own infant residing “out of reach.” This continued

bodily connection with my own children provided me a way to get to know them as an Other and to build a new relationship with them outside of myself. The loss of self I associated with birth was transformed into the gaining of a new relationship with my baby through breastfeeding. My turning to the nature of the lived experience is what allows the reader to wonder and deeply question the phenomenon of study with me, to discover what is enveloped and what presents itself through the unwrapping. This unwrapping is not unlike that of a gift with paper spiraling from its beginning point, revealing the gift's different angles and facets until it is completely uncovered.

### **Investigating Experience as We Live It**

This activity includes the sharing of lived experiential accounts from those who have experienced the phenomenon through as many sources as possible. It is within these sources that the essence of the phenomenon exists as the meanings to be uncovered by the researcher and participants. In beginning to investigate experience as we live it, I draw upon personal experience as a starting point, beginning in Chapter One with my own personal experience of breastfeeding. A phenomenologist often uses personal experience as a starting point because the experience of one individual represents the possible experience of others (van Manen, 1990/2007). Doing this assists me as a researcher in my task of looking into the meaning of the phenomenon under investigation.

Also included in this second activity is the tracing of etymological sources and idiomatic phrases, and obtaining experiential descriptions from others through protocol writing, interviewing, observation, literature, and art. In Chapter Two, I look deeper into mothers' lived experiences of breastfeeding their "out of reach" infants by

tracing the etymology of the language used to describe the experience of mothering and breastfeeding. Doing so alerts me to possible indications of the meaning of breastfeeding at a distance, as tracing the etymologic sources of these words provides a way for me to reconnect with the original lived experiences from which those words arose (van Manen, 1990/2007).

In Chapter Two, I also consult the scholarly literature on the topic of becoming a mother in the NICU as part of my preliminary investigation, as well as poetry and essays written by mothers experiencing preterm birth and motherhood in the NICU. The poetry and essays assist me in further unlocking the experience of mothers who breastfeed apart from their babies, and provide a lens through which I can gaze more deeply into the scholarly literature. Literature is unique in its ability to “announce fundamental life experiences which are available for our interpretive rendering” (van Manen, 1990/2007, p. 70), with poets having special abilities, resulting in their work being frequently encountered in phenomenological writing.

A poet can sometimes give linguistic expression to some aspect of human experience that cannot be paraphrased without losing a sense of the vivid truthfulness that the lines of a poem are somehow able to communicate. (van Manen, 1990/2007, pp. 70-71)

Using varied literary sources, and in looking back at the text of prior conversations with mothers, I reflect on their experiences as captured through language. In looking to phenomenological and other scholarly literature on becoming a mother in the NICU, I am able to shed additional light on my phenomenological question by creating additional sources with which I can engage. Deeply reflecting upon the way other women have made interpretive sense of mothering in the NICU allows me to

consider facets of meaning I have not previously contemplated, leading me to see feeding as a central aspect of mothering.

Going forward, I continue my interaction with the texts of mothers who have lived the experience of breastfeeding a child “out of reach.” The textual sources that I collect include verbatim transcriptions of audiotaped participant conversations through interviews, and reflective participant journals. The goal of obtaining experiential descriptions from others lies in searching for the nature of a phenomenon as an experience that is in essence a human one, and this is where phenomenology differs from other qualitative research approaches (van Manen, 1990/2007). The purpose of hermeneutic phenomenological research is specific and twofold, as it may be used as both a way to gather experiential narrative material and as a way to cultivate a conversation with the research participants concerning the meaning of an experience (van Manen, 1990/2007). The first purpose is more of a gathering activity, while the second one falls under the following activity of reflecting on essential themes and the art of writing and rewriting, as the textual excerpts are used to engage in conversation with participants about the meaning of an experience, once preliminary thematic analysis has taken place.

### **Reflecting on Essential Themes and the Art of Writing and Rewriting**

The two activities of reflecting on essential themes and the art of writing and rewriting have an inextricable connection when conducting hermeneutic phenomenological research, and are therefore, presented together in Chapter Two from preliminary conversations, as well as in Chapter Four throughout the thematizing process. The purpose of hermeneutic phenomenological reflection is to

take hold of the essential meaning of something, thus gaining insight into the essence of a phenomenon (van Manen, 1990/2007), and this reflection is done through the conducting of thematic analysis. Van Manen writes that themes “are the stars that make up the universe of meaning we live through” and that it is “by the light of these themes we can navigate and explore such universes” (p. 90). Phenomenological themes can be understood as the experiential structures that make up an experience and are used to describe an aspect of the structure of a lived experience (van Manen, 1990/2007). Analyzing a phenomenon involves determining precisely what the themes are. The phenomenologist grips the essence of a lived experience through phenomenological description and then releases that experience into the view of others in phenomenological rendering with something more than a simple reconstruction of the experience, bringing the reader to a place of understanding through transcendence. The goal of thematic descriptions is to develop a text that illuminates themes while remaining true to the universal quality or essence of the experience (van Manen, 1990/2007).

In isolating thematic statements, van Manen (1990/2007) describes three approaches: “1) the wholistic or sententious approach; 2) the selective or highlighting approach; 3) and the detailed or line-by-line approach” (pp. 92-93). In identifying thematic aspects of lived experience descriptions, the wholistic approach engages the researcher in deliberating with the text as a whole in order to portray its basic meaning as a whole, while the highlighting approach involves reading a text over and over and highlighting salient or particularly illuminating phrases (van Manen, 1990/2007). In generating themes from the texts of lived experience, researchers can

also use the detailed reading approach. It is through this approach that each and every sentence or sentence cluster is examined to discriminate just what it shows about the described phenomenon (van Manen, 1990/2007).

As hermeneutic phenomenology is fundamentally a writing activity with the ultimate aim of creating a phenomenological text (van Manen, 1990/2007), in order to describe and interpret the phenomenon, we must gain an understanding of it.

Creating phenomenological text is the foundation of a hermeneutic phenomenological research project, with writing occurring throughout the research process;

phenomenological methodology is sensitive to the subtle undertones of language. I have rendered the results of my thematizing into a meaningful, poetic description of the phenomenon through use of the vast possibilities of language. Gadamer

(1975/1997) writes to the connection between writing and the reflecting on essential themes through questioning:

This is why understanding is always more than re-creating someone else's meaning. Questioning opens up possibilities of meaning, and thus what is meaningful passes into one's own thinking on the subject... To understand a question means to ask it. To understand meaning is to understand it as the answer to a question. (p. 368)

In doing hermeneutic phenomenological work, phenomenologists blend writing into the research activity and into active reflection uniquely using the literary devices of metaphor and anecdotes. Van Manen (1990/2007) quotes writer Virginia Woolf on the use of metaphor:

By the bold and running use of metaphor, the poet will amplify and give us not the thing itself, but the reverberation and reflection which taken into his mind, the thing has made; close enough to the original to illustrate it, remote enough to heighten, enlarge, and make splendid. (p. 49)



Anecdotes can serve as methodological devices in phenomenological writing to make comprehensible some notion that easily eludes us. Among the functions of anecdotes is their ability to get to the heart of lived experience, thus exposing hidden meanings. Van Manen (1990/2007) captures the value of anecdotal narrative:

Methodologically speaking, story is important because it allows the human science text to acquire a narrative quality that is ordinarily characteristic of story. A hybrid textual form is created, combining the power of philosophic or systematic discourse with the power of literary or poetic language. (p. 121)

### **Maintaining a Strong and Oriented Pedagogical Relation**

Van Manen (1990/2007) explains that the text of phenomenological research should be oriented, strong, rich, and deep. When researchers are oriented, they do not separate texts from life, and as hermeneutic phenomenologists, “We are not simply being pedagogues here and researchers there – we are researchers oriented to the world in a pedagogic way” (van Manen, 1990/2007, p. 151). A text that is strong expresses the most solid “pedagogic interpretation of a certain phenomenon” (van Manen, 1990/2007, p. 151). For a text to be rich, “The meanings of the lived sense of the phenomenon are not exhausted in their immediate experience” and “its description is concrete, exploring a phenomena in all its experiential ramifications” (van Manen, 1990/2007, p. 152). Maintaining this orientation throughout the research is vital in creating a text that stirs and brings to the surface the deep meaning that rest beneath the visage of life’s day-to-day experiences.

### **Balancing the Research Context**

This last activity takes me back to Heidegger’s (1927/2008) idea of the hermeneutic circle and of interpretation and textual meaning as a way to interpret the nature of being. Within the interpretivist framework, summations made over specific

situations are not scientific generalizations, but instead are part of a range of experiences within a given present time frame, and taken as a whole, incorporate past into present (Short, 1990).

In balancing the research context, we must remain aware of the effects our research may have on the individuals and institutions involved in our research projects. The value of interpretive knowledge in the case of this research study lies in a mutual understanding that arrives from mothers sharing what their breastfeeding experiences mean to them with others who have reasons to want to know.

How can one gain insight into the lived experience of another? We primarily do this through language. In listening to one another's stories and attending to the language used to express and share our experiences, we can gain this insight as we engage in hermeneutic phenomenological conversation.

### **Methodological Process for Engagement of the Study**

The authenticity of the lived experience of breastfeeding in the NICU can be revealed through this hermeneutic conversation, and can lead us to greater understanding. In the following sections, I explain the methodological processes in which I engaged while conducting my study. I discuss the guides, the route of excursion, and finally the journey's deliberation.

#### **Route of Excursion**

In the following section, I describe how I conducted this study. I provide details about the participants who serve as my guides along the way as they allow me to gaze into their lifeworlds as mothers, and I discuss the ways in which I sought their participation in this project, as well as the informed consent process. I discuss my

gathering of textual sources, which were in the forms of transcribed participant conversations and reflective journal entries. Finally, at the conclusion of this section, I discuss the process used to analyze these textual sources.

**Guides.** In this hermeneutic phenomenological study, I examine the lived experience of mothers providing breast milk to their babies born preterm and at VLBW. My guides on this journey are a diverse group of 10 mothers who have lived the uniquely human experience of breastfeeding a child “out of reach” in a NICU. These mothers share their stories through conversation, and conversation serves as a way to co-construct the meaning within their experience.

The criteria for selection of the mothers include the following: 1) they gave birth to and provided breast milk for their baby born preterm and at VLBW, 2) their baby received expressed breast milk (exclusively or mixed with formula) during his/her stay in the NICU when on full enteral feedings, 3) their baby has been discharged from the NICU, 4) it has been no more than 6 months since the birth of their baby, 5) and they were fluent English speakers. As English is my only fluently spoken language, I am choosing to exclude non-English speaking mothers from participation in this study due to the in-depth nature of the conversations. I utilized an eligibility checklist to ensure all mothers meet the criteria for inclusion (see Appendix A: Eligibility Checklist).

***Gaining participation.*** I recruited mothers for participation at the time of their first visit to the NICU Follow-Up Program at the University of Maryland Hospital for Children (UMHC). All biological mothers of infants born preterm and at VLBW were considered via the UMHHC NICU Follow-Up Program by means of their

first scheduled appointment. The NICU Follow-Up Program exclusively follows babies from (but not restricted to) UMHC, Mercy Hospital, Anne Arundel Medical Center, and Holy Cross Hospital born at or less than 32 weeks gestational age or at or less than 1500 grams, as well as those with any high-risk medical condition. Infants attending the NICU Follow-Up Program were no longer residing in the NICU. My decision to gain participation from mothers at this point in the lives of their babies was an attempt to ensure that their participation in the study did not add any undue stress, as babies at this time were medically stable and residing at home.

The Developmental Specialist identified potential mothers after they had scheduled the first NICU Follow-Up visit for their baby, and she provided the appointment time of any potential participants to me. At this time I went through the eligibility checklist to determine which mothers I would speak with regarding potential participation in this study. During that first NICU Follow-Up appointment, I approached potential study participants confidentially within the examination room designated for her and her baby at the beginning of their scheduled appointment, while they were waiting to be seen by a neonatologist. At this time, I provided an overview of the study and went through the eligibility checklist with interested mothers. I then explained the requirements for participation, as well as her right not to participate in the study. I explicitly stated that nonparticipation in the study would in no way affect the quality of care that she and her infant would receive in the NICU Follow-Up Program. At this time, I also informed mothers about their right to ask questions about the study, refuse to answer any questions related to the study (even

after granting their consent to participate), and to withdraw from the study at any time.

***Informed consent.*** If mothers indicated verbally that they were willing to participate in the study, I then presented them with the consent form and reviewed it before requesting a signature (see Appendix B: Consent Form). I obtained informed consent only after I was ensured of each individual mother's awareness that participation in the study was voluntary, including the right to refuse to answer specific questions and to withdraw from the study at any time. I again assured mothers that choosing not to participate in or withdrawing from the study would in no way affect subsequent NICU Follow-Up care. I described the research objectives, procedures, risks, and benefits at this time as well.

Before requesting mothers to sign and date the consent form, I asked each participant if she had any questions regarding the nature of the study, with the intent of ensuring understanding. I reiterated that there would be no judgments made based on the information provided by the participant and that any information provided would assist other parents of VLBW infants, as well as NICU professionals. Finally, once consent to participate was granted, I provided each participant with a copy of her consent form for her records, and obtained her individual contact information in order to schedule our initial conversation.

### **Gathering of Textual Sources**

In this section, I discuss the two types of textual sources that I gathered along the way, which include transcriptions of participant conversations and participant reflective journals. Each participant engaged in two to three conversations with me.

During the initial conversation, I gathered some preliminary information, provided and explained the reflective journal, and began to engage in the conversation process. During the second and third conversations, we continued our conversations in more depth, as well as reviewed the preliminary themes provided to them, and discussed reflective journal entries.

I captured all participant conversations via a digital voice recorder and subsequently transcribed them verbatim. Each mother was provided with an overview of the study and its goals prior to beginning the conversations, as well as being reminded that they were participating voluntarily and could withdraw at any time during the course of the study. Finally, I discussed the efforts I took to protect their confidentiality and safely store all information they provided.

### **Participant conversations.**

Dialogue is the encounter between (wo)men, mediated by the world, in order to name the world. (Friere, 1970/2006, p. 88)

Van Manen (1990/2007) describes interpretation through conversation as a relation between the speakers, and the notion or phenomenon that keeps the conversation intact. He goes on to describe the purpose of conversation as a way of prompting participants to reflect on their experiences in order to determine the deeper meanings or themes of these experiences. Being granted access to the lived experiences of mothers through conversation offers me the opportunity to be “informed” by their lived experience and able to “render the full significance of its meaning” (van Manen, 1990/2007, p. 62).

All participant conversations were conducted individually, in the homes of individual participants, and were captured via digital audio recording, and

subsequently transcribed. Once I completely transcribed a conversation, I listened to the audiotape again while reading the transcription to ensure its accuracy, making changes as necessary. After reviewing the individual transcriptions in their entirety, I identified the study subject on each page of the transcription by an alias. Mothers received copies of my preliminary themes (based on our first conversation) at least two weeks prior to our scheduled second conversation. At this meeting, I provided mothers with the opportunity to clarify or revise any of their statements from the first conversation to ensure they felt their thoughts had been accurately represented.

Each initial conversation with participants began with the use of open-ended conversation starters allowing for focused, yet conversational, two-way communication (see Appendix C: Conversation Starters). Additional questions became a part of the conversation as mothers brought forward their experiences. I used such additional questions as a means of encouraging mothers to focus and reflect on their experiences, and describe their experiences as they were lived.

I engaged in second conversations (and a third as necessary) with each mother in order to bring the phenomenon forward, and to pursue preliminary themes gleaned from the initial conversation. I read and reread transcripts before scheduling the second conversation with each participant, in an effort to unearth preliminary themes and identify additional questions and points needing further clarification. This second and third set of conversations scheduled with each mother were conducted as a means of maximizing interpretive insight gained through deeper reflection on the experiences brought forward in the first conversation. This second conversation between researcher and participant is an opportunity to interpret the significance of

preliminary themes and weigh their appropriateness (van Manen, 1990/2007). At this time, mothers also had the opportunity to discuss and share aspects of their entries in the reflective journals.

**Reflective journaling.** During the time between the initial and second conversation, I left each mother with a reflective journal and asked her to share any ideas that came to mind after our first conversation. I welcomed any such reflection in the form preferred by each mother (including notes, poetry, drawings, photographs, and other modes of expression that they could capture on paper). Mothers kept the journal until the time of the second or third conversation, at which point I collected it from them. Mothers also used the ideas in their journal to engage in our second conversation.

As noted by van Manen (1990/2007), writing is inherently reflexive, making it difficult for the writer to stay close to an experience as it was immediately lived, as writers tend to include explanation and interpretations with their description of the experience. Therefore, the additional conversation followed the reflective journaling period, where the mothers were encouraged to focus directly on the actual experience represented in their journal entry and describe it in as much detail as possible.

**Confidentiality.** As the only potential risk in the study was the possibility of a breach of confidentiality, this was substantially limited through the securing of transcribed data, which were kept in a locked briefcase and stored in a locked file cabinet. In addition, all electronic data were password protected. I assured mothers that I would keep their information stored safely, and reminded them that they had the right to refuse to answer study questions at any time. I also reassured participants that



withdrawal from the study would in no way affect the quality of subsequent care in the NICU Follow-Up Program.

### **Journey's Deliberation**

I used two copies of each unabridged transcript in this process. The first copy was kept intact, and I used the second copy to organize segments across interviews into thematic categories. Each set of transcriptions from a given conversation were printed on colored paper, with each participant assigned a unique color. In doing this, I was able to match segments to the original transcript, allowing for the clipping of individual segments of texts in order to chart emerging themes, while retaining a connection and reference to the whole. I also kept my own journal to record ideas about preliminary themes and their relationships as they emerged during reading and re-reading. My writing in this journal was ongoing throughout the research process.

Analysis of textual sources in the form of transcribed participant conversations and reflective journal entries began as I engaged van Manen's (1990/2007) wholistic reading approach to isolating thematic statements. This involved reading and rereading of the participant transcripts in their entirety to see what spoke to me and then beginning interpretation and description of the conversation as a whole. After this initial reading, I moved to the selective reading approach, as I read and reread, I identified and highlighted salient phrases and ideas that directly related to the experience of providing breast milk to one's infant living "out of reach" for each mother. After doing this I summarized the textual sources gathered from the individual participants through interpretation and description, while

retaining each mother's voice prior to looking at individual units of meaning through use of the line-by-line approach.

Thematizing is a way to arrive at the experience of breastfeeding at a distance and within this process I identified themes and recurring patterns of meaning (ideas, thoughts, and feelings) throughout the text. The task of determining incidental as opposed to essential themes is both a difficult and controversial element of phenomenological human science research. The researcher must discover the aspects that make a phenomenon what it is, and without which it could not be (van Manen, 1990/2007).

Once I completed the transcription of an entire conversation, I reread it a third time, with the purpose of identifying emerging themes. I kept a record of these emerging themes using my reflective journal, underlining segments of the transcription and linking the segment to the preliminary theme using removable post-it notes. It is at this point that I mailed a list of preliminary themes to the mother and called to schedule our second conversation. After I repeated this process with the transcriptions of at least three transcribed conversations, I began to organize these identified segments into themes. Doing this allowed for the easy movement of text across themes and helped bring aspects of individual themes into view, while simultaneously viewing the relationship between and across themes as a whole.

After the second conversation and along with the reflective journals, I identified cross-cutting themes and grouped them under much broader themes. I determined, at this time, if a third conversation was desired. I then worked with the final set of broad themes across participants, using segments of the text as support in

order to grapple with the meaning of breastfeeding in the NICU. I also addressed what the pedagogical insights were from the study, so that NICU professionals might more fully live their pedagogic relationship with mothers and their babies.

### **My Unearthing**

May the road rise to meet you;  
 may the wind be always at your back;  
 may the sun shine warm upon your face,  
 the rains fall soft upon your fields.

And until we meet again,  
 may God hold you in the hollow of his hand.  
 (Irish Blessing)

These words visit me from the grave of an Irish Nana taken too soon. As the clouds lift, I am confused and exposed, yet find myself contented as I reveal that I am simply - going. So, where is that you ask? Like the Irish blessing given to a traveler embarking on her next journey, the way of doing hermeneutic phenomenology does not provide one with a route to a predetermined destination, but rather the consciousness to navigate the overlapping and meandering pathways that lay before her. Instead of setting out on a mapped journey and following specific thoroughfares, the road did indeed *rise to meet* me, as the paths taken depended upon what life's texts presented to me.

I am forever changed. I engage hermeneutically, in a way that causes me to see the world as a more wonderful place. I find myself more deeply reflecting upon and wondering about my experiences and the experiences of Others, but more importantly feeling comfortable in doing that. I have had a quotation hanging on my wall for close to ten years now. It states, "Be patient toward all that is unresolved in your heart and learn to love the questions." I do not remember where I found it or if,

when I found it, there was an indication of who said it, but I do remember that it immediately drew me in. The message resonated with me, so much so that I copied it on a piece of paper, then framed it and put it on my wall. It was not until after my introduction to phenomenology that I came across it again in its truer, fuller form:

...have patience with everything that is unsolved in your heart and try to cherish the questions themselves, like closed rooms and like books written in a very strange tongue. Do not search now for the answers which cannot be given you because you could not live them. It is a matter of living everything. Live the questions now. Perhaps you will then gradually, without noticing it, one distant day live right into the answer. (Rilke, 1945/2002, p. 21)

Just as described, my journeying through phenomenology has gradually shown me a way and brought me to a place where I can begin to live into answers. My own reflection more deeply transforms me. I more deliberately seek understanding of myself, of Others, and of the world. It seems I have found a way of research that complements the way I choose to live, and that the way I choose to live further strengthens me as a researcher. For me, this is the beauty of phenomenology. I envision myself as part of the hermeneutic circle. My way of seeing is altered, brilliantly less clear. I own this and take it with me, will embrace it, savor it, and share it. I now prefer to allow the truth I dis-cover to present itself as Heidegger's (1927/2008) *unconcealment, as a self-showing*, without worry of verifiability through multiply confirmed findings or compatibility of its fit within a theoretical framework. Although I do realize that I could have chosen a less prickly path along my way to clearings and expanded horizons, I find bittersweet comfort in Heidegger's words regarding phenomenological investigation:

It should not at all be our task to satisfy the demands of any established discipline. On the contrary, such a discipline can be developed only from the

compelling necessity of definite questions and procedures demanded by the things themselves. (Heidegger, 1927/2008, p. 72)

## CHAPTER FOUR BEING A BREASTFEEDING MOTHER: TRANSFORMATION IN WAITING

The in-between space of the NICU seems like a waiting place. After the ritualistic cleansing and dressing, stepping inside brings you to a space where you can feel your own breath, your own pulse. It is a place still in its quiet teeming life. No mothers casually arrive at this space in-between pregnancy and traditional early mothering, but rather in haste and carrying their ideas about breastfeeding. They leave unaccompanied by their babies and with their ideas further shaped by the events surrounding their birthing experiences.

As these extraordinary mothers have guided me through their journey to motherhood, the role breastfeeding played in it for them appeared magically, almost as an elixir for what ailed them. Overall, the NICU space is recalled as a supportive and safe place to become, where they learned to be mothers of babies born early, very small, and whose needs are different from the plump, full-term ones to which they were accustomed. At times, though, it was more of a proving ground, with mothers not quite feeling welcomed and not quite receiving the support they needed. At first glance this may appear to be a waiting place, but letting your gaze linger allows for seeing the great transformations that occur here.

The etymology of the word transform, meaning to change the shape or form of, is formed from two Latin words, *trans* meaning across and *formare* meaning to form (Oxford University Press, 2013). The suffix, *tion*, is used to make abstract nouns out of verbs and its addition reveals something becoming out of action. It is out of the *doing* that something is made into more than it was before, perhaps

something better. Through these mother-stories, transformations unfold and mothers and babies are presented among one another once again. As the subjects of their own stories, these mothers emerged as the writers of their bodily poetics, more easily authored during pregnancy.

Mothers have cared for their babies after birth since time immemorial, yet early mothering in the NICU often lacks traditional early mothering experiences that include not only motherly feelings, but also such motherly actions of feeding, cleaning, and keeping warm. As we listen, breastfeeding shows itself as having played a part in remedying the dis-eases that often accompanied the untraditional path of becoming a mother in the NICU.

### **My Mother Guides**

Ten mothers welcomed me into the world they shared with their children at the beginning of their lives *with-out* them. Their identities outside of this world include those born within the United States and without. They are white, black, and something in-between. They are self-identified as African-American, African in America, Argentinian, Guatemalan, Latina, mixed, and not at all. They are caring for their babies with and without the fathers, some married and some not. They are first-time, second-time, and forth-time mothers. Their babies are the results of planned and unplanned pregnancies, derived in the usual way and through the wonders of science. They now live with their babies on their own, with their parents, and with their men. Their experiences span four NICUs, where they delivered their babies vaginally and by emergency C-section. They are administrative assistants, homemakers, law professors, waitresses, and currently unemployed. Their extended

families are overseas, minutes away, and estranged. All were sent to the hospital before completing their 30th week of pregnancy and did not return home until after the birth of their babies. All became mothers of a single baby, born preterm and at VLBW, and provided their breast milk to them as they began life in the NICU. Our conversations took place within the first six months of their children's homecoming.

### **Thoughts and Experience In-form-ing Being**

Indeed, thinking should give *itself* as a gift to the body. But in fully giving itself, it would not *insist* that the body's way of being must *conform* to its own set categories, would not *object* to the body's own most way of being and giving itself. On the contrary, thinking would *open* to the body, would listen, would shift into a more receptive attitude, an accepting attitude, and an attitude whose spelling of graciousness the body would feel and find fulfilling. (Levin, 2003, p. 41)

Our minds work within our bodies, while our bodies influence our minds.

The following introductions begin to tell the story of the breastfeeding experiences of ten women. As you will see, each woman's body gave itself in a way that could not be ignored by her thinking. These bodies demanded their thinking open up and "shift into a more receptive attitude." Bodily being, at this point in their lives, required recognition and from within this perception each one's ideas were in-formed, giving them new shape.

Marcella, Sophie, and Talia had decided during their pregnancy that they were absolutely NOT going to breastfeed their babies! They were experienced mothers with children who had done just fine on formula. Marcella and Talia had tried unsuccessfully to breastfeed their older children, while Sophie nourished her older daughter with formula from the onset.



**Marcella.** Marcella found herself ambulated from one hospital to another in her 28th week of pregnancy. She woke up not feeling well one morning and shared that "it just felt like I was getting sick, like bodily sick...like I was getting the flu or something." By the time she arrived at her local medical center, she was experiencing shooting pains, and "they were registering, but they weren't [showing] as intense as" she "was feeling them on their little scale" and she was sent home. Less than three hours later Marcella describes that the pain had "started hitting" her "big time." Upon arriving back at her local medical center, she was immediately given magnesium sulfate, which she describes as "the worst drug to be on" and was casually informed that they were unable to handle babies born under 34 weeks gestational age. Marcella was panic-stricken when she found out she was unable to stay at her hospital. This did not fit into the dream of her baby's birth. This was not what she had envisioned, whatsoever.

He continued to tell us that they don't handle that earlier stage at that hospital. They can handle, I think they said 30-weekers...no 34-weekers. That's it, nothing lower than that. Then I went into a complete panic. They gave me the steroid shot, in my booty (*laughing*). I haven't had a shot in my booty since I was a baby. I'm like are you kidding me! So they rolled me over and they stuck the needle in my booty and I'm like yeah, okay. This was NOT part of the plan. (Marcella)

That the early birth of their babies was "not part of the plan" was commonly experienced, and this loss of their dreams surrounding the births of their children also caused disruptions in the mothers' plans to breastfeed. What else may have been lost for mothers in the early birth of their babies?

As Marcella wasn't able to establish breastfeeding with her older daughter and did not think she would be able to with her son, she decided on formula early in her

pregnancy. The idea of breastfeeding only reentered her mind after giving birth. It was the nurses who initially re-presented the possibility, with information about the health benefits, to her and her husband (who urged her consent).

The nurses were sitting there talking to us...they were really proactive and...they were...asking me whether I was going to breastfeed or give him formula ahead of time. Because even though he wasn't on feeding yet, they could still rub it into the mouth, whether it be breast milk or formula, just to get him used to it. And then...my husband was told...I was sitting there wheeling myself back to the room and the nurse mentioned it to him, where it was beneficial to the baby, a lot better because of the nutrients and the antioxidants and everything else and blah, blah, blah. And the next thing I know, here comes my husband with the breast pump. Yes (*laughing*) I just looked at him, like apparently I don't have a choice? (Marcella)

Even after hearing about the benefits of breast milk, Marcella does not sound as if she was convinced—"blah, blah, blah." She may have initially agreed due to the urging of her husband, but what was it that drew her in to follow through with the *doing* of breastfeeding? At the time that I spoke with Marcella, she was still breastfeeding her then 9-month-old son. What insisted that she continue?

**Sophie.** Sophie did not have any complications with her pregnancy, until she began feeling sick and nauseous the week prior to a normally scheduled prenatal visit during her 30<sup>th</sup> week of pregnancy. That very day, on the recommendation of her midwife, she was suddenly admitted to the hospital. Sophie continued to want to formula-feed her baby, even after the nurses initially informed her of the benefits of breast milk. The nurses approached her a second time, and another discussion about feeding ensued.

Well, they came inside and started talking again to me about it, and I said well, because I wanted her to gain weight and stuff...I would pump while I was in the hospital. (Sophie)

After this initial verbal agreement, though, she had not yet begun pumping.

For Sophie, it was *seeing* her baby that called her to provide breast milk.

After she was born, after looking at how tiny she was. I said well, I want her to get the nourishment she needs and all the nutrients in her system. So, I was just going to go ahead and breastfeed because I didn't breastfeed my last child. But then because the winter storms...I just got discharged, and it was hard for me to get back and forth there to give her the milk. So, I wasn't able to give her...my milk anymore. They just went on and gave her the premature milk and stuff. I think for a baby...it's best to drink from the mother than to have artificial milk, so I wish I could have sent her some more milk and stuff, but I wasn't able to make it to the hospital with all that snow. (Sophie)

What was it about seeing her baby that called Sophie to breastfeed? What might the sight of her baby have revealed to her about her-self, about her *ability*? What must it have been like for Sophie to have to leave her baby and be unable to get back to her?

**Talia.** Talia's oldest child was born preterm and began life in the NICU. Her pregnancy with her daughter was complicated from the beginning and she tells how she tried to explain to her doctor that her pregnancy felt similar to that of her eldest, but "by the time they listened and started the progesterone shots, it was already too late." At 29 weeks she found herself having her fourth C-section in a familiar hospital. Talia was adamantly not going to breastfeed her baby.

I have four kids. My first son, when I had him I had problems developing breast milk. They put me on 50 million prescriptions and they told me to take these over the counter vitamins and this would help and that would help. Nothing worked, so I ended up stopping pumping for him. I didn't even attempt with my other two and with her I wasn't going to either, because I knew I had problems developing milk, and so it wasn't even—it didn't cross my mind. We just automatically knew she was going to be a formula baby like the other ones. (Talia)

Upon initially seeing her daughter for the first time Talia described it as "overwhelming." As she looked at her daughter, she began to recall her NICU experience with her son and was consumed with thoughts of "everything that we have

to go through and the *time*, all the *time* she has to be in here." Talia was more concerned with preparing, as her pregnancy was unplanned, which was compounded by not expecting her baby so soon. She explained that her family was concerned with "all this stuff that we had to do...still buy" and "where she's going to sleep."

Providing breast milk was not on her list of priorities. Talia goes on to describe that changing her mind about breastfeeding was more of a *giving in* to the nurses' requests.

...and when she was in the NICU, a whole bunch of nurses had come up and I was pretty much dead set. No, I want her on formula. I don't want to go through the whole trying to develop milk again...the soreness and just all that stuff. And I also have a disease, which also doesn't help with developing milk and it dries you out. They were saying well, even if you can get the first bit...and the colostrum? I can't remember what it was called. At least she can get that in her system and it really helps even the tiniest bit. Even if we just put an ounce to her or three ounces, anything helps. So kind of, I was like okay we can just try it. Just kind of because everyone was on me about—well try, well try, well try. So I was like okay, well I'll just try—giving in. It was more okay, everyone just leave me alone, and I'll try. (Talia)

Talia seemed to be trying to express that she was not interested in breastfeeding, but felt pressured into it. What meaning resides in Talia's resistance to providing breast milk? Could her resistance somehow represent an attempt at gaining some control over the wilderness of the NICU? How is it that an outspoken, strong-willed, dedicated mother of four could not find her voice in the NICU? What can the apparent dismissal of Talia's wishes tell us?

Errin and Shamari were still undecided as to whether or not they would breastfeed their babies. Each had considered it, but was not sure that it was something she wanted to do at the time of her baby's early birth. Perhaps they

thought that their bodies would not cooperate, or perhaps they were overwhelmed with the events surrounding the births of their babies.

**Errin.** Errin knew that her pregnancy was high-risk due to previous miscarriages, and she monitored her body's signs diligently. At about 13 weeks of pregnancy she began spotting and visited her doctor, thinking that perhaps she had an “incompetent cervix.” Her doctor sent her to a specialist and she was told that everything was fine. During her 24th week of pregnancy, she began having back contractions and upon calling her doctor was instructed to go to the nearest hospital right away. Initially Errin was hesitant, because the hospital closest to her place of employment was not the one in which she planned to give birth. Eventually she went, and upon arrival they examined her baby via “ultrasound and everything looked fine,” but when the doctor examined her he stated that she had “no measurable cervix.” At that point, she was told she would be staying at the hospital to “prevent” her from having the baby for as long as possible. The next day, her water broke. She describes her birthing experience.

It was traumatic. I mean this was my first child. I was not expecting to have a C-section and I just remember, the NICU team comes in and they tell you all the risks and like they give you this crazy pamphlet about the chances of survival and...all these things were running through my head...so, the C-section itself went fine. I was probably mentally afraid for him and then what was going to happen—all these things. I can't even remember the actual delivery part because I was so upset, so it wasn't the best delivery. I'll put it like that. (Errin)

Again, the idea of plans and expectations make an appearance. Errin dreamed of a full-term vaginal birth, but that was not her reality. Although she was initially undecided about the idea of breastfeeding, after her son was born early she made up

her mind. For Errin, his early birth and her *seeing* him were motivation for her to provide breast milk.

Before I was on the fence on whether I would breastfeed or not, but since he came early I knew I wanted to. So, I started pumping that next day right after the delivery. Probably that same [day], I was...so distraught. They had someone come and talk to me about the importance of pumping, and so I just wanted to do everything I could. Especially after I saw him and saw how tiny he was, and all the machines. And of course, being me...I was reading my iPhone about premature babies and breast milk and NEC (necrotizing enterocolitis) and...the risk of NEC and of course he winds up getting it, my luck. So, I knew that it was important to give him breast milk. (Errin)

What was it about seeing her “tiny” baby that called Errin to provide breast milk? Was her response to this calling simply to prevent further illness? What part did the technology of the NICU with “all the machines” play in this calling? What meaning might be held within her baby’s machines?

**Shamari.** Shamari went to her normally scheduled doctor's appointment at 25 weeks and reported that she was feeling pressure. She explains that her doctor "really didn't want to check" her, and that she would do so only if Shamari truly did not “feel comfortable—just to double check.” Upon checking Shamari the doctor exclaimed, "Oooo, Ms. Thompson, what have you been doing?" A bewildered Shamari asking for clarification was told that she was dilated and that it was “not a good thing” because she was only 26 weeks pregnant. Soon after, Shamari was admitted to the hospital and spent a week there before requesting to go home on a monitor. Her request was granted, but she was back at the hospital that evening, three centimeters dilated. Shamari found herself called to provide breast milk by the early birth of her baby.

...when I first found out that she came early, that's when I said I'll do the breast milk because they said that would be better for her. So, I said well I'm

going to go on and do it, because I wasn't going to breastfeed at first. As soon as I found out that she came early I said...I'm going to...so she can get bigger quicker. (Shamari)

Shamari went on to explain that her obstetricians spoke with her about the benefits of breastfeeding even before she gave birth, but that she was not persuaded at that point to do so.

Well, the doctors...always told me that it was best for breast milk...for a baby, but they kind of didn't convince me too much. So, when I got to the hospital and I realized all this was happening and the head of the NICU came down and talked to me about [breastfeeding], that is what really convinced me that, okay this is a good thing for her. I decided that I would just go ahead and try it. He told me how...it would help her out a lot. I really wasn't convinced until all of this is going on. So I kind of woke up and realized—yeah, this is a good thing. (Shamari)

What was it about the early birth of her baby that called Shamari to provide breast milk, when prior to then she was not convinced that it offered anything more than formula?

The next five mothers, Lucy, Quelita, Tami, Yadirah, and Wenda, had each made the decision to breastfeed while they were still pregnant with their babies. Ironically enough, though, each became uneasy and unsure about actually doing this after their babies were born.

**Lucy.** Lucy's pregnancy was going well up until 27 weeks, when she began “having really bad back pain” that only got worse. A visit to her hospital, which did not have a NICU, revealed preeclampsia. She was to be helicoptered to the closest hospital with a NICU, but it was too foggy and that resulted in an almost two-hour ambulance ride. Although Lucy's plan was to breastfeed her baby from the beginning, and she agreed when NICU professionals spoke of it, her baby's birth at a mere 27 weeks gestational age resulted in her not feeling at all ready.

I was [already] going to breastfeed him and I don't think anybody came to talk to me about it. But, probably like the third day maybe somebody had mentioned it, a nurse. Then, they got all the equipment in there for me to start trying to pump. That's a whole ordeal, especially when you are not ready for it or anything. I wasn't sure anymore. (Lucy)

Lucy shared how awkward it was for her parents and husband to have seen the baby before she did. Even after she was able to see him, it somehow was not enough for her. She explains, "You get to see him, but you always have that thought even if it's in your head that you will be able to *hold* your baby when you have him and him being in the NICU, you can't do that." Could being the last one to see her baby have somehow displaced her as mother? How might Lucy being unable to hold her baby have affected her early relationship with him?

Lucy did not feel ready to provide breast milk for her son, but she did. What caused her to move out of uncertainty and into *doing*? Could the events surrounding her baby's early birth somehow have shaken her confidence, her belief in her own abilities? Did she perceive herself as unprepared, unqualified, unable?

**Quelita.** Quelita's obstetrician noticed early on in her pregnancy that there was extra fluid around her baby, so she had been receiving monthly ultrasounds. At 28 weeks she went to work normally and noticed that she was going to the bathroom a lot, but did not consider until she got home that her water may have broken. She then went immediately to the hospital, and by the time she got there her amniotic sac had completely emptied. Quelita describes her labor and delivery.

So they put me on bed rest, started me on...antibiotics...and also started me on steroids—trying to increase her lungs. They got the full session of steroids [in] and I slowly but surely started contracting...They had started me on Magnesium to decrease the contractions, but it had a reverse effect on [me]. It was *increasing* my contractions. So they stopped it and...when I started going into labor, I had got until about three centimeters dilated and



they...gave me the epidural and then I stopped [progressing through labor]...The bleeding was just too much and so the doctor was like, we need to go in and we need to take her out because she's gonna start getting some of that blood and she may get an infection. And so they rushed me back into the emergency C-section. (Quelita)

What impact might the idea that Quelita's blood could infect her baby have had on her? What could the situation of the medicines having a reverse effect have shown Quelita?

Quelita's decision to breastfeed was disrupted when she realized she would be coming home without her baby.

It was a decision that I made initially in the beginning. But then, because she didn't come home with me I wasn't sure how I was going to be able to. I didn't really know how the pumping would go and...to try and keep her on the session [predetermined feeding time allocated by NICU professionals] and keep up with her and everything. (Quelita)

What must it be like to have your newborn baby not come home with you, to be forced to leave your baby behind? Quelita seemed to wonder if she would be able to remain in tune with her baby, to "keep up with her," in their separation.

**Tami.** Tami knew something was going wrong with her pregnancy after her first trimester. She reported swelling to her doctor to no avail, and finally resorted to taking pictures of her feet and legs to demonstrate her concern. She was scheduled to come back in two weeks, but convinced the doctor to see her again in one. Tami explains that visit.

By the time I went back again, I had gained like ten pounds in a week. My blood pressure had shot up, my feet never went down, so then they sent me...told me to go straight to the hospital...and I never came back out. (Tami)

Tami initially thought that she was being kept for a 24-hour observation and sent home, but she quickly found that not to be the case. One of the nurses told her

"yeah sometimes moms, they'll be here for like a month or two," and with that Tami figured she'd be in the hospital until her due date. She explains what happened next.

But, next thing you know two days later my blood pressure didn't come down, my protein levels shot up. So, I had to have her and that was really, really scary. They did a sonogram in the room and everything - like she's fine - I was the problem. (Tami)

What meaning does it hold for mothers to find that they were "the problem"—that they are the reason their baby is forced to be born early?

An overwhelming NICU team then visited Tami.

It scared the life out of me! Like, NICU people came in there, doctors...it probably was about seven of them. They were like a SWAT Team, like you've got to have this baby now! They are trying to get IVs in my arm. I was so swollen. They stuck me so many times. It was terrible. It was a very scary few hours. I mean, it went by fast when I think about it, but it seemed like an eternity at the time. (Tami)

Surely, Tami's dreams of the birth of her baby did not include a SWAT Team! How could this beginning have shaped her experience going forward? She then goes on to express how her baby's early birth transformed breastfeeding from something she wanted to do into something she had to do.

I was thinking that I was going to do it before anyway, because I didn't get to do it with the first kids, but her being premature I was like, I really have to do this because she's going to need this milk. I'd rather for her to have that versus the formula to help her start getting stronger faster. (Tami)

Tami viewed her daughter as needing to get stronger, as vulnerable. In exploring the linguistic history of the word vulnerable, a new perspective of Tami's decision to breastfeed is presented. From within the Latin *vulnerare* meaning "to wound" (Harper, 2001/2012), Tami's breastfeeding seems to move from an act of choice to one of necessity. Was it her daughter's vulnerability that made

breastfeeding a necessity for Tami? What might the early birth of her daughter and being “the problem” have revealed to Tami about herself and her own vulner-ability?

**Yadirah.** Yadirah went to her normally scheduled prenatal visit during her 24<sup>th</sup> week of pregnancy only to find that she was already dilated. She was admitted to the hospital and stayed there for two weeks on bed rest until her daughter was born. Having a truly difficult time discussing the birth of her child and her time in the NICU, she often began to cry, and in her most difficult moments fell silent. In telling of her delivery, Yadirah simply said, "It was really hard," as she tilted her head to gaze at her sleeping baby. I sat with her in her contemplation for some time and then we began to speak about pumping breast milk for her daughter.

Oh yes, right after I had her. I think like four hours later. Well, whatever I had I took because it wasn't much. I was only getting like 20 to 60 ccs, but it was like that throughout the whole time. (Yadirah)

Yadirah knew that she wanted to breastfeed all along and began pumping breast milk for her baby just hours after birth and continuing for four months. She wanted to do all she could for her baby, and was disappointed with what her body had produced.

It was very frustrating for me because I knew that the best thing that I could do for her as her mother, was to breastfeed her, because of all the benefits that has. I felt terrible, very unhelpful, [and] guilty that something was wrong with my system that I couldn't provide enough breast milk for her. But now that I look back, I know that I did everything I could to get more breast milk and I was just trying to blame myself for everything that went wrong. (Yadirah)

What must this have been like for Yadirah's body not to seem to meet her baby's needs, again? What part did self-blame play in her experience? Was the experience of providing breast milk for her daughter anything other than a reminder of her inability?

**Wenda.** Wenda's pregnancy was going just fine until week 21, when she started experiencing pains in her legs, buttocks, and back. She visited her obstetrician's office twice only to be told that it was too early for her to be experiencing labor pains and that her baby was most likely "sitting on a nerve." Before completing her 22nd week of pregnancy, she awoke to strong contractions and wound up alone in the hospital later that day, four centimeters dilated. A doctor sutured her cervix closed using a procedure called cervical cerclage, and at that point Wenda's personal goal was to make it to 30 weeks. Set up in an inverted hospital bed, she was able to remain this way for an additional week before her son was born. Having refused pain medication, at eight centimeters dilated she was prompted by a doctor to begin trying to push the baby out. She refused and requested that they check the fluid levels around her baby. They did and once told that the baby had enough fluid, she promptly stated that she was not ready to give birth. At that point Wenda knew that she was not going to make it to 30 weeks, but wanted to hold on for as long as she could. She held on for a few more hours until her baby would wait no more. When her favorite doctor arrived to deliver the baby, it suddenly came to mind that she was supposed to have a C-section and she latched onto that idea.

He came in and he was like, "Okay sweetheart, I need to check you."...And then he checked me and he was like, "You are going to have a baby right now." And, I said, "What? You said I was going to have a C-section again because I had a C-section before, and the possibility of me not having a C-section again is deadly, and something might go wrong with the baby! Or even me. I might bleed to death!" And he's like, calm down, Wenda. The baby is very, very small. I said, "I don't know what you are talking about but you said I need to have a C-section!"...I started crying. All this time I wasn't crying and now I am crying. I'm like my husband is not here. I don't know what I am going to do. We had already agreed on the C-section...and that was something we talked about. And...there is no time to make a decision. (Wenda)

What was it about this change in plans that made Wenda so distraught? What did not having the agreed-upon C-Section mean to her?

For Wenda, following through with her initial decision to breastfeed her new baby after all of the unexpected events related to her delivery became a priority, and was simply a matter of figuring out how to do it. She did breastfeed her first child, but had only limited experience using a breast pump. She was not exactly sure how she was going to be able to navigate the process, but was determined to do so. At her request, the nurses brought her a pump and showed her how to operate it.

As soon as I got into the room...what is that? Recovery? They gave me a pump right away and I started pumping, and sure enough I got some drops the first day. And they took it down [to the NICU]. (Wenda)

Somehow Wenda pushed right through uncertainty and on to *doing*.

Each mother arrived somewhere in-between their breastfeeding decision and their action. Some lingered here longer than others, walking the invisible thread between making one's mind up and the actual *doing*. Early birth and existing at a distance from their babies allowed most to linger here longer than would the circumstances of traditional motherhood. Their babies did not announce their requirement for nourishment immediately in the way that full-term babies do, with most of them requiring no nourishment at all just yet, and none of them requiring breast milk in particular. The specialized preterm formula was ready at hand, and rumored to increase a baby's weight more quickly than the milk mothers can supply. Without breast milk being the absolute necessity, what unique purpose could its provision serve?

Stepping back from the direct nutritional value of breast milk, and even its medically protective qualities, a *dis-ease* is diagnosed. This dis-ease is not of child, but of mother and exists not as our modern medical definition would suggest. Disease's meaning in this sense lies deeper within its early 14<sup>th</sup> century roots of discomfort and inconvenience, and from the French *desaise* signifying a lack or want (Harper, 2001/2012).

### **Unfolding Remedy and Diagnosing Dis-ease**

The word diagnose comes from the medical application of the Greek word diagnosis, from *dia* meaning apart and *gignoskein* meaning to learn (Harper, 2001/2012). What is it about being apart from something that encourages learning? Stepping back changes our perspective and alters our point of view, often leading to a different knowledge of things. After multiple conversations and journeying through pages and pages of transcribed breastfeeding stories, this collection of experiences teaches that the meaning of this phenomenon is located centrally, as part of a much larger unfolding.

In pregnancy, the boundaries between self and other are already troubled as the woman's body nurtures another human being within. This is an extraordinary biological and immunological situation. When viewed through a masculinist, biomedical lens, this situation represents an anomaly that is fraught with danger, rather than as a norm and something for which the adaptive female body is well designed. In the Western world, we insist on constructing the mother and baby as separate (and sometimes competing) entities, imposing boundaries between what is self and other. This is evidenced, for example, in some medico-legal arguments that attempt to enforce a treatment (e.g. caesarean section) on the pregnant mother, imbuing the fetus with rights as a citizen though it is not yet born. This is not necessarily the case in other cultures. The Swahili word 'mamatoto' reflects an alternative way of thinking about the pregnant mother. 'Mamatoto' means 'mother- baby' inferring a new entity that is neither mother nor baby; it is both. (Davis & Walker, 2010, p. 461)

In the event of preterm birth, babies are not only born prematurely, but so are mothers. A prolonged separation follows this early and abrupt physical one, as babies begin their lives apart in the NICU. The *doing* of providing breast milk to their babies living at a distance enabled mothers to balance and often transcend the dis-eases of the NICU. Through this balance, it appeared absent mothers and babies were presented and the mother baby unit, or *mamatoto*, was re-presented. These mothers, though, were not simply doers; they simultaneously existed as doers and undergoers of providing breast milk for their babies. They were neither completely active nor completely passive within this process, but seemed to possess aspects of *both*.

Grammatical voice in English *actively* expresses the subject as the doer of an action or *passively* expresses the subject as having undergone an action. There is another voice, one that no longer truly exists in the English language, although its shadows remain. This other lost voice, known as the middle voice, expresses our experiences that are not entirely active or passive, but instead convey a letting relation that coalesces active and passive elements (Davidse & Heyvaert, 2007).

The Greek expression *phainomenon*, from which the term “phenomenon” derives, comes from the verb *phainesthai*, meaning “to show itself.” Thus *phainomenon* means what shows itself, the self-showing, the manifest. *Phainesthai* itself is a “middle voice” construction of *phainō*, to bring into daylight, to place in brightness...visible in itself. Thus the meaning of the expression “phenomenon” is *established* as what shows itself in itself, what is manifest. (Heidegger, 1927/2003, p. 73)

As opposed to existing in a linear fashion, dis-eases were intertwined and often overlapped—more salient at one time or another. The experience of providing breast milk “shows itself” as a remedy, both provided and received by mothers. Once unwrapped, the remedy of breast milk revealed these common dis-eases that accompanied preterm birth and

mothering in the NICU that came in the forms of self-blame, displacement, and dismemberment. As they provided breast milk, mothers seemed as if they were relating from the perspective of a forgotten middle voice, while creating bridges between self-blame and self-forgiveness, displacement and emplacement, and dismemberment and membership.

### **Caring from a Di-stance**

Heidegger (1927/2003) presents the ontic-ontological priority of *Dasein*, or human being-in-the-world, as being “ontically “closest” to itself, while ontologically farthest away; but pre-ontically...surely not foreign to itself” (p. 58). *Dasein*, in its simple and factual existence of human being-in-the-world is readily grasped, but the *nature or meaningful composition* of our being-in-the-world is constituted by care. We care about our being-in-the-world, but as humans our being-in-the-world often evades our understanding. Like the lyrics of the song, “Some Nights,” by the American Indie band Fun, which is currently topping the charts in such far reaching places as Australia, Honduras, Ireland, and Japan (with its power pop, afrobeat, and folk rock elements); we *wonder*. It sings human being-in-the-world.

But I still wake up, I still see your ghost  
 Oh Lord, I'm still not sure what I stand for, oh  
 What do I stand for? What do I stand for?  
 Most nights, I don't know anymore...  
 (Reuss, Basker, & Dutton, 2012)

We all ontically stand, but what do we ontologically stand for? This seems *Dasein's* question and in human-being we exist in this in-between. A mother's caring for her baby in the NICU, too, seems to be a dance in this in-between. It is done at a di-stance, characterized by something existing of both presence and absence. She is ontically mother to her baby, a relationship of *closeness* that is unquestionable.



Ontologically, the distance brings into question the meaning of *being a mother*. She is in the middle of it. Does she wonder who she is? If so, what stops her “bones from wondering just who I am, who I am, who I am. Oh, who am I?” (Reuss, Basker, & Dutton, 2012).

Heidegger (1927/2003) brings forward three temporal dimensions of care related to the future, past, and present as *possibility*, *facticity*, and *falling*. This ontological meaning of care as temporality displays these notions in possibility, as *Being-ahead-of* and relating to a future-oriented present-ness; facticity, as *Being-already-in* and relating to a past-embedded present-ness; and finally falling, as *Being-alongside*. How might the the temporal dimension of the present be experienced by mothers of babies temporarily residing in the NICU? Kidd (1990) further elaborates Heidegger’s notion of falling as being either authentic or inauthentic and distinguishes her idea of care from concern.

Falling, can be inauthentic, what I call concern, as awaiting the future and authentic as waiting-towards the future, which I call care. If the present is held within the authentic temporality, which is authentic itself, we can speak of, as Heidegger would say, the moment of vision. I like to think that there is a possibility of caring for persons and for things it is concern. (pp. 1-2)

*Dasein* acquires its understanding from time and “the outward evidence of this but of course *only* outward is the determination of the meaning of Being as *parousia* or *ousia*, which means ontologically and temporally ‘presence’; [*Anwesenheit*]” (Heidegger, 1927/2003, pp. 69-70) .

For Heidegger, the present is not some endless series of now points that I watch flowing by. Rather, the present is something that I can seize hold of and resolutely make my own. What is opened in the anticipation of the future is the fact of our having-been which releases itself into the present moment of action. (Critchley, 2009, p. 13)

This threefold structure of care illuminates the present-absence of mothers in the NICU, with presence existing alongside (an active waiting-towards) and absence always within its relation to presence (a passive waiting-for). Could their “anticipation of the future” *with* their babies open the fact of their “having-been which releases itself into the present moment of action,” of *doing*? Providing breast milk for their babies becomes the *doing*, required in the taking over of what has been and movement again toward possibility (once so apparent in pregnancy). It is the *doing* that allowed mothers to be ahead-of once again, re-dis-covering their dreams, and moving toward self-forgiveness.

Mother dis-eases in the NICU also took on a threefold structure. Self-blame appeared along with the preterm birth of their babies, almost instantaneously. A profound and abrupt dis-place-ment emerged within the shift of clearly existing as the most important person in the lives of their babies during pregnancy, to being pushed to the periphery after birth and existing as a mere bystander. Dis-member-ment showed itself as a multi-faceted isolation, manifesting by means of the physical separation from their babies and a sense of aloneness within an untraditional motherhood.

Taking a closer look at the dis-ease of self-blame, the same body that mothers viewed as to blame for the preterm birth of their babies is re-presented through the action of providing breast milk. This breast milk, made of the proteins and sugars from her very blood and brought about by the existence of mother and baby together, showed itself as not simply for the purpose of newborn nutrition, but as a remedy to

her dis-ease. This remedy came by way of the self-sacrifice of providing breast milk, which through the presencing of an absent mother lead her to self-forgiveness.

The next dis-ease, dis-placement, was experienced as mothers had to leave their babies in the care of others and became dependent on these others for access to their babies. No longer seeing themselves as having an established place in their babies' lives, they felt re-placed. A new meaning of providing breast milk is revealed here, as it allowed mothers to play a unique and essential role in the health, growth, and development of their babies. Providing breast milk emplaced them in the world of the NICU, the world of their babies. Through the pumping of their milk, absent babies were presenced, and mothers once again became ir-re-place-able.

Finally, dis-member-ment was experienced, as mothers were separated from their babies through the birthing process, and unable to re-connect or re-member themselves due to the early NICU experience. Pumping breast milk seemed to give mothers a sense of bodily attunement with their babies and back to experiencing a shared rhythm. Through this action mothers and babies were re-member(ed) by way of a new connection, leading to mothers perceiving themselves as once again, gaining member-ship into this group known as *mamatoto*, a shared life by way of care. This unfolding, of mothers' re-collections of self-blame, displacement, and dismemberment, revealed breastfeeding at the center of each. Providing breast milk assisted mothers in living authentically, *toward* their future with their babies, as a remedy to the NICU dis-eases of self-blame, dis-member-ment, and dis-place-ment.

### **Self: Presencing an Absent Mother**

"It's me, Mommy, I love you."

Inside I say, I'm so sorry I let you down.  
 You should still be growing inside me.  
 We should have had more time.  
 (Anonymous, 1998)

The most prevalent sentiment in each mother's breastfeeding experience was a deep sense of self-blame and ensuing need to compensate for the preterm birth and low birth weight of her baby. This sense was further deepened as mothers were required to leave their babies behind, in the care of others, and left to wonder about their well-being. After this obligatory desertion, the imagination of dark possibilities often ensued. These unspoken thoughts seemed to feed further the need to compensate through self-sacrifice.

Side by side with the destructive impulses in the unconscious mind...there exists a profound urge to make sacrifices, in order to help and put right loved people who in fantasy have been harmed or destroyed. (Klein, 1964, pp. 65-66)

Talia and Errin imagined their worst fears coming true, yet when they spoke about those imaginings during our conversations, they spoke *around* them. Their words fell far short of the emotion that filled the space between us as we sat in “the kind of silence we are confronted with when we face the unspeakable” (van Manen, 1990/2007, p.113). With hesitation, Talia shares thoughts of her daughter dying in the NICU. She would try to shut these thoughts out of her self.

There was no (*crying*) – sorry. There was no way she couldn't. If she hadn't made it, even though that bond wasn't there, I couldn't deal with not having her once I had her. She has to. There is no way. If she doesn't, there is just nothing. (Talia)

Errin envisioned her son's machines failing him and painful medical procedures. She simply wanted him home with her, for fear he would be mistreated in her absence.

Errin shares, "I felt very protective of him, like I want to get him out of here, like what are they doing to him?"

These thoughts manifested as mothers faced their children's vulnerability, and pushed them toward doing something to counter their imaginings. Perhaps mothers felt their vivid, menacing thoughts could otherwise contribute to their babies' conditions. Breastfeeding emerged here as a way to compensate, and through this bodily sacrifice, mothers uncovered a way to balance self-blame, while directly contributing to the success of their babies. Managing self-blame through self-sacrifice provided amends enough for mothers to allow themselves a walk along a path of self-forgiveness. Interestingly, the noun *desert* has an alternative meaning of a "suitable reward or punishment" from the Latin *deservire* meaning "serve well." These ideas of abandonment, repentance, self-sacrifice, and amends leading to remedy are curiously entangled.

### **Self-blame**

From a phenomenological viewpoint, shame and guilt may be regarded as emotions which have incorporated the gaze and the voice of the other, respectively. The spontaneous and unreacted performance of the primordial bodily self has suffered a rupture: In shame or guilt we are rejected, separated from the others, and thrown back on ourselves. This reactive turn of spontaneous experience is connected with an alienation of primordial bodiliness that may be described as a "corporealization": The lived-body is changed into the objective, corporeal body or "body-for-others." (Fuchs, 2003, p. 1)

Without answers as to why their babies were born preterm, many mothers reached a place of hopelessness through self-blame. Sophie, like other mothers blamed herself for the preterm birth of her baby, and as a result, harbored guilt.

I knew she was going to be low birth weight because I was struggling with my own weight...I didn't even gain any weight with her. It was maybe because I

was depressed...and I wasn't really hungry and my mood was up and down...so, I barely even gained weight with her. So, I kind of...beat myself up for that. I'm like, if she would've gained her weight she would have lasted, and been bigger than what she was. (Sophie)

Fuchs (2003) considers the experience of shame as meaning “that the lived-body has taken up and internalized its being seen; the exposure as corporeal body before the eyes of the others has become a part of its feelings,” and in essence, he asserts that “*shame is the incorporated gaze of the other*” (p. 228). Looking at her baby, who is indeed her-self, caused Sophie to experience shame. In *seeing* her baby's smallness, she seems to become the Other, yet gazes at what was her-self and feels guilty. Wenda's self-blame also led to shame. Her first visit to the NICU left her horribly ashamed of this baby her body produced. The word *shame* emerged from the Proto-Indo-European word *skem*, from *kem* meaning to cover (Harper, 2001/2012). Within her actions, Wenda truly lives shame's deep meaning.

I see my baby inside this thing...I looked at my husband's cousin and I said, “That's not my baby.” I've never seen anything this small before...so I looked at him for a while and I'm like gosh, my husband is going to be – What is he gonna say? How is he gonna act when he comes and see's this baby? Oh my gosh! What is this? (Wenda)

Wenda's shame was revealed when others, including herself, *looked* at her baby. How is it that she was incorporating *the gaze of the other*, when the other's gaze was not physically upon her? It seems that the sight of her baby was “the exposure as corporeal body before the eyes of others.” She was being seen and was ashamed. Perhaps this viewing revealed her responsibility or caused her to question her response-ability. Did she question whether others would blame her for her baby's condition?

For Wenda, this shame was not remedied quickly. In her attempts to shield

him from the eyes of others, and in accordance with shame's deep meaning she kept him hidden, much as she did when she was pregnant. Within her covering she seemed able to protect him once again, while at the same time protect herself. It was an offensive move. Protection, in its noun form, means "a covering over" (Harper, 2001/2012). Wenda was providing herself immunity from experiencing the additional dis-ease that seeing her baby (as a part of herself) through the eyes of others evoked. Did she preserve some of her-self within his covering? Through this covering, could she have been giving herself time to heal, to make herself whole again?

I would bring a blanket to cover the thing [isolette] so that people couldn't really see him. Because, I always felt like these people were staring at him—and they were. They were. But, eventually I realized that they have a reason to...I think if he wasn't my child...I would be staring too because of him being so small. (Wenda)

Errin describes her self-blame as leading to feelings of guilt. Her words begin to give us some insight into the role breastfeeding played as a form of necessary self-sacrifice, almost as if trying to repay a debt.

Well, from a personal perspective I felt like my body had failed him. Maybe a lot of mothers feel like this—a huge sense of guilt that I could not carry him to term and so I wanted to do. Here was something tangible that I could do and that I felt like I needed to do to help him. Almost like one of those things, where jeez, this is the least I could do. To give my son breast milk when my body couldn't keep him in as long as he should have been in. So, I need to do this for him. (Errin)

Leder (1990) introduces the concept of the dys-appearing body. For these mothers, not only has a part of their bodies (the baby) disappeared from them, but what is left of their body seems something that was not good enough to sustain the baby. Their bodies now appear to them as dysfunctional, resultant from their inability

to fulfill their obligation to their babies. Although all mothers see an end to pregnancy in birth, for these mothers, their temporality seems in limbo. They are no longer with their child in any of the ways they expected.

Thus, the presencing of the body in dys-appearance is still a mode of absence—etymologically, “to be away.” In the modes of disappearance previously addressed, the body is away from direct experience. This could be called a *primary absence*. It is the self-effacement that first allows the body to open out onto a world. In dys-appearance the body folds back upon itself. Yet this mode of self-presence constitutes a *secondary absence*, the body is away from the ordinary or desired state, from itself and perhaps from the experienced “I”. This presence is not a simple positivity. It is born from the reversal, from the absence of an absence. (Leder, 1990, pp. 90-91)

Yadirah also felt the need to do something to make up for being unable to continue to carry her daughter in pregnancy. Although she was only able to provide small amounts of breast milk, she continued to push.

I mean for me it was that I was not getting enough and I just did everything. I took everything that everyone told me, like fenugreek, mother’s milk...I think it is called. I did everything. I was getting enough sleep, but I felt like nothing worked and it was very depressing to see...other moms there. And they used to come with a lot of milk (*begins to cry*). Oh, my God (*whispering and wiping her eyes*). (Yadirah)

Yadirah's body was again not rising to meet her daughter’s needs, and at the time of our conversations she was still heavy with the weight of her response-ability. In the preterm birth of her daughter, she too, was prematurely thrust into a *cessation of time*. The physical weight of her baby no longer remained, but preterm birth left behind another weight in a dys-appearing body. As if her self-sacrifice was not enough, she seemed unable to have yet remedied her guilt, and it remained a burden.

### **Self-sacrifice**

The self-sacrifice of breastfeeding seemed to restore a sense of equilibrium; through their own bodily sacrifice mothers were restoring a balance. Providing breast



milk was presented as a good thing to do to help the baby, and even though pumping their breasts seemed something foreign and was not required of them, they did. In wanting to do everything possible for their babies, they went beyond what was necessary. In thinking about providing breast milk as self-sacrifice, I was drawn to Natalie Diaz's (2012) poem, entitled "Self-portrait as a Chimera," where she proclaims, "I am what I have done. We do. We do. We do and do and do" (p. 77). At the heart of human adaptation seems doing, but how might shame dys-able the body? When is it that we know we *can* do something? It is *doing* that helps us to see what we can do. Awareness of our *being able* to do is born in the moment of doing. Doing is embodiment. It is the residence of self-confidence. At the heart of mothering seems doing. Yet, we will see that within the doings of these mothers something was also done to them.

The mothers who welcomed me into their worlds relied on the technology of the hospital-grade electric breast pump with double pump kit, in order to provide breast milk to their babies, and its use required significant time, as well as significant discomfort. It was in regarding the act of pumping breast milk as a bodily sacrifice that encouraged mothers to push through this discomfort, frustration, inconvenience, and pain. The act of pumping in itself was not an enjoyable one and it quickly began to consume their days and nights. Marcella describes pumping breast milk as frustrating because she wanted to do more, and she felt initially that her body, once again, was not cooperating.

Frustrated! The first couple of times you get these itty bitty little drops and it's just like you want to give him everything you possibly can because you know the benefits and stuff and knowing that it strengthens – I mean she [a nurse] broke it down for us. (Marcella)

Yadirah continued to express her frustration in terms of her body still not being able to give her baby enough. It saddened her to recall that she was "left with no milk" and that disappointingly, "they had to start with the formula." Breast milk, for Yadirah, did not ever fully serve as amends. It remained a reminder of her deficiency. Could the competitive nature of motherhood in the NICU have fostered this, with its constant calculations of centimeters, cubic centimeters, ounces, grams, and degrees?

Other mothers expressed the desire to give up pumping breast milk for their babies at one point or another after being discharged from the hospital, within the initial weeks of their babies residing in the NICU. Talia vividly recalls pumping breast milk for her daughter. She shares that the bodily experience "was just uncomfortable" and that "the whole time" her "toes were curled" and that all she could think was "when is this going to be over."

Levinas (1969) writes that freedom is "to maintain oneself against the other, despite every relation with the other to ensure the autarchy of an I" (p. 46). As the Other who was their baby called upon them as mothers, they gave up their freedom for the good of their babies in accepting the response-ability of providing breast milk. For mothers, this freedom was noticeably lost in relation to lived body and lived time. The way these mothers seemed *able to respond* in their present absence was through bodily and temporal sacrifice.

**Altar(ed) body.** The idea of sacrifice is central across the world's largest ancient religions of Christianity, Islam, and Hinduism, which comprise more than half of the world's religious adherents. Among Chinese Traditional, Judaism, and

Sikhism, and more subtly in Buddhism, sacrifice, too, plays a significant role in the narrative. In considering the concept of sacrifice, we often conjure images of surrendering something prized (even life itself) for the sake of something considered as having a higher claim, and this is further illuminated in the roots of the word sacrifice, which lie in the Latin *sacer* meaning sacred and the root *facere* meaning “to do, perform” (Oxford University Press, 2013). Within the sacred work of providing breast milk, the mothers presented here sacrificed their bodies, and in this bodily being, emerged altered.

As opposed to the mind-body dualism proposed in the familiar dichotomy of the Cartesian model, Heidegger (1927/2003) presents us as interwoven entities living along with others, in time and place. We are all embodied beings. *Dasein* as Being-in-the-world, is the essence of human existence, and "accommodates the corporeal and the lived in a harmonious manner" (Thoibisana, 2008, p. 2). In *Dasein*, there is no separation of consciousness and physicality. They are incorporated. Sophie, in her struggle with providing breast milk and the additional challenges that came with consistently transporting her pumped milk to the NICU, expresses that her "breasts were tender and sore," that she “was uncomfortable doing it,” and she “didn't want to anymore.” Quelita also lived this *incorporation*. Through her altar(ed) body, she found herself wanting to give up on breastfeeding because of the discomfort she experienced, only to find the support to persevere from within the relationship with her mother.

It hurt in the beginning and I wanted to give up. Yes, there were so many times but it was my mother who was just like...*(shaking her head)* mm mmm...just take your time. You know take a little breath...use some lanolin

cream and let them air dry. Once you let them air dry they'll toughen up!  
And so yes, that's what we did and all is good! (Quelita)

How might guilt and shame, increased by the distance from their newly born babies, have contributed to the discomfort of these mothers? Fuchs (2003) presents the idea of an alteration of bodliness brought about by shame. Such an alteration could result in turning the body's discomfort into a *dys-comfort*. *Dys*, being a word forming element meaning "bad, ill, or abnormal," differs from *dis* meaning "lack of, not, apart, away" (Harper, 2001/2012), therefore increasing the intensity from farness to not only far away, but other-than.

Although, Sophie and Quelita's somatic experiences were similar, their situations were quite dissimilar. Sophie did not know anyone else who had breastfed her baby, let alone provided breast milk from afar. For Sophie, the distance was compounded, as she found herself unable to get to her baby once she was discharged from the hospital. A toddler at home and terrible winter storms without personal transportation made trips to the hospital close to impossible. This compounded difficulty magnified her discomfort. Quelita's reliable means of transportation and only having one child to care for eased her access to her baby. She also was afforded the assistance of another, her mother, who had her own lived breastfeeding experience, which perhaps lessened her discomfort. Quelita's situation supported her in continuing breastfeeding, while Sophie's seemed to work in an opposing way.

**Present(ed) time.** The time given from mothers to their babies, whom they are without, is time given as a gift, an offering. This given time is presented in the meantime (while awaiting their babies' homecomings), as these mothers are past pregnancy, yet ahead of their future at home with them. Without present(ed) time

mothers could become stuck in the present, inauthentically *falling* within the *cessation of time* that birth reveals. Being a mother without her baby, mothers exist in the in-between. Instead of being present, in *being-before*, they exist in the meantime, time in the middle.

The gift of present(ed) time is a sacred gift of self, and made through action. Even though pumping breast milk for their babies represented a significant sacrifice of time, mothers had committed themselves to doing it. Present(ed) time is more than a sum of seconds, minutes, and hours. It seems that mothers who were sacrificing more personal time lasted longer in breastfeeding than those who were called to sacrifice time that was tied to others whom they cared for outside the NICU.

Many mothers viewed pumping as consuming, and Errin clearly expresses this sacrifice of body, as well as time.

It was exhausting actually. It became like a full-time job and I started to feel like my body wasn't my own, but I was ok with that because like I said I felt this was one thing my body could do for him. I set up my entire day just around pumping. But it was a lot easier for me because I wasn't working. So I could wake up at 4 am and pump and then be on a 3-4 hour pumping schedule all day long really. It did give me the sense that my body is not my own and that I live to be a milk machine for Marc (*laughing*). (Errin)

Sophie and Quelita both expressed their time and commitment to making this sacrifice. Pumping their breast milk for their babies was essential.

I think every 2 hours or 3 hours you've got to like constantly do it to... stimulate the nipple...to have milk come out. So that's what I was doing, it was kind of tiring because I wanted to go to sleep, but I had to do that. (Sophie)

I pumped every three hours religiously, on the clock every three hours. And I did both at the same time and I would just freeze it until she was able to get extra milk and then once she was able to get milk I would just transport it daily. They did have a nice little supply of frozen milk down there just in case

one day I missed or something, but I never did so they wound up giving it back when I came home. (Quelita)

Lived time is experienced as past, present, and future. It is ancestral time as “the parent and the child both share a history...which has its own horizons” (van Manen, 1997/2007, p. 105). The idea of ancestral time lends to the temporality of being between past and present, yet ever pushing toward the future. It is carried within us from our past and into the our future. For Marcella, the caring she provided for her child through the gift of her breast milk fit into what she saw as an ancestral tradition of mothers and children.

For me it was something that was given through my mother. My mother and what she learned from her mother. You don't put yourself first, ever. Your children come first. You do everything for your children. You sacrifice and do everything for them and in the end when you get like 90 years old you are hoping that they will take you in and take care of you (*laughing*). (Marcella)

These women present(ed) their time as a gift from within their altar(ed) bodies, which were given up and forever changed, for the betterment of their babies. This self-sacrifice, made through the pumping and provision of their breast milk, again presenced these mothers within the lives of their babies from afar. The di-stance, a posture of nearness from within farness, assisted them in achieving self-forgiveness.

### **Self-forgiveness**

For most mothers sharing their stories, providing breast milk to their babies presented them as doing something extra for their babies, and that made them better mothers. This assisted them in feeling good about themselves, as mothers, after preterm birth and balanced the blame they took upon themselves. Although they could not hold onto their babies in pregnancy, these mothers gave breast milk after birth, and that is something they knew not everybody did. Marcella contrasts her idea of providing breast milk with providing formula. She was able to own a part of her son's wellness.

I like it because I noticed a lot of times in the NICU... The babies that were formula fed weren't progressing as much, and I noticed that and I felt good. And I felt bad, not that I was judging the other mothers because that is not a time to judge a parent. But at the same time I felt good because I know for a fact that the breast milk was helping him advance more and get fatter and bigger and stronger and longer and everything else. He was doing really good. He was gaining a pound a week. In the beginning it was a little bit iffy. As he started getting bigger, he started gaining and when he came home, he was nothing but breast milk baby. He started gaining a pound and a half a week. And they [medical professionals] were scared. The doctor's office was like, "What are you feeding him?" I'm like nothing, just breast milk. (Marcella)

Marcella was proud of what her breast milk did for her son. His increased growth and development was owed to what her altar(ed) body present(ed).

As mentioned earlier, Wenda was ashamed of the baby her body produced, and her pride in her breast milk seemed to be the one thing that came to her assistance. She was again useful to her baby, and this usefulness seemed to counter the initial fears she held of what her husband's impression of their baby would be. Babies can only receive breast milk from without, and her seeming uselessness from within became a usefulness without, from within.

They said as soon as we get it we'll just rub it on his lip. The colostrum is really good for them, so we're gonna just – even though it is just one drop, but it's very, very important and they taught me how to do it. They gave me instructions that every two hours, as often as you can; just keep on doing it. And I'm like okay, if that's what I have to do, that's what I have to do. So, I kept doing it and a day later, milk. Real milk started coming and I'm like, wow! This is amazing. Because, I didn't have to pump with my daughter until I started working. So, that was an experience for me. They started storing the milk at the hospital and sure enough when my husband came we went there together to go see the baby. (Wenda)

Quelita also contrasted the qualities of her breast milk with formula, and in doing this, a sense of pride was uncovered. Providing breast milk reveals her self-

portrait as good mother. It is her doing, and the acknowledgment of this by the NICU professionals, that allowed her to dis-close this.

When she [her daughter] was in the NICU a lot of the times the doctors would say they really felt like that [breast milk] was the reason why they felt her time in the NICU was so good. She didn't really have a lot of bad episodes or whatever because she was breastfed, or she was getting breast milk and she was getting so many of the nutrients and natural antibodies that are not found in formula. So, no matter what else I did I wanted to make sure that I was able to do that for as long as I could. (Quelita)

Wenda also saw breast milk as contributing to her baby's wellness. For her, it seemed his growing as a result of her milk was part of what allowed her to see him as a baby and this led to her being able to allow others to view him. Upon arriving at the NICU with milk for Paul, Wenda received news that he had experienced an upsetting setback and she ran out of the room crying. She remembers this as the first time she cried in the NICU. This point in time for her was quite revealing of her weakness, and this vulnerability seemed to allow for strength of acceptance. Wenda was not only able to forgive herself, but found the strength to allow her situation to be of benefit to those around her. She tells of the moment this happened.

I came back in and I prayed on him and I felt a little bit better and that's when I started thinking, wait a minute. I had never seen a baby that small. How many other women in here with these big babies probably have never seen a baby that small, and they don't know that they exist? And maybe they are gonna have another child again. Since this one came out at 30 weeks...and big, how do I know that...maybe their next child is not gonna be a tiny one like mine? And if they are gonna have a baby tiny just like mine, maybe it's time for me to just uncover Paul and allow them to see him...that they know that it's okay...to have a baby that small. And, so I met a couple of other women (*sounding surprised*) that their babies were bigger too and they were in there just to look over. They didn't have to be inside an isolette and they would come to me and say hi to me. I talked to them and they said how many pounds was he? They would ask me questions. The more that they asked me questions, the more that I was more open to letting them see Paul. To allow them to share that moment with me in knowing that yes, there are babies this small. They are not aliens...they are still babies...who grow with



it [breast milk] just like other babies. Maybe even more (*shrugging her shoulders with a knowing smile*). (Wenda)

This di-stance, a farness and nearness, resides in the separation of what was once united. Mother and baby are no longer joined, due to a birth that was followed by an unavoidable separation. As mothers lived this separation bodily, they pumped breast milk from afar and delivered it to their babies residing apart from them. These mothers were not with their babies, yet they presenced themselves among their babies through their breast milk, and these babies were no longer without their mothers. Through breast milk, absent mothers were bodily presenced. What, though, of the babies' absence from their mothers?

### **Place: Presencing an Absent Baby**

#### Separation

Your absence has gone through me  
Like thread through a needle.  
Everything I do is stitched with its color.  
(Merwin, 1962, p. 207)

Up until birth, mothers are absolutely indispensable to their babies. They are the ones ensuring their growth and development through their bodily connection to them. As a result of early birth, mothers were immediately transformed from the most important person in their babies' lives to a mere bystander. In having to leave their babies in the care of others and being dependent on those others for access to their babies, mothers experienced displacement. This manifested in the second major unfolding of feeling displaced, experiencing emplacement through providing breast milk, and becoming irreplaceable once again. This loss of place was experienced profoundly, abruptly, and problematically as a *dys-placement*.

Entire cultures can become profoundly averse to the places they inhabit, feeling atopic and displaced within their own implacement...this dis-

implacement, or “dys-placement” as it could also be called is endemic to the human condition in its ineluctable “uncanniness”; *Unheimlichkeit*, not-being-at-home, is intrinsic to habitation itself. (Casey, 2009, p. 34)

Are mothers in the NICU displaced within their own emplacement? Could what is being dys-placed be mothering itself?

Mothers in the NICU experience a loss of their dreams of idealized births, *perfect* babies, and the returning home with their newborns after birth. Instead their experience in the NICU has no “orientational markers” (Casey, 2009, p. 110) and is disconnected from the natural world of falling in love with and caring for one’s baby. In their nostalgia, could mothers be “literally pained at the [non]return home” (Casey, 2009, p. 38)? Could their walk through the NICU as desert be dys-orienting, with markers only recognizable by NICU professionals? Although from the outside, we may consider the NICU as making it possible for mothers to be with their babies born preterm and at VLBW, could the NICU be experienced as existing *between* mother and baby?

### **Dys-place-ment**

Traditionally, mothers are supposed to be with their newborn babies, yet mother of babies born preterm and at VLBW find themselves not temporarily apart due to the normal ups and downs of life and being disconnected, but rather interminably so and due to abnormal, insalubrious circumstances. As babies began their lives in the NICU, mothers no longer saw themselves as having an established place within these new lives. For these mothers, feeling out of place was experienced as more of a dys-place-ment. Although they possessed the title of mother, they struggled to envision and assume their identified roles and responsibilities, finding

themselves dys-placed by their own babies, and also NICU professionals. Their babies were very small, often sick, and attached to large machines by cords, wires, and clamps. In having to hand over the care of their babies to others, mothers experienced a lack of autonomy, and became dependent on doctors and nurses for access to their babies. Once this access was granted, mothers described being watched and their care scrutinized.

Scrutiny comes from the Latin *scrutari* meaning “to examine, search (as through trash)” from *scruta* meaning “trash, rags” (Harper, 2001/2012). The etymology of the word scrutinize brings the word’s harsh reality and suppositions to the forefront. What must it have felt like to be scrutinized in the care of one’s infant? Is care not something that mothers are most naturally and typically expected to *do* as mothers?

**Response-ability dys-place-d.** Mothers’ dreams of a healthy full-term infant were lost upon seeing their babies in the NICU. Facing the baby, in the way the babies presented themselves, represented a loss of response-ability for mothers. They were unable to relate. Within our conversations and through their stories, the mothers disclosed that the way their babies presented themselves was dys-placing to them.

Babies born preterm and at VLBW present themselves quite differently than full term babies, as “their eyes may be fused shut,” “their earlobes may look like flaps of skin on the sides of their heads,” and “their skin is a darkened red color” (Feldman, 2011, p. 93). Even though Talia had experienced the NICU with her oldest son, beginning again with her youngest daughter was no easy task.

I don’t remember anybody being this tiny...I can’t maneuver her. It was awkward. It was weird because I have three older children and I have

changed diapers, flipped them around, changed clothes, turned them over. You just flip them around so natural and with her it's like okay, let me lift this one leg and wipe really easy because I feel like if I push too hard you're going to bruise and it was...awkward. (Talia)

The sight of Talia's baby caused her to feel unable to care for her. She felt as though she was going to hurt her.

Babies enter the world with only one power – the power to elicit the emotion of tenderness and a caring response to them from other humans, especially and specifically from their mothers. Everything about an infant is designed to bring about such a response. She is small, soft, vulnerable, harmless and engaging. Her need for care and protection is obvious. Her cry evolved to make her mother (and other humans) anxious and concerned. It is a signal of distress to which emotionally appropriate human beings respond to with efforts to be of help. (Kimmel, 1998, para. 4)

While Talia was dys-placed by the size and fragility of her baby, Errin found herself dys-placed by how sick her baby was. She had trouble finding her voice and actively participating in his care, until she felt he was strong enough. It was similar for Errin:

I think that was the turning point, because when I was at the point when I didn't know whether he was going to make it through the night it was difficult for me to give any input because I just wanted them to save his life. But, once it was clear we had gotten beyond that then I felt more comfortable saying, "Hey why do you keep giving him this or giving him that? What about this? What about me doing that?" (Errin)

Errin experienced the dys-placement of her ability to mother within her baby's illness. It was difficult for her to provide any input until she had some indication that her baby was going to be okay.

**Professional dys-place-ment.** Errin was the only mother who mentioned the NICU doctors in her expression of dys-place-ment, and this was closely related to their role in keeping her baby alive, where she gladly accepted their authority, and knowledge. Although she believed that the doctors were qualified to care for her

child from a medical perspective, she still struggled with having to hand over complete care of her baby to them. She was eventually unwilling to hand over the motherly role she still held in protecting her baby, although she did initially.

It was tough for me initially to...I guess, completely trust the doctors, or I wouldn't even say trust, to have like more than a one sided relationship with the doctors. I think everyone sees a doctor and they think doctors are omnipotent and that you are just going to listen to whatever they say and take it. So, it probably took me about a month once he was more stable to say, no this is my child, and I am going to have more than a one-sided relationship with the doctors who are caring for him and to ask more questions. I tried to go to rounds every day if I could and to be involved in what they were doing, and if I had questions or disagreed to voice my opinion about it. (Errin)

More often than not, mothers found themselves displaced by the nurses caring for their children. Their skill and expertise, along with the roles nurses embodied as *experts, allowers* and *nursemothers*, were most displacing to mothers.

*Expert nurse.* Marcella was truly amazed with the ease with which nurses cared for her son in the NICU. This experienced mother was afraid to handle her baby, and she did not feel that she quite measured up.

You want to handle him with such care and then you see how the nurses handle him and you're like (*astounded*), "How do you do that?" They're just rolling him. They're just flipping him over...I don't care what you're telling me. I'm still scared. No! I was petrified. (Marcella)

While Marcella experienced fear and inadequacy, she was less surprised by this than Errin was. Errin felt quite adequate within her life outside of the NICU. She clearly expressed that her education and experience provided her the confidence to move through and be successful within life's countless circumstances. She began by discussing what she considered the vertical relationships that existed among *other* mothers and NICU professionals within the NICU environment.

I think a lot of it has to do with...let's say, background. So, people [parents] in the NICU come from all different kinds of backgrounds, but I'm a lawyer. I'm a law professor...so it's easier for me to feel like I can talk to people and there's not, like a vertical relationship. (Errin)

Errin's description of vertical relationships as hierarchical imply that two people were communicating within a framework that placed the NICU professionals in a superior position and the parent in an inferior one. This description of communication stands in stark contrast to Gadamer's (1975/2006) idea of horizons:

Every finite present has its limitations. We define the concept of "situation" by saying that it represents a standpoint that limits the possibility of vision. Hence essential to the concept of situation is the concept of "*horizon*". The horizon is the range of vision that includes everything that can be seen from a particular vantage point...A person who has no horizon does not see far enough and hence overvalues what is nearest to him. (p. 301)

Errin seemed to have expanded her own horizon to incorporate the perspective of the professionals in the NICU. She accepted that her son's life depended on the NICU professionals' understandings, history, and capabilities. The verbal exchanges that Errin described occurring in the NICU between some nurses and mothers did not seem like conversations; they were something *other-than*. Within conversation, ideas are exchanged between individuals, and the horizon of each individual is broadened by the history and culture brought along by the other. She did not, though, see conversations occurring in the NICU and felt the nurses generally did not always allow themselves to be moved into the horizons of mothers. The point of these interactions was to impart information, to make things known, but not to seek understanding or connection. Knowledge was passed from nurse to mother, yet these nurses did not open themselves up to expand or grow. They often did not allow

mothers to move them apart from, or outside of, their powerful role as the baby's nurse, and failed to connect with mothers on the most human of levels.

Errin then further went on to express that even though she did not hold the belief that doctors were superior to her, when her son became increasingly ill, "it kind of broke down anyway" because "you're helpless;" there is "nothing you can do and you are at the mercy of people who are experts and can take care of your child." This dependent relation is one of imbalance. Power is inherent in the nurse patient relationship (College of Registered Nurses of British Columbia, 2006). The nurse holds more power within her specialized knowledge, access to privileged information, and influence within the NICU environment. What does it mean for mothers to exist within this dependent relation? For mothers, nurses, and babies, it is full of tension.

Talia expressed disdain for the lack of autonomy she experienced. The expert nurse minimized her role as mother by imposing her expertise.

Yeah, loosen the leash a little bit! I felt like I was like getting a new job or something and I'm in training. Yeah...I'm her mom. I don't need you telling me how to do this or what to do. (Talia)

Within Talia's quote, we begin to see how the experience of being scrutinized begins to reveal itself. Sartre (1956) helps us to understand that it is not until we perceive ourselves as being watched by someone else that we become aware of our own presence. In perceiving ourselves being perceived, we are objectified and our embodied selves become less comfortable and more measured. In a sense we begin to see ourselves as we may appear to Others. In the experience of these mothers, they saw themselves perceived as inadequate, and attempts to guide and assist, as with Talia, were often not well received. It is not until mothers were able to find their

voices and assert themselves in confidence that they seemed able to find their place. This not only required belief in their own abilities through *doing*, but is born out of trusting relations. In becoming the object of someone else's gaze, we are objectified and feel reduced. For mothers in the NICU, being watched intellectualized the pursuit of caring for their infants, and as opposed to thoughtfully moving through care, their focus veered from their baby to the watcher. Prior to mothers being watched by their babies' nurses, they were allowed by them.

*Allowing nurse.* Mothers of babies in the NICU obviously found themselves dependent on NICU professionals for the health and welfare of their babies. This dependency on nurses who presented themselves as *allowers*, reached further into the sensitive realm of mothers' access to their babies. The word allow is from the Latin *allaudare*, and is comprised of the joining of *ad-* "to or toward in space and time" and *laudare* meaning "to praise" and "permission based on approval." Mothers in the NICU found themselves having to ask permission for access to their babies, and if allowed, were then subsequently watched as they did so. Within this allowing, though, mothers described nurses as supportive and helped them grow. Looking carefully at the language mothers used illuminates their dependency, as nurses regulated when and how interactions with their babies would occur. At times, this allowing and regulation caused mothers to grow into a sort of uncertain motherhood, as they even felt unready to take their babies home when it was time. They were not confident in themselves, even though their babies had spent months in the NICU and they were *taught* how to care for them. But, self-confidence involves trusting yourself and believing in your abilities. How could mothers be expected to gain such



trust, if confidence resides in *doing*? How can we expect mothers to be sure of and believe in their abilities if they are not *doing*? What role could the allowing nurse play here?

Wenda, Tami, Shamari, and Sophie described their need for support and gratefulness for the nurses. In the language they used to describe this, the nurse as *allower* is uncovered and manifests in the mothers' further dys-place-ment.

One thing that really made me sure of what I was doing was that there were a couple of nurses that were on Paul that were very confident of themselves and they knew what was going on and they *didn't mind* me doing what I needed to do. They would *let me* and *allow me* to change his diaper, touch him, bathe him, feed him, hold him. (Wenda)

Wenda expresses that the nurses “didn’t mind” her *doing* for her baby. What could this reveal about how Wenda felt she was viewed? Interestingly, Wenda attributes the nurses’ allowing to their own self-confidence. Perhaps she felt that only the more confident nurses were allowing her access, knowing that if something happened while the baby was in Wenda’s hands, they were able to straighten out the dys-order.

Tami seems to attribute the nurses’ increased allowing to not only the progress of babies, but also to the progress of parents. How is parental progress conceptualized in the NICU? How is it measured?

Um, well the nurses in there, they were pretty good. I guess as she [her daughter] progressed, the parents there as they progress, they start *letting you* handle them because I guess they [babies] are getting a little stronger. (Tami)

Tami’s words further illuminate the idea that until the babies are strong enough, their mothers were unable to satisfactorily care for them.

Shamari also attributes the nurses’ allowing to the baby’s progress, and although she is sympathetic to what she considers “the nurses’ reasons,” she

expresses how much the *doing* actually meant to her.

I mean you can't *do* much with the baby when they are first born...it was a big thing when they started *letting me* change her diaper because *I couldn't* change her diaper at first and then *we* [she and her boyfriend] would take her temperature. Those things were kind of big for me because *I couldn't do* anything at first and now they would *let me* start doing little things like the temperature and the diaper. (Shamari)

It seems difficult to believe that Shamari could not be taught to participate in her baby's care sooner. Teaching is complex and requires much beyond having mastered what it is to be taught.

Teaching is more difficult than learning. We know that; but we rarely think about it. And why is teaching more difficult than learning? Not because the teacher must have a larger store of information, and have it always ready. Teaching is more difficult than learning because what teaching calls for is this: to let learn. The real teacher, in fact, lets nothing else be learned than—learning. (Heidegger, 1954/1968, p. 15)

In the NICU, when nurses take over the care of the babies and only demonstrate to mothers what should be done, they are depriving them of their own learning opportunity. How difficult it must be for nurses to be the true teachers they need to be, to let mothers learn with a vulnerable baby placed in their care. They would have to be comfortable in mothers responding to the needs of their babies, as the babies present them. For Heidegger, the process occurring between teacher and learner is co-respondance (*Ent-sprechung*) and it allows learning to happen. Shamari was finally living this co-respondance with her baby's nurse and as a *nurseteacher*, she was comfortable in *letting-be*. She allowed mothering to happen for Shamari. In Shamari's case, the nurseteacher allowed her to realize her motherly knowledge and supported her in the *doing*, thus making her care visible to herself and others. Even this welcomed and cherished nurseteacher, though, began as a nursemother.

*Nursemother.* Nurses most often presented themselves, from the beginning, as providing all care for the babies. This left mothers with nothing at all to do, except to listen to what had already been done for their babies while they were gone. Sophie expressed these feelings of being re-placed.

Basically, every time I came in they just explained to me what had [happened], how she'd been. They'd tell me like, they drew blood and tested her for this, tested her for that and if she's picking up...sucking on the bottle or stuff. I was like, ok, I guess my job is done here then (*laughing uncomfortably*)—until she came home. (Sophie)

Errin also expresses her desire to mother her child in the NICU, and her difficulty having to ask to do so.

It's hard having to ask permission to hold your child especially when he's really sick. Or, to have to count on other people to like, do things for him like simple things change his diaper, take his temperature – like make sure he's okay. Especially during the night...that's a staple of a parent's job. (Errin)

Heidegger (1953/1996) presents us with leaping in and leaping ahead, as two differing ways of helping others. In leaping in, concern takes over and displaces the other, and what was to be taken care of has already been cared for. In the nurses' leaping in, even if out of genuine concern, are they robbing mothers of their response-ability? When nurses rush in to take “care of things at hand” (p. 114), where are mothers left?

In contrast to this, there is the possibility of a concern which does not so much leap in for the other as *leap ahead of* him, not in order to take “care” away from him, but to first to give it back to him as such. This concern which essentially pertains to authentic care; that is, the existence of the other, and not to a *what* which takes care of, helps the other to become transparent to himself *in* his care and *free for* it. (Heidegger, 1953/1996, p. 115)

Within each of the roles played by nurses, as expert nurse, allowing nurse, and nursemother, mothers were dys-placed. The expert nurse pushed mothers aside with

her vast knowledge of the NICU language, procedures, and equipment. The allowing nurse pushed mothers aside as she controlled access to the baby. Finally, the nurse-mother pushed mothers aside by taking from them their very role as mother, leaving them to have felt unnecessary.

These nurses seemed to cause mothers to move into an inauthentic way of being as they stood dys-abled and *waiting for* the future, as opposed to *waiting alongside* the future and *participating in* their movement towards the future. Kidd (1990) also considers Heidegger's positive modes of solicitude as leaping-in and leaping-ahead-of and describes leaping-in as a "stripping away from" and "a taking away of one's possibilities" (p. 2). Nurses' reactions often manifest in *leaping-in* and take away a mother's possibilities of experience. Leaping in can turn a teachable moment into a missed opportunity for learning. The notion of *leaping-ahead-of*, though, gives back one's own possibilities.

Whereas, a response, based upon responsibility, which involves a choice, is positive, it is a leaping-ahead-of to give one back one's ownmost possibilities. This is caring. Caring is sharing, a dialogue upon the ground of *Inbetweenness*. Self-worth is developed by caring and sharing. (Kidd, 1990, p. 2)

Instead of reacting to what mothers are doing in concern, perhaps nurses should consider responding, as in *leaping-ahead-of*, and returning to mothers their "ownmost possibilities." Is not caring allowing another to be? Caring manifests in the dis-closing of possibilities, rather than taking them away. Where we have possibilities, we are emplaced. Could the sacrifice of providing breast milk from afar have placed mothers within the worlds of their babies?

## **Em-place-ment**

Each of the mothers placed a significant amount of focus on establishing her place in the life of her baby, and here a new meaning behind breastfeeding was uncovered. Pumping breast milk presented mothers as playing a unique and essential role as protector, of their babies, through the medicine of breast milk. From the Latin *medicina*, meaning “the healing art,” this cocktail made from the proteins and sugars from her very blood, flows outward to heal the work of art that is her baby. This most ancient act could only be performed by mothers, and was well respected by all as fostering growth and development. Acting in this role, mothers did not need the permission of nurses, nor were they watched as they performed. Breastfeeding emerged here as providing a unique place for mothers once again, but within the world of the NICU, as her breast milk was extracted and transported through machinery and into her baby’s body via the great wonders of technology.

Although mothers eventually gained confidence in caring for their babies, they had an ongoing and conflicting need for support from knowledgeable NICU professionals, with feeding as essential to care. Breastfeeding, in this way, presented mothers as doing something essential—protecting their babies, even in absence. Casey (2009) writes, “To exist at all as a (material or mental) object or as (an experienced or observed) event is to have a place—to be implaced, however minimally or imperfectly or temporarily” (p. 13). The role of *provider of breast milk*, the almost magical elixir, emplaced mothers in their babies' NICU world and appeared to drown out its overwhelming and constant background. Breastfeeding not only brought mothers forward as still existing, but as purposefully essential.

**Elixir.** Unable to take their babies home with them, the pumping and providing of their breast milk *presenced* mothers in the NICU with their babies. As their babies were nourished with it, their mothers were bodily tending to them from afar, through the medium of their protective elixir.

Errin and Marcela both acted, almost immediately, once the nurses informed them of the benefits of breast milk for preterm babies. For Errin, breastfeeding emplaced her as a “stay-at-hospital mom.” It was *necessary* for her to continually deliver milk, and even when she was absent, she knew that her “milk was always there.” They were each providing what only she could, and each was emplaced by pumping breast milk.

I literally started pumping not even an hour or two after he was born. So, I started pumping right away...and then I had something to give. The benefits that they told me was strengthening of the lining of the stomach, a stronger stomach, tolerance when they're sick, less illnesses, not as many fevers, everything else. (Marcella)

What must it have felt like for Errin and Marcella to have been useful to their babies again, after feeling pushed to the periphery of their care?

Wenda attributed her baby's rapid progress to her breast milk. Providing breast milk provided her with a purpose, a reason for existing as mother, even when others were carrying out all other motherly roles. For Wenda, providing breast milk for her son became the priority and served as a concrete representation of her importance in the life of her baby.

I started pumping. It got to the point that I had no place in my...small freezer. It was full...so I ended up having to go to one of the stores. I bought me another big freezer. The one that looks like a , and then eventually that got full. So, I started using the freezer in the house. I gave away all the food in the freezer and my husband is mad because I gave away his meat. I said, “What's important your meat or the baby's milk?” And he's like, “But you

have two freezers full! Is he gonna even have time to drink all of that?" I said, "Yeah...even after he turns one, he can still drink it." (Wenda)

As Wenda continued to pump vast amounts of breast milk for her son, she seemed to be over-compensating for what she was not otherwise able to provide for him. Her fear of running out of milk caused her to furiously pump to prove her own self-worth. Her idea that nothing was as important as the baby's milk seems to indicate that she saw herself as enmeshed through her magical elixir. Wenda went on to express the pride she felt in the milk that her body had produced. Luckily, her milk stood up to the nurses' calculations.

They [nurses] have this way to check the calories in your milk supply and when they checked mine they said I had 29 calories, and I was like what does that mean? What can I do to make it better? Because I thought 29 calories wasn't enough. They said no, 29 calories is way more...someone else had 19. The most we have ever gotten is 22, but 29 is like—you are like a superman. They said continue the good job. Whatever you eat, keep eating. (Wenda)

Quantifying the value of Wenda's milk in calories, and the subsequent judgment made based on that, allowed for comparison and seemed to make the provision of breast milk somehow competitive. The NICU's technological calculations made the immeasurable measurable. In Wenda's case, this was a source of pride and seemed to boost her feelings of self-worth. I wonder how the mother whose breast milk had 19 calories felt she was measuring up. The once private world of nursing, as a component of mothering, manifests here as public and subject to scrutiny, comparison, and judgment.

**Hospit-able nurse.** The notion of a hospital as an institution for the sick was initially recorded in 1540. The word's ancient meaning lies in the Latin *hospitale* meaning guest-house, derived from the Latin adjective *hospitalis* (of a guest or host)

(Harper, 2001/2012). Many mothers spoke of hospitable nurses who supported them in caring for their babies, and helped them to feel at home.

A suffering person, new or not, arrives to my welcome. Immediately the tables are turned. Nothing happens unless I surrender the leading role...and allow the patient to lead me, to teach me, to take me hostage, to inhabit me. My welcome creates the possibility that the other may welcome me into her world of loss, confusion, and devastation. The welcome becomes the one who may be welcomed...we are all responsible to the face of the other and the other is whoever comes to me in need. Whoever is the sufferer who I meet and disturbs my comfortable complacency and requires me to respond.  
(Orange, 2012)

This excerpt from a keynote speech given by Donna Orange, a practicing psychologist educated in both philosophy and clinical psychology and psychoanalysis, entitled “Clinical Hospitality: Welcoming the Face of the Devastated Other” was given at the 2012 International Human Sciences Research Conference. Listening to this speech awakened many thoughts for me related to mothers in the NICU, as well as the work of Emmanuel Levinas.

Levinas (1969) writes about the other as a “stranger...who disturbs the being at home with oneself” (p. 39). It is the *welcoming* of this stranger-Other, as described by Levinas, which is the ethical response. Mothers in the NICU existed, too, as strangers. They are guests and how they were received by the nurse-hosts shapes their experiences there.

Quelita expressed how overwhelming the open, bounded space of the NICU was, with tiny babies hooked up to machines everywhere she looked. Unless she kept her line of sight under strict control, she was watching everyone, and everyone was watching her. It was the support and encouragement of the nurses in letting Quelita learn, as opposed to stepping in to take care of her baby, which assisted her in moving



from passive to active caring. Receiving this support led to a belief in herself, and in her own response-ability.

It was the nurses that made that transition for me soon. From the time that she was able to start feeding, even from the tube they would do little stuff like – “Do you want to hold the tube?” and I would be like (*shaking her head from side to side*). And they would be like, “No, you can hold the tube.” Or when she was able to be...wiped down to bathe, you know they would just be like, “You can wipe her down” or, “Mom, you can change the diaper. You can take her temperature”. So they made me comfortable early. It was not an option at some points (*laughing*). So by the time she was up to doing stuff, when [there was] a nurse that had not had us before I was just like, “I can do it.” (Quelita)

The nurses in Quelita’s case had confidence in her, and pushed her even when she did not yet have the confidence in herself to care for her baby. What was it about these nurses that enabled them to support her in this space, and within this way?

Open space is liberating, but it also raises the fear of getting lost in the uncharted and the unknown. So a learning space must be hospitable—inviting as well as open, safe and trustworthy as well as free. (Palmer, 2007, p. 77)

It seems some nurses’ hospitality made the open, foreign space of the NICU a hospitable place of learning, but although open, this space was simultaneously restrictive. The walls of the NICU were inescapable, if the intention was to be with one’s baby.

The boundaries around the space offer some of that reassurance, but when those boundaries hold us to difficult topics, additional reassurance is required. So a learning space must have...places to rest, places to find nourishment, even places to seek shelter when one feels overexposed. (Palmer, 2007, pp. 77-78)

The NICU lacks spaces where mothers can retreat to and rejuvenate without leaving their babies. Is there room, within the environment of the NICU, for cultivating spaces? Such spaces within the NICU could be a dwelling space for Mamatoto, welcoming mother and baby together in hospitality.

Sophie also describes how the nurses encouraged and supported her in interacting with, and beginning to care for, her baby.

They showed me how to...handle her properly and stuff, since she was so fragile at the time, so it really helped. They showed me how to feed her at first through the tube in her nose and they inserted it in her mouth and they were showing me how the feeding tube and stuff and they later on transferred her to the bottle. So and they showed me certain procedures to do with her and stuff so. (Sophie)

If we think of mothers in the NICU as students learning to care for their children born preterm and very small, and nurses as their teachers, we can envision the NICU as a sort of classroom.

Hospitality in the classroom requires not only that we treat our students with civility and compassion but also that we invite our students and their insights into the conversation. The good host is not merely polite to the guest—the good host assumes that the guest has stories to tell. (Palmer, 2007, p. 82)

Lucy expresses the support she received from nurses who were *in tune* with her.

They were all very good, very helpful. Some more than others, but (*laughing*) definitely of those ones who were more in tune with what you were doing and teaching you and that type of stuff. I look at it as a blessing now that he was in there, because we learned so much with him being in the NICU. So I am kind of afraid of the next one coming, on my own from like, day two (*laughing*). (Lucy)

Some nurses in Lucy's case believed she had a story to tell. Their ability to be in tune with her means that they took the time to listen, and to notice what Lucy brought with her into the NICU, giving consideration to what Lucy wanted. As Lucy spoke about nurses being in tune with what she was doing, the idea of hospitality emerges. Lucy valued the nurses that “took the time to teach or say this is what you can *do*, or you can *do* this.”

There were also those mothers who did not ever feel quite at home in the NICU, even after their babies had lived there for months. Experiencing emplacement in the NICU is to feel at home, and creating pathways for mothers who feel isolated and alienated in this space is critical to supporting them in caring for their babies.

### **Ir-re-place-able**

For many of these mothers, the newly established responsibility of providing breast milk to their babies made them feel once again irreplaceable. Through their breast milk, mothers were able to interact with their babies in a more natural way and owned a part in their success. It was not achieved completely without them. These mothers redefined their identity to one that was once again central to the lives of their children. The notions that better moms provide breast milk and that breast milk leads to better outcomes were prevalent. Even in their physical absence, babies were presenced among mothers as they pumped their milk. This emplacement provided mothers with a distinct role and responsibility that could not be carried out by nurses or doctors. Mothers were again directly contributing to the success of their babies.

Wenda describes the magic of her breast milk, and it becomes the reason for all that is good.

The first time they just put it on his mouth but after that they kept feeding him through a tube and things started happening where – changes, he opened his eyes (whispering in amazement). His skin is a little bit tougher now that I can actually touch him. He had no breakdowns. They said expect breakdowns. Expect this. And he had no breakdowns, except the fact that he had moments where he was not breathing well and he would extubate himself, on his own. He would just rip the thing off his face! (Wenda)

In having perceived her breast milk as accounting for her son's success, Wenda began to view even his breakdowns as acts of strength, demonstrated by his extubating

himself. The magic of her breast milk was giving him that strength and the power to have an effect on his world. The word magic is based in the Persian word *magush* and from the Proto-Indo-European *magh meaning* "to be able, to have power" (Harper, 2001/2012). The power of her breast milk was making her son powerful. Was power being turned over to mothers, as they grew into their distinct role as providers of breast milk?

Talia also saw breast milk as better—as offering “something more than formula,” as she compared her two children's NICU courses. She owed her daughter's short stay of just over a month to the milk she provided, while her firstborn son was formula-fed and in the NICU for three months. She attributed her daughter's shorter stay to what she was able to do for her as a mother, and for Talia, this was a source of pride and accomplishment.

Providing breast milk allowed these mothers to play a unique and essential role related to the health, growth, and development of their babies. It emplaced them in the world of the NICU, their baby's world. Absent babies were presented and mothers, once again, became irreplaceable within the lives of their newborns.

### **Members: Re-presenting Mamatoto**

All mothers, in a way, are dismembered through the birthing process. After birth mother and baby are no longer one, and are reunited as mother holds her baby outside of herself for the first time. They begin to build a new bond. Mothers of babies born preterm and at VLBW, though, find themselves reintroduced to their babies quite differently. Post birth, babies are whisked away by medical professionals and are reintroduced to their mothers, but are not quite *reunited* with

them. They exist at a distance, and the intimate contact hallmarked by early bonding is further restricted by the culture and technology of the NICU. Unable to spend long amounts of time with their babies, and instead only shorter amounts of time *near* them, a mother's dismemberment is not only prolonged by the circumstances immediately surrounding early birth, but is continued and compounded as mothers are obligated to leave their babies behind. Their babies are of the NICU—a world disconnected from that of their mothers. Breastfeeding emerges again here, as assisting mothers in re-member(ing) themselves, in becoming one again with their babies. In the end, mothers changed their view of the NICU, transforming it from an unfamiliar, estranging place and into an oasis with a meaning of breastfeeding uncovered as reestablishing connections between mothers and babies.

Sophie describes how it felt to leave her baby in the NICU. Even though she was aware that she was unable to care for her baby at that point and was leaving her baby in qualified hands, this awareness did not make it any easier to bear. It seemed to highlight, for her, that her hands were inadequate.

Hard, hard cause I was—I did cry. I started to cry...because that didn't happen with my other baby. So, to leave my baby in the hands of other doctors and people I don't know, it was...hard. I wanted her to be home and stuff, but I knew she had to get well before she could come home with *me*.  
(Sophie)



(Sampson, 2011)

The preceding fiber art piece depicts a playing card. One of many historical uses of which was the inspiration for this piece. Included on the card's face is an inscription symbolizing the loss of baby Jackie. My mother and aunt have vivid memories of themselves as children spending summers in their grandmother's one-

room-cabin in the Catskills, nightly praying the decade of the rosary on their knees. This ritual ended with an offering of prayers to a litany of people, including one for my mother's youngest uncle, Jackie. The circumstances surrounding his death as an infant remained unclear, but his absence lived on. True to form, my great-grandmother would conclude the prayers by cursing the country of England, Jackie's doctor, and Roosevelt (she stood squarely against war and what it inevitably did to children and families). The secrets surrounding Jackie's death were deeply embedded in the time, and shrouded in mystery. So much so, that in her memory my mother's sister, (ten years her junior) thought they were praying for Jack Kennedy (whose portrait was eventually hung with pride on the wall just above them).

“Decoding the Past: Secrets of the Playing Card” (Kohler & White, 2006) is a documentary that reveals an early history of cards, including their use as a form of communication. Taking advantage of the fact that they were inexpensive and only printed on one face, the blank backs of these sturdy cards offered endless possibilities, from currency and love letters to invitations and escape maps during World War II. In 18th century Netherlands, though, the playing card is found to have served a different purpose. As extreme poverty drove women to abandon their babies at orphanages and convents, they would leave a playing card with a personal message inscribed on the back. Those mothers who planned to return and reclaim their baby tore the card, taking one piece and leaving the other inside the baby's blanket, along with hopes of survival and remembrance.

For Quelita as well, leaving her daughter in the NICU was difficult, especially knowing that those with whom she was left in the care of were integral to her

daughter's wellness. Quelita felt disconnected and passively exerted herself by quizzing the nurses. It seemed her way of railing against a forced abandonment.

It [having to leave my daughter] was critical because there was actually one nurse that I requested not to...handle her, because I didn't think that she was very attentive. You know just small little things...one evening it was just bath time and stuff, and she couldn't find things and she was asking me! I knew where they were, but I had a problem with her asking me where they were. So you know, little stuff like that. It was really, really important to me to know the nurse. You, know. Know what you were doing! I knew exactly what they were doing. Every morning the doctor would always come over, talk to me and explain to me what was going to be done. So I already knew. But, I would always ask the nurse – just to see if she knew. (Quelita)

In having experienced these feelings of abandonment, and then continuing to live apart from their babies, mothers had to find ways to not only move through them, but to achieve balance within their circumstances. Within a dismemberment that was lasting, mothers found a way to *mother* at a distance by providing breast milk. Doing this allowed them to perceive themselves as connected to their babies, while their bodies worked together in shared rhythms. Mothering is in the *doing*, and these women began to *be* the mothers they were and considered themselves prior to their dismemberment. They remembered themselves, and once again along with their babies, regained membership into *mamatoto*.

### **Dys-member-ment, Lasting**

On the monitor, she bobbed and floated in a pixelated haze. But next to her loomed a mysterious shape that had not been there two days before: a clot of blood the size of a fist, created as the placenta had begun to tear loose from my body. A nurse pumped drugs into an IV to stall the labor, and gradually they took a tenuous hold. But it was clear to everyone that the reprieve was temporary. My baby and I were coming apart. (Benham, 2012)

Although traditionally mothers are physically dismembered as they move from a single entity in pregnancy to two more separate beings, as a normal part of the



birthing process, they are most often quickly reunited with their babies. Through this they experience a continuation and enhancement of shared bodily rhythms, and emotional bonds begin to replace the preexisting physical ones. Predominant in each of the conversations with mothers was an unwavering feeling of continuing to exist at a distance, an open-ended and unnatural one, after the early birth of their babies. For mothers of babies born preterm and at VLBW, their dismemberment becomes a *dys-member-ment* through the abrupt, medicalized separation, strange culture, and unnatural technology of the NICU environment—and this dys-member-ment is lasting. Mothers were left feeling that a part of them was indefinitely missing from their-selves, yet still hauntingly with them. This lasting state seemed to feed and strengthen their desire to be one again with their babies, as well as their feelings of desertion and abandonment. These feelings were amplified by their fears of further, more permanent loss.

**Fear of loss.** Feldman, Weller, Leckman, Kuint and Eidelman (1999) examined attachment from the perspective of mothers and under the conditions of proximity, separation and potential loss, using an ecological approach. They conducted interviews with three groups of mothers: those giving birth to healthy full-term infants and maintaining full proximity, those giving birth to healthy preterm infants who were separated from their babies, and those giving birth to babies born at VLBW who experienced potential loss and continued separation. The mothers' responses existed on a continuum from the highly anxious state associated with separation to the disengaged and reduced state of involvement commonly associated with loss.

Whereas mothers of normal healthy babies experience medium-to-high levels of thoughts and worries, initial separation increases these preoccupations. However, with prolonged separation and concerns with potential loss, these thoughts and worries significantly decrease. At a certain point on the continuum from proximity to loss, the highly arousing state of “separation” turns into the diminished reactivity characteristic of “loss.” (p. 936)

This state of prolonged separation, coupled with the potential of loss presented by a sick baby, seem to create an environment where disengagement on the part of mothers seems more probable; yet, these mothers were able to remain engaged.

I wanted to wear red. It's my favorite color. But, I could not wear red the whole time Paul was in the hospital...because in my culture if somebody shows up at a funeral with a red outfit, that means that they killed that person. And I couldn't wear red because it kept reminding me of that and if anything happens to Paul the day that I walked in with that red outfit, I am to blame for everything. (Wenda)

This fear of loss came early for the mothers of children who began life in the NICU, and Wenda's fear of loss carried over into such everyday thoughts of what she was going to wear. Perhaps they realize too soon that they cannot unconditionally protect their babies, and this is amplified by their distance from them so early on. For other mothers this fear comes later, maybe when they first leave their child with a babysitter or when they go off to school for the first time. Perhaps for some it doesn't come until their children go off to live on their own, but it seems to come in one way or another for each of us.

#### The Poetics of Progeny

i trust you today  
with my fourth child  
third born of my body  
an-other work of art

uncomfortable  
in clothes and shoes  
i wish him to be

- free and smiling  
laughing even  
the wind across his face

often preferring  
grayed temples and wrinkles  
– wise, raspy voices  
to the pudgy faces of his others  
i wish his old soul quiet walks in open air  
fanciful stories of seas, earth, and sky

so much of this world  
is not that  
instead, he is surrounded  
by the machine-made objects of Abram  
too loud – he covers his ears  
too bright – he covers his eyes  
he does not cope well  
with the abrupt,  
the unnatural

i am afraid of him collapsing into himself

do we go?  
back to the farmhouse,  
the cottage,  
the cabin,  
the asi  
the world as his teacher

i have considered it  
still...  
considering it  
secretly contemplating  
whether bliss may only find him there

for now, though  
i present him to you  
naked,  
head thrown back  
in the middle  
of a giggle  
in hopes we are understood

- embraced even

supported in our journey  
as he makes sense of this *civilized* world  
as it is here, he must exist  
at least for now  
(Sampson-Kelly, 2011)

Placing our children's welfare in the hands of others who may treat them poorly, unkindly, or simply without regard is difficult at best. How can we allow mothers permission to grieve such separations? Can we expect mothers to feel at ease when placing their children in the care of others, not to mention their vulnerable, newly born babies? How can we comfort mothers in this time of loss without minimizing their dis-eases or dismissing them as unfounded?

NICU professionals are expert and highly qualified to care for infants born preterm and at VLBW, but is it not a mother's ancestral role to *be-with* when her children are sick or would otherwise be alone? I re-call my own experience of dwelling in a chair next to my child's hospital bed for eight days. As I paced the halls during one of his procedures, I glanced into the parentless rooms of other children and can only now imagine the grief and heartache those parents must have endured. I was encouraged countless times by lovely doctors and nurses to take some time for myself, to go home and shower, to rest. I refused to leave, but now recognize that I was allowed to stay. It was only when my own mother arrived that I went home to shower and change. My response-ability then extended far beyond who I was in time and out toward the Others who supported me, and it is only this that allows me to live with it in a positive light. What of mothers who for a montage of reasons find themselves un-response-able in such moments?

Young (1984) suggests that birth also represents a “cessation of time” (p. 54), and in essence, an end to the growth and change that mothers were thrown into as “pregnant existence entails, finally, a unique temporality of process and growth in which the woman can experience her-self as split between past and future” (p. 46). Mothers of preterm infants are more fiercely thrust into the end of pregnancy, this cessation of time, and for them dreams are lost. Could this manifest in a fear of loving one’s baby for fear of further loss?

The word loss has its roots in the Proto-Indo-European *leu* meaning “to loosen, divide, cut apart, untie, separate” (Harper, 2001/2012). As pregnancy comes to an end in birth, all mothers are loosened from their babies bodily. In the NICU, though, this loosening reaches toward separation. This separation is widened as mothers are submerged in the NICU professionals’ worldview.

### **NICU worldview.**

A virtually overwhelming technological imperative operates the entire ethos of the NICU, particularly on the physicians. Survival to discharge from the unit is the main focus and measure of success. Death is viewed not as a natural event but as a failure of medical practice. The most aggressive forms of treatment are applied on all but the most severely neurologically compromised infants. (Weiz, 1990, p. 264)

The NICU worldview is a technology-dominated one, yet focused on the humanly matters of breath, warmth, and sometime later, nourishment. In the Level III NICU, nurses directly care for babies. They are in charge of ventilators, incubators, and feeding tubes. They monitor hourly and make sure babies are responding, all the while recording the information provided by technology. Nurses are required to be diligent, even as their work is overseen by neonatologists. High-tech healthcare is provided and progress meticulously measured, but what those of the NICU may view

as intuitive markers of progress, are often counter intuitive to outsiders. The culture of the NICU is hallmarked by a unique vocabulary, unwritten rules, norms, and expectations. It is a place that mothers become a part of only through their relation to their baby. The NICU culture is supported by its technology. The NICU technology, in turn, is highly influenced by its culture.

*NICU culture.* In this foreign world of their children, the NICU professionals' cultural norms and values were disconnecting for mothers as they tried to establish new relationships with their babies.

The tertiary or level III NICU represents an unusually insular and self-contained institutional system, even within the world of specialized acute care in large medical centers. NICUs tend to be physically isolated from other hospital areas and access is limited for the protection of infants. Although clear authority patterns exist, various NICU personnel work closely and intensively together, as neonatology is a “high touch” area of medicine for the physicians as well as for the nurses. Since a fairly large number of cases present some dramatic and ethically perplexing decision problems, a sub-culture of unit solidarity as well as decision-making by consensus tend to emerge. Moreover, NICUs seem, as cultural systems, to avoid using an explicitly ethical vocabulary when decisions are made; the “medicalization” of ethical questions is widespread. (Weiz, 1990, pp. 263-264)

What must it be like to find oneself here? Although mothers absolutely exist *in* the NICU, do they ever become *of* the NICU? Might we consider the possibility of unique roles that only mothers-as-strangers can play, that they could be more suitable for or capable of doing *because* they are strangers? In his essay entitled *The Stranger*, Simmel (1908/1971) offers an idea of the stranger as neither an “outsider” without connection to the group, nor a “wanderer” who comes and then moves on. Instead, the stranger stays and becomes a member of the group; yet exists at a distance from its “native” members. The words stranger, host, and guest all find their roots within the same Proto-Indo-European word *ghostis*. How can we welcome

these mothers-as-strangers into the hospital's NICU in hospitality?

Soon after the birth of her son, Lucy felt isolated and left out, as others were able to see him before her. She describes being on the outside, and this struck her as strange.

Yeah, well with me obviously they were able to go down, my husband was able to go down first and I guess somebody showed them what to do so they (husband and parents) are showing me what to do which is a little odd. You just don't know what to do, you don't want to look around at the other little babies and you are just trying to familiarize yourself with what is going on in there. (Lucy)

Lucy went on to describe the foreign culture of the NICU. She was not sure how to behave. She did not know what to say.

I do think also, it's a little bit uncomfortable when you first go in there to interact with your own baby because you just don't know what to do, how to do it, what you should say. You don't want to talk too loud because you just kind of feel weird in and of itself, because of the situation. (Lucy)

The situation is a foreign one. It was apparent to Lucy early on that she would have to learn the culture of the NICU, and she did.

So it is a little weird at first, but you do get used to it and know what to do and just go in and do your routine and visit the baby every day and get to know the nurses in there. (Lucy)

Talia was never quite able to feel like a part of the NICU. She was unable to relax, and this made reconnecting with her baby impossible. She was uncomfortable not knowing the ways of the NICU, the cultural norms, or what was acceptable. She felt as if she were being judged.

Yeah, you just can't [relax]. It's like okay are they going to say I'm doing this wrong, or are they going to say this is wrong and every little thing you do you have to think in the back of your head, "What is so and so going to say about this or what is this person going to say." So you're constantly, you can't just relax and do something when your mind is constantly running about anything

that is going to come afterwards. Like I said it was easier when I just got home. (Talía)

Errin also had difficulty reconnecting with her baby and she shares that “The first two weeks it was harder to establish a connection, because everyone else was taking care of him.” As opposed to fulfilling their need to reconnect, mothers experienced further isolation from their babies, and this isolation was furthered by the NICU’s technology.

***NICU technology.***

Thus we shall never experience our relationship to the essence of technology so long as we merely conceive and push forward the technological, put up with it, or evade it. Everywhere we remain unfree and chained to technology, whether we passionately affirm or deny it. But we are delivered over to it in the worst possible way when we regard it as something neutral. (Heidegger, 1927/2003, pp. 311-312)

There is perhaps no other place where we exist as more *unfree and chained to technology* than we do in the NICU. When in this place, one is surrounded by technology. It is a physical part of the babies who live there. For mothers, most of this technology bears the awesome responsibility of sustaining the lives of their babies as they struggle to live outside of them, and without the physical motherly support they were accustomed to within them. Although they were encouraged to believe otherwise, technology in the NICU for mothers was anything but neutral.

They would tell me, “Don't worry about the wires, just act like they're not there.” Alarms would be going off and no one would do anything. They'd say, “Oh, it's nothing. It's okay.” It didn't feel okay. (Yadirah)

Yadirah expresses her difficulty not responding to the NICU alarms in ways that she would react any and everywhere outside of there. The nurse's response to Yadirah's reaction to the alarms seems to further dismember her. Yadirah wanted to *do*



something about it because in her world, an alarm alerted people to danger. The nurse's response left her to feel as though she didn't know her baby, or how to interpret her needs and care for her. Heidegger, like Yadirah, seems to be telling us that the simple, casual use of technology is not enough, that somehow humanity requires something more. What are we to consider about our relationship with technology in the NICU? Knowing what we gain from its use, what also might we be giving up?

The ventilator made her belly heave with such force her chest dimpled under the ribs. Wires snaked from electrodes on her chest. A red sensor glowed on her foot. An IV ran into her hand. A wheeled pole next to her bed was stacked with three levels of pumps dosing out caffeine, antibiotics, pain medication and sedatives. A hanging bag contained liquid intravenous nutrition, precisely calibrated each day. She was so obscured by tape and technology that I struggled to imagine her naked face. (Kelley, 2012)

Mothers in the NICU experienced its high-tech world as something to overcome in their desire to re-member themselves, to reconnect with their babies. Not only did the isolette, wires, and chords create physical barriers, but also the babies' feeding tubes and connection to NICU machinery served as constant reminders to mothers that their babies still needed to grow yet healthier and stronger before they could fully care for them.

In exploring how NICU technology might influence the relation between parents and their babies, van Manen (2012) discovered that while importance of the highly technological NICU environment to the life of the child is paramount, it is balanced with the effects these technologies have that are beyond their intention, and "may put into question the humanizing meaning of contact between parent and child" (p. 6).

The mother's breast and skin is part of the symbiotic self-other. The psychology and anthropology of touch and bonding signifies the importance of the subtleties and complexities of contact. But the experience of holding, touching, gazing and mutual sensing may be hindered or helped by the NICU technology. The newborn in the isolette may lack the opportunity for this primordial contact that is critical in the shaping of the deeply human. (van Manen, 2012, p. 96)

The technology of the isolette did not welcome touching the baby, but rather forced looking in from the outside. Its see-through plastic walls contained technology essential to the life of the babies it housed, magnified the babies' vulnerability, and caused mothers to fear the possibility of further damaging them.

I was scared to touch him. I didn't want to do anything wrong. He was under the bilirubin light...he was on the oscillator and then the vent. So, it was hard to see him as like a baby, like my baby, probably until he came off of the vent. (Errin)

Errin expressed difficulty even seeing her son as *a baby*, let alone *her baby*. The presence of the technology overtook that relation and further dis-membered her, making her anxious and uncomfortable.

Talia expressed fear that she would hurt her baby. She worried that the cords connecting her daughter to the various machines would break.

I kept getting to the point like, I'm going to break her. Something is going to break. Something is going to break off. Some cord, something is going to break. (Talia)

Her baby's cords connected her to machines that kept her warm. Not being able to be outside the warmth of the machine for too long led to limited access to the baby.

Talia's lack of response-ability suddenly became apparent when the nurses stepped in.

Uh, huh (*knowing laugh*)...it was awkward the first time I changed her clothes and diaper. I got to the point I was taking so long the nurse came in and was like oh, I'll just finish, because the longer you keep these open the colder

she's going to get so...I'll just go ahead and finish. (Talia)

How might the nurses have responded in this situation in a way that empowered Talia to rise to meet her daughter's needs, as opposed to taking this opportunity away from her?

NICU professionals view technology is a means to an end. This idea is presented by Layne (1996), a parent-ethnographer who authored a first-person narrative of her experience while her son lived in the NICU. She speaks of the term *graduation*, commonly used by NICU professionals in reference to babies moving along a path from illness to wellness.

After we had been regular visitors in the NICU for sometime, we discovered, or more accurately were taught by the nursing staff, to recognize a number of markers of linear progression through the NICU. Each move from one such marker to another was described by the nursing staff as a "graduation." One clear marker was the type of bed that the child occupied. Very sick children are kept in open warming trays where they can be reached quickly. After the child has stabilized, she or he is moved to an isolette, a lucite box equipped with two portholes on each side through which the baby can be touched or spoken to. While this looks to laypersons as less "normal" than the open beds they first occupied, we learned that the move to an isolette signaled definite progress; it meant Jasper was one step closer to being able to come home. And once he was moved to an isolette we were also allowed to dress him in the clothes we had bought for him in anticipation of his birth. The final stage of progress in terms of furniture is to a crib, which usually coincides with another important "graduation"-from the special care nursery to the intermediate nursery, a kind of halfway house for preemies. The final graduation, of course, is being able to go home and to become officially an "alumnus" of the NICU. (p. 635)

This view of technology does not consider what technology *means* to us. The end is reuniting mother and baby at home, but how do we experience technology in the *meantime*? Heidegger (1927/2003) explains that technology is much more than a means to an end.

Technology is therefore no mere means. Technology is a way of revealing. If we give heed to this, then another whole realm for the essence of technology

will open itself up to us. It is the realm of revealing, i.e., of truth. (Heidegger, 1927/2003, p. 318)

Technology in the NICU reveals something about ourselves and about our relationship with the world around us. Are there NICU technologies that bring mother and baby closer in the meantime? Can we engage in a re-vision of existing technology from this perspective? If we view technology simply as a tool, a neutral tool, then we miss opportunities for reflection that can assist us in being more consciously active users, and designers of, technology.

In our consumption of technology, we have to question it and teach others to do so, as the mere unquestioned use robs us of its full potential. What might our vast consumption of technology in the NICU teach us about breast milk, a natural resource it extracts and delivers? Can the pumping and delivery of breast milk emerge as a way to reconnect in the absence of *traditional* motherhood?

We see that NICU technology reveals something more about its tiny residents, and their mothers. Through the technology the vulnerability of the babies to their mothers is blatantly revealed. While they have most recognizable parts, they are not yet ready for survival outside of their mothers and require intervention to do so. They are not-yet-complete beings that have been thrust into the world, and their lives depend on intricate machinery and the expertise of healthcare professionals. NICU technology, too, revealed the mothers' lack of response-ability. It made it apparent to them that their known ways of mothering would not suffice. The NICU demanded something different of, and within it they were revealed as unsure, fearful, and inadequate.

Both the culture of the NICU and its overwhelming technology exist for the

purpose of survival to discharge. Sustaining the lives of the babies who reside there is its intelligible priority. While the NICU's culture is highly influenced by the presence of technology, the aggressive use of it also reveals a focus on survival of the child's body, as opposed to a focus on the whole child in *mamatoto*. None of these technologies are utilized with the purpose of bringing mother and baby together. Even the hospital grade electric breast pump with double pump kit, has a purpose within the NICU worldview that exists outside of this idea. Its overwhelming promotion is in response to research indicating corporeal health and developmental gains due to breast milk's nutritional superiority to formula, and so is encouraged. Mining deeper, this NICU technology reveals mothers as *doing* the work of mothering. It is observable and tangible. It is proof of caring, nurturing, and led mothers to be re-member(ed).

### **Re-member(ed)**

Through the pumping and provision of breast milk mothers were able to reestablish a lost connection with their babies. They were not forgotten. Within the *un-doing* of their motherhood in dis-member-ment, providing breast milk became a way to care for their babies in a most motherly way. They again existed as *mamatoto*, reflecting the view of the nursing mother and infant dyad as a single, connected unit, rather than as two separate individuals. They were re-member(ed). Through this interrelation what affects one affects the other, and what is good for one is good for the other. Within the notion of *mamatoto* lays the concept that infants and mothers are meant to be together and supported as one being. Can we imagine the possibilities for the NICU, if culturally we espoused this view?

Even though mothers lived apart from their babies' world of the NICU, they were together again in the shared bodily rhythms that the commitment to breastfeeding created.

I think it [pumping breast milk] helped me to stay connected to her. Only because I felt like I had to do it. Even though she wasn't eating at the time, I was like this is the only way that she is going to eat. So, that's why I did do it so much—religiously. I mean I would carry my bag everywhere I went. I have pumped in bathrooms, anywhere I was if it was at that 3-hour mark... Well, the biggest fear that I had was my supply going down because she wasn't able to physically feed herself. So I just made sure that I always did. (Quelita)

Quelita's bodily connection to her daughter was once again apparent. The technology of the breast pump revealed this to her, about herself. She was a part of her daughter's life, ensuring her growth and development, and engaging in the *doing* of protection. Quelita clearly and deeply felt their attachment.

Oxytocin is a mammalian hormone that makes a grand appearance during and after childbirth through cervical stimulation, facilitating both birth and mother-baby attachment, (Lee, Macbeth, Pagani, & Young, 2009). The strong association between oxytocin and mother-infant attachment is further illuminated and makes another appearance when nipples are stimulated during breastfeeding, which is responsible for milk let-down (Galbally, Lewis, Ijzendoorn, & Permezel, 2011).

Oxytocin, from the magnocellular regions of the paraventricular nucleus and supraoptic nucleus, is transported by neurosecretion to the posterior pituitary (neurohypophysis) where it is released in pulses into the circulatory system. Cervical stimulation during parturition and nipple stimulation during nursing are proximate stimuli for the release of oxytocin. In addition, the magnocellular cells that release oxytocin are capable of remarkable morphological plasticity. Like other neurons, oxytocinergic cells are normally separated and thus insulated from each other by glia. However, during parturition and lactation, glial processes retract, allowing the formation of multiple synapses and permitting rapid communication among oxytocinergic cells. Increased connectivity among oxytocin-producing magnocellular

neurons facilitates the pulsatile release of this hormone. (Carter & Altemus, 1997, p. 165)

How might this relate to mothers of children born preterm and at VLBW, who often undergo cesarean sections and for whom breastfeeding poses unique challenges?

Experiencing a sense of isolation as a stranger within the NICU, with obstacles posed by their babies' technologies, mothers found it difficult to establish desired re-connections with their children. Quelita spoke about how providing her breast milk helped re-member herself, to be one again with her now physically distant daughter.

I don't know if she was a social worker...she was having counseling sessions with us. So, she was giving us different materials on like, how to bond and that in addition to the kangaroo hold was actually the other thing that really prompted me to breast feed. Because she was explaining to me how it gives you the extra sense of connection, and I started to get on her schedule. I was pumping and stuff on her schedule. So it worked out. (Quelita)

Pumping gave Quelita a sense of that shared connectedness, as she and her daughter were in tune and engaging in a most ancient dance of motherhood within the space that was their distance. Even though they were apart, they were working together.

Through her language, we can see that she takes ownership of her daughter's 3:00 AM feedings. Quelita refers to her daughter's 3:00 AM feedings as "my 3:00 AM feeds."

You know my 3:00 [AM] feeds everyday, ask any NICU nurses there. Every night at 3:00, I would call her because I was always up. So, I would just call and you know [ask], how is she? We were right there together. (Quelita)

Pumping breast milk for her son also provided a way for Wenda to re-member herself as with her child. Through her breast milk, she was once again caring for her son, and in a way, that no one else in the NICU had the ability to do. Her milk,

through the technology of the breast pump and feeding tube, served to re-member her and her baby. They were once again bodily connected.

And I think that it was the fact that I tried to become one with him, because I felt like he was still in my belly and the only thing I could do was to protect him. He's out there, but he's really inside of me still. So, I ate a particular way, so that he could be healthy. I thought in a particular way, so that he wouldn't feel my sickness. Everything I did, I did it for him just so he could grow. Because the happier I was, the sooner he would get better. So, I tried to become one with him and I think that's why I became more comfortable. (Wenda)

This shared schedule in breastfeeding seemed to give mothers a sense of maternal identity. Although physically apart from one another, the bodies of mother and child worked in harmony. Errin also shares her thoughts on pumping and the schedule she shared with her son. She knew that while she was up pumping breast milk for him, he was simultaneously receiving it.

I would get up in the middle of the night, pump, and then call and check on him every night at 4:00. I would get up and pump every 3-4 hours around the clock because I didn't have anything else to do and I was so, so worried about him. His stomach, especially since he got the NEC and like, the thought of giving him formula. (Errin)

The adjective *synchronous* is from the Late Latin word *synchronus* meaning "simultaneous," and stems from the Greek word-forming element *syn-* meaning "together with," and *khronos* meaning "time" (Harper, 2001/2012). Through the pumping and provision of their breast milk, mothers' bodies worked right along with those of their babies, and this became a way to engage in mothering. The bodily remembrance experienced through the simultaneous pumping and provision of breast milk seemed to bridge the distance between mothers and their babies. Pumping breast milk, in the stolen hours just before dawn, served to reunite mothers with their



babies from afar. Chad Powers Smith's (1928) poem, "Synchrony," chants this act of mothering.

Here we are pausing in the busy fuss  
Of love and death and change that make our days,  
Come to this single moment snatched from time  
Some billion years out of the common slime.  
(p. 19)

This "single moment snatched from time" by mothers to pump breast milk belongs to them. As mother pumps, her body becomes motherly in the present absence of her baby, and as babies are nourished by their mother's milk, they are indeed mothered, cared for, and protected. Existing as the ancestral mother in her *doing*, and although the pump may illuminate the concreteness of their separation, their bodily being is in communion. Casey expresses the "density of the remembering/remembered body and the way in which it provides an original past for remembering as a whole" as having a *thick autonomy* (Casey, 2000, p. 179). Mothers, as they re-member(ed) in this way, truly experienced this thick autonomy.

Shamari expressed that pumping breast milk "helped because it helps you to get into the rhythm of getting up, doing this (*gesturing with her hands*), doing this (*gesturing again*)." She and her child were re-member(ed) through the primal rhythms that the *doing* of mothering moves to.

The technology of the breast pump and feeding tube revealed things quite different from those of the other NICU technologies. These technologies revealed a way to connect with babies, as opposed to a barrier to doing so. They revealed member-ship. The word ending *-ship* can be traced to the Anglican *-scip*, meaning a state or condition of being, and traveling deeper to its even earlier beginnings

unearths the proto Germanic word *-scap* meaning to create or ordain (Harper, 2001/2012). In member-ship, *mamatoto* is again created. *Mamatoto* is ordained. From the word's ancient roots in the Latin *ordinare*, the bodily being of mother and baby is again "placed in order" (Harper, 2001/2012).

### **Member-ship**

As time went on, for many mothers, the landscape of the NICU began to change. The NICU slowly moved away from the seeming fruitlessness of a desert, toward that of an oasis, a place that was away from life's other demands and where they could just *be* with their babies. The roots of the word oasis lie in the deserts of North Africa, and sprout from the Coptic word *ouahe*, meaning dwelling place (Harper, 2001/2012). For these mothers, the NICU transformed from a built space into a dwelling place.

In some ways the NICU was kind of like a refuge to go...especially when I got to the point where I was able to start to kangarooing him, because I could just hold him and talk to him and listen to music on my iPod...It [the NICU] was just different and just because...I didn't have anything else to do but worry about him. So, then I was there [in the NICU] all the time. Yeah, they were probably happy to see me go (*laughing*). (Errin)

For Errin, re-member(ing) herself through providing breast milk for her son, transformed the NICU from a place built to suit the needs of her baby and into a dwelling place for them both. She had regained her member-ship into *mamatoto*, and although she was still a stranger in the NICU, she had something to offer. The breast milk she provided gave her a unique purpose here and helped her to feel that she deserved to be welcomed. Through this purpose, she became a part of this world as attached to, and as one with, her baby. Dwelling according to Heidegger (1927/2003) is to remain in place and be situated in a certain relationship with existence. We build

in order to dwell. He uses the metaphor of a bridge to express a relationship between building and dwelling.

Thus the bridge does not first come to a locale to stand in it; rather, a locale comes into existence only by virtue of the bridge. (Heidegger, 1927/2003, p. 356)

NICUs have been built for the dwelling of babies, yet mamatoto comes back into existence by virtue of NICU technology, the breast pump and feeding tube, which serve as a bridge, and it is the bridge that brings mamatoto back into existence.

Mothers began to welcome and look forward to their time there, so much so that they were sad to leave and returned to visit. Shamari and Wenda clearly express this sentiment.

I love that NICU and they love her. I still take her up there. ...After a while I got used to the NICU and I kind of didn't want to leave – laughing. I just wanted to take her home but I didn't want to leave. (Shamari)

They said being a 23-weeker, normally they are looking at keeping them until he makes that whole four months at the hospital or even longer and he was out in 101 days to be exact. It was a lot of days, but when it came to the end it was not a lot of days because at first it was like forever and all of the sudden when they said, be ready next week he is coming home. I'm like no, he's not ready. (Wenda)

Pumping breast milk seemed to give mothers a sense of bodily attunement with their babies and back to experiencing a shared rhythm. Although they had left them to be cared for by better equipped others, through this role of supplying breast milk, mothers were supported in maintaining a connection with their babies. They were not forgotten and their babies are re-membered as well, by way of a new bodily connection. This led to mothers once again, gaining membership into this group known as mothers, sharing the lives of their children and caring for them. Existing as mamatoto transformed the NICU into a dwelling place for them. The bridge created

by NICU technology brought this once hidden dwelling place into existence for mothers.

### **Finding a Space to Recommence**

In privileging us to view their dis-ease in the NICU, these mothers provided the opportunity to picture revisions of what can occur there. What might our revisions include? Each mother in this study was simultaneously managing the need to compensate for preterm birth, the desire to find a place within the new lives of their babies, and the urge to reconnect with them. Each unfolded as a transformation, shaped by the experience of providing breast milk for their babies. In becoming breastfeeding mothers, many found balance and this presented a way to manage their dis-ease.

The same body that mothers viewed as to blame for the preterm birth, displaced as no longer necessary, and dismembered by way of necessary abandonment is now re-presented through the action of providing breast milk. This breast milk made of the proteins and sugars from her very blood, and brought along by the existence of mother and baby, are not simply for the purpose of newborn nutrition. Pumping and providing breast milk made it possible for physically distant mothers to be a presence in the NICU with their babies, for babies to be a presence with their mother outside of the NICU, and for *mamatoto* to be re-presented, as mothers and babies found themselves once again connected.

Breastfeeding offered these mothers a way to transcend the dis-ease they experienced mothering in the NICU. In the next chapter, I explore ways to re-cognize how we may be more supportive of these mothers in the NICU in light of the

meaningful insights I have gained into this most human experience. The word commence is from the Latin *com* meaning “together” and *initiare* “to initiate” (Harper, 2001/2012). Let us find a way to begin again, together.

**CHAPTER 5**  
**POSSIBILITIES FOR THE ENVIRONED NICU: CONTINUING TO BUILD**

This is no place  
 For anyone  
 who wants  
 soft hills  
 and meadows  
 and everything  
 green  
 green  
 green...  
 (Baylor, 1975, p. 1)

Humans both ancient and present have adapted to their environments. The very word environment denotes “the state of being environed,” from the French verb *environer* meaning “to surround, enclose, or encircle” (Harper, 2001/2012). Our environments shape the way we live, even when we have built them. The NICU is one such environment, built to care for babies born very small and too early, where mothers unexpectedly and strangely find themselves. Is there room here to care for mothers as well, and provide relief from what ails them? In this chapter, I continue my trek through the environed NICU, lay out new understandings as a foundation for what we *do*, and consider how the things we do change our circumstance and the circumstances of our Others. How can the essence of mothers’ experiences in providing breast milk in the NICU inform how we live with, nurture and care for them and their babies in this space?

**Perceiving Remedy**

The roots of the word remedy are found in the Latin *remedium*, from *re* meaning again and *mederi* meaning “to heal” (Harper, 2001/2012). The mother guides have unveiled the meaning of their lived experience of providing breast milk

as a way to remedy the struggles they underwent in becoming a mother in the NICU. These mothers seemed to be born prematurely, as well, and not quite ready to *be* mothers of their newborns. They were required to become differently-abled in order to mother their babies. For these mothers, breastfeeding does not happen as a natural result of childbirth. They were not faced with a hungry baby, ready to suckle and triggering the release of prolactin to signal their breasts to begin lactation (Vergara & Bigsby, 2004). Instead, the provision of breast milk is a much more deliberate act, as the mother must engage with the technology of the electric breast pump in order to will her body toward milk production.

Through the stories of their breastfeeding experiences, we are able to see the symptoms of self-blame, dismemberment and displacement that comprise the general dis-ease that accompanies this becoming. If we can use what their stories show us to envision different ways of being, what elements might such visualization provide? The following three sections respectively contemplate the following questions and offer possibilities in response to them: Does the potential exist to assist mothers as they contend with the emotional burden that the early births of their babies generate? In what ways might the NICU become a more human place to become and grow as a mother? Can we imagine the creation of pathways for mothers who feel isolated and alienated within the NICU environment?

### **Turning the Stream of Compassion Within**

Probably the most salient experience by mothers in the NICU was a profound sense of self-blame. Can we as professionals in the NICU even begin to address this

issue? Is it our responsibility? In what ways could the NICU become a more human place to forgive and grow in motherhood?

Forgiveness is commonly understood as a response to having been wronged by another, and some agree that we can engage in self-forgiveness when we perceive ourselves as the wrongdoer. Self-forgiveness, in the case of mothers in the NICU, is quite unlike both the ‘traditional’ idea of forgiveness and the less conceptually clear view of *self-forgiveness* (where we forgive ourselves for self-inflicted wrongs). Once again, mothers seem to exist in a hazy in-between. They are simultaneously agent and subject, wrongdoer and victim—and not. Although mothers and babies clearly existed as one when the ‘wrongdoing’ was committed, they are separated after birth, and it is in the face of this Other (the baby) that mothers were called to seek forgiveness.

While the belief exists that only the victim of the wrongdoing is in a position to forgive, where does such thinking leave mothers in the NICU, who blame themselves for the preterm birth of their babies and their resulting early life apart from them? As their babies are not in positions to communicate conventional forgiveness, what part can *self-forgiveness* play?

Snow (1993) asserts that self-forgiveness can be viewed more broadly and stand in the place of traditionally accepted interpersonal forgiveness when interpersonal forgiveness cannot be achieved, in that it “plays this role because of its most interesting characteristic: it restores our capability to carry on as functioning agents even after we have committed moral wrongs or harmed others” (p. 75). Self-forgiveness, then, can serve to re-present, those who consider themselves wrongdoers,



as moral, decent, and good, when interpersonal forgiveness does not present itself. The stories of these mothers indicate that self-forgiveness is possible and that it is achieved as they continue to exist for their babies, even in their physical absence, by providing for them and ensuring their growth and development.

Let us now imagine a re-vision of the role NICU professionals may play in assisting mothers in the experience of self-forgiveness. Primarily, we must accept the strong potential for self-blame and the resultant need to remedy it. We can achieve this by pushing ourselves toward understanding. Allowing ourselves to engage in conversation with mothers, and supporting mothers in conversations with other mothers in the NICU, makes the possibility of noticing those experiencing self-blame, and discovering what their babies' forgiveness could look like to them. Is it weight gain? Is it calm response? Is it the experience of mutual touch or gaze? Identification of what their babies' acceptance may look like to them, and facilitating the achievement of this re-presentation, can support mothers along their way to self-forgiveness. The idea of supporting mothers as they contribute to their babies' growth and development through breastfeeding is one way to do this, but surely, there are others. These envisioned alternative ways of being include the ideas of greater caring for, and support of *mothers'* efforts in the NICU, yet this simple recognition and understanding do not automatically lead to these outcomes. The difficult task for NICU professionals here seems to exist in actively supporting mothers, as *they support* their babies' progress.

Perhaps these mothers' journeys toward self-forgiveness can be viewed through the lens of Derrida's (2001) idea of pure or true forgiveness, in that it is

unconditional and remains always open. He writes, “Forgiveness is not, *it should not be*, normal, normative, normalizing. It should remain exceptional and extraordinary, in the face of the impossible: as if it interrupted the normal course of historical temporality” (p. 32). The apology is never requested by her baby, although mother and child may more fully exist as self and other, and is never quite accepted either. Forgiveness in this case is not an overt communicative act, but perhaps the babies’ receptiveness and acceptance of their mothers is forgiveness, and this is something we should tend to as NICU professionals. Letting mothers know that what they are *doing* matters, by recognizing and encouraging their efforts, this becomes paramount.

These uncoverings move us to consider the possibilities that exist in the NICU in support of mothers without judgment, as they experience self-blame. Showing mothers that we are confident that they will not hurt their babies, and actively recognizing what mothers are able to do are vital actions to take. Mothers who are unable to provide breast milk can easily be supported in much the same way. The potential of mothers viewing this as yet another failure of body, urges us to not minimize what mothers *are* able to do. Congratulating mothers on their babies’ successes (growth, development, less reliance on technology) is also something to consider, as the baby’s continued existence and perseverance can become a form of forgiveness for mothers who find themselves less able to *do* for their babies initially. This is forgiveness that cannot be reduced to the often emptiness of the words, *I’m sorry*.

I would be tempted to contest this conditional logic of the exchange, this presupposition, so widespread, according to which forgiveness can only be considered on the condition that it be asked, in the course of a scene of repentance attesting at once to the consciousness of the fault, the

transformation of the guilty, and the at least implicit obligation to do everything to avoid the return of evil. (Derrida, 2001, p. 34)

Derrida expresses that forgiveness exists perpetually just outside of us, and does not require an apology or repentance. This perspective presents forgiveness as never finished, and I believe the mothers I learned from shared this view. They expressed that they could never quite do enough to make up for what their children had gone through, even months after their babies returned home. It was only in the *doing* that they were able to walk in self-forgiveness, and each expressed the need for support in doing so.

### **Crafting a Home Away from Home**

I liken the dis-ease of dis-place-ment experienced by mothers in the NICU to Levinas' (1969) metaphor of the home where nurses become the hosts, mothers the guests, and the babies, perhaps, the lodgers. Although there are other NICU professionals who can serve as hosts, the nurses were brought forward by mothers as being the primary daily presence in the NICU space. Levinas (1969) asserts, "To welcome the Other is to put in question my freedom" (p. 85). Here, in the presence of her lodgers and unfamiliar guests, the nurses' freedom seems questioned, and the experience of the mother, as stranger, is uncomfortable, disturbing even, as "the Stranger who disturbs the being at home with oneself [*le chez soi*]" (Levinas, 1969, p. 39). NICU professionals, especially nurses, assume the care of babies; after all that is their purpose here. Yet, mothers also call these nurses to hospitality. Can nurses learn to recognize this call, and accept responsibility, too, for mothers who arrive at the door of the NICU? How can nurses welcome and help mothers to feel comfortable enough to make themselves at home?

Again, I consider the words of Levinas:

To approach the Other in conversation is to welcome his expression, in which at each instant he overflows the idea a thought would carry away from it. It is therefore to receive from the Other beyond the capacity of the I, which means exactly: to have the idea of infinity. But this also means: to be taught. The relation with the Other, or Conversation, is a non-allergic relation, an ethical relation; but inasmuch as it is welcomed this conversation is a teaching. Teaching is not reducible to maieutics; it comes from the exterior and brings me more than I contain. In its non-violent transitivity the very epiphany of the face is produced. (Levinas, 1969, p. 51)

Welcoming provokes the understanding of others and oneself, and demands taking action. Response-ability seems to exist as a welcoming of difference. How can NICU professionals welcome mothers to learn about their babies? Should NICU professionals allow themselves to be called to respond, to give up their freedom to turn *only* toward the babies enlisted in their care?

One possibility that NICU professionals can do to support mothers' emplacement is to greet them in welcome. Some mothers told stories of nurses that did not acknowledge them when they would come into the room. Many mothers indicated through their stories that the nurses and other NICU professionals continuously referred to them as "mom" and to the baby as "your baby" or "the baby." These actions were displacing for mothers. Instead, let us consider asking mothers what they want to be called, as the use of "mom" and "your baby" are generic and distant. Smiling and speaking to others is more than a courtesy; it is a welcoming, and such a welcoming is emplacing.

The living-moving body is essential to the process of emplacement: *lived bodies belong to places* and help to constitute them... By the same token places belong to lived bodies and depend on them... Just as there are no places without the bodies that sustain and vivify them, so there are no lived bodies without the places they inhabit and traverse... Bodies and places are connatural terms. They inter-animate each other. (Casey, 1996, p. 24)

An essential trait of places presented by Casey (1996) is that “places gather” (p. 24), yet “as place as gather bodies in their midst in deeply enculturated way, so cultures conjoin bodies in concrete circumstances of emplacement” (p. 46). Viewing the NICU as a gathering place begs us to consider introducing a mother to the other guests (mothers). Providing a parent resource room could be considered, with access to a parent library of books, current videos, and a list of electronic sources (with information on drugs, procedures, alternatives and NICU language).

It seems, too, that the presence of mothers and babies should influence the NICU. While NICU professionals occupy this place for a time, as well, they do not do so in the same way as mothers and children. We, as professionals, make the choice to be there, yet we are only there because of mothers and babies.

Just as we are asking nurses to meet mothers in welcome, mothers, too, must reencounter their babies in welcome. What might a conversation, a rendezvous, between a mother and her newly born baby in the NICU look like? The mothers here expressed the sharing of their bodies, the gift of their breast milk, as one such conversation. Are there others to be had? Supporting mothers in *doing* leads to a change in role from nurse as teacher to nurse as *facilitator*.

### **Redrafting the Roles**

The principles of attachment theory (Ainsworth, 1973; Bowlby, 1969) depict attachments developing within the setting of early infant-mother interactions, with maternal sensitivity to infant signals posited centrally (Ainsworth, Bell, & Stayton, 1971, 1974; Ainsworth, Blehar, Waters, & Wall, 1978).

An emphasis on the unique, intimate, and embodied connection between mother and child is combined with efforts to convince women of the benefits of breast milk for their babies and technical advice that will help them to better manage their bodies in this regard. A common thread running through both models...though, is the invisibility of the mother as a subject with legitimate needs and wants. Even when the emphasis is on the special and embodied relationship that breastfeeding allows, this is connected to children's needs through the expert concerns of attachment, bonding, and brain development. (Wall, 2001, p. 604)

It seems that in our efforts to encourage mother-infant attachment and its relationship to social-emotional development, we focus closely on the experience of the child.

Can we expand our view to encompass mothers' experiences within this relationship?

Interestingly, as well, through a systematic review of scientific literature related to traditional breastfeeding and the mother-infant relationship (characterized by the maternal bond toward the infant and infant attachment toward the mother), Jarno, de Weerth and Riksen-Walraven (2008) conclude that a positive role of breastfeeding on the mother-infant relationship is not supported by empirical evidence. Was there a positive role in the breastfeeding experience revealed in the stories of these mothers? Were mothers' needs and wants at all visible here?

Through their experience of *breastfeeding apart*, the mothers here show us that they were able to begin developing the core relationship defined as mother-infant attachment after birth, as they engaged in the act of providing breast milk, yet before their babies were developmentally able to participate in the dance of parent-infant synchrony. After preterm birth, and before their babies were able to reciprocate, their mothers continued crafting a connection in a new way as they pumped and provided breast milk for their children. These women bring a unique perspective to the idea of breastfeeding in the traditional sense of bringing baby to breast. Attachment, for

them, seemed not achieved through the traditional reciprocity inherent in physically being with their babies, but as a manifestation of their separation. Providing their breast milk assisted mothers in reconnecting with their babies from a distance. Is supporting mothers in regaining a connection with their babies, and perhaps connecting with one another, a possibility in the NICU environment? How might we facilitate their re-member(ing) in *mamatoto*?

As my study did not look into the identities of NICU professionals, how is it that I can suggest a redrafting of roles? What stood out positively in my conversations with mothers were those NICU professionals who were exceptions to the norm, as opposed to the more commonly encountered objective professionals who were “focused on the baby’s schedule” (Talia) and “focused on sticking to the script” (Errin). Exceptional nurses and the occasional doctor or therapist were those who connected with mothers on a most human level and from an orientation of care. Those who acknowledged and gave credibility to the intuition of mothers and acted on their suggestions were most praised, and these responses were associating for mothers. They began to feel connected to their babies as they became a part of their lives in the NICU.

Rogers (1979) writes of his person-centered approach to interpersonal relationships as it applies to the learning process, and the climate that promotes this process. He provides three conditions that, when present, lead to, among other things, the *facilitation of learning*. These three conditions are genuineness, acceptance and empathetic understanding. This person-centered approach is built on “a basic trust in the organism” (p. 2); in other words, we all have a tendency toward *self-actualization*

or becoming. In line with Rogers' work, I see a parallel from his *freedom to learn* to Heidegger's (1954/1968) *letting-learn*. Regardless of whether these optimal conditions are met, even under adverse circumstances, he views life as attempting to become itself (Rogers, 1979). Perhaps under the most favorable of conditions, we tend towards becoming our very best *selves*.

Perhaps showing mothers how things can be done and then take a back seat, while mothers *do* the doing of caring for their babies is an option. Sharing and posting schedules is something else to consider as mothers expressed over and over their adverse feelings related to *asking* to care for or even interact with their babies. How can the roles of NICU professionals be redrafted to support mothers and babies in *mamatoto*? Instead of the NICU professional (most likely the nurse due to her intimate relationship with baby) existing as teacher, maybe her role should be a facilitator. The word facilitator is a Latin agent noun, placing one in the role of performing the action of a verb, which in this case is to facilitate. The word facilitate dates back to the 1610s, and from the French *faciliter* meaning "to render easy" (Harper, 2001/2012). Nurses in this light would be asked to assist in making easier the task of reconnecting with their babies. Here, nurses are asked to take notice and to create a favorable environment for mothering to occur.

### **Unveiling Mother's Milk as more than Pure Resource**

How can the essence of what mothers experience when providing breast milk in the NICU inform how we live with, nurture and care for mothers and their babies in this place? As hermeneutic phenomenology naturally moves into pedagogy and action, it is the hope that our unveilings assist us in bringing about living conditions



in the NICU with mothers and their babies that are inherently human. Of the pedagogical insights to explore in the support of mothering in the NICU is the recognition of mother's milk as more than pure resource.

### **Be-side(s) Scientific Truths**

In considering Heidegger's *Question Concerning Technology* (1954/1993), a mother is revealed here as more than a standing reserve of breast milk. The technological machinery of the hospital-grade electric breast pump with double pump kit shows the milk it accesses as more than a calculable caloric source of nutrition, but rather an extraordinary elixir for both mother and child. Breast milk unveiled is a remedy, healing wounds beyond the physical. When the very personalized technology of the hospital grade electric breast pump exists in combination with the technology of the donor milk bank, its orientation is changed. The orientation of this technology as it related to the mothers in this study revealed these mothers as motherly, revealed mother and baby again as *mamatoto*. When technology's orientation becomes instrumental, there is a problem. Technology's instrumental orientation to the world transforms the world into a standing reserve.

Modern technology, Heidegger has written, also reveals. But its revealing is different from that of the older crafts. When Heidegger states that *the essence of technology is by no means anything technological*, he means that technology's driving force is not located in machines themselves, and also not in the human activities that are linked with modern styles of production. There is also a questioning concerning our use of the technology of the electric breast pump with which we must engage. This questioning on one hand reveals a mother as motherly (as *mamatoto*); but on the

other hand as in the cases of Yesenia, Talia and Sophie, it can expose mothers to vulnerability. It opens them to judgment by others, as well as themselves.

Because the essence of technology is nothing technological, essential reflection upon technology and decisive confrontation with it must happen in a realm that is, on the one hand, akin to the essence of technology and, on the other, fundamentally different from it. (Heidegger, 1954/1993, p. 327)

These mothers disclosed the milk they provided to their babies as more than the important scientific truth it demonstrates through the measured health, growth, and development of their babies. The view of breast milk, as a mere caloric source of nutrition, reduces us to mere calculators and puts us at risk of exploiting breast milk as a resource to be increasingly demanded and accessed.

### **A Question Concerning Donor Milk**

The potent benefits of human milk are such that all preterm infants should receive human milk. Mother's own milk, fresh or frozen, should be the primary diet, and it should be fortified appropriately for the infant born weighing less than 1.5 kg. If mother's own milk is unavailable despite significant lactation support, pasteurized donor milk should be used. Quality control of pasteurized donor milk is important and should be monitored. New data suggest that mother's own milk can be stored at refrigerator temperature (4°C) in the NICU for as long as 96 hours. Data on thawing, warming, and prolonged storage need updating. Practices should involve protocols that prevent misadministration of milk. (American Academy of Pediatrics, 2012)

The essence of donor milk lies not in its donation. It is not in the giving, nor the receiving that its essence lies, but in what it can take away. As researchers and NICU professionals push forward in their exploration of the possibilities of donor milk, its role should be strongly considered.

The noun, donation, appears in the early 13<sup>th</sup> century and is rooted in the Latin *donationem* meaning a presenting or giving (Harper, 2001/2012). The noun form springs from the action of the past participle stem of *donare*, meaning to give as a

gift, and from Sanskrit, to Old Church Slavonic, to Lithuanian, Old Irish and Welsh, we see all forms of this word as stemming from the word *do* (Harper, 2001/2012).

The base element is the essential *do*. While a gift may be given to the baby, what might be taken away from the mothers? If someone else is doing all of the *doing* for their babies, where, once again, are mothers left? What consideration in such a case should we make to ensure that mothers are able to forgive themselves and are emplaced, and are re-member(ed)?

The question of donor milk brings to the surface many other related questions. To whom should donor milk be offered? Should it be to the sickest of babies? Should it be provided to the babies of mothers who are attempting to produce breast milk, but cannot due to contraindications? Would our answer to this differ if the contraindication was due to a drug addiction as opposed to a virus? Do we offer breast milk to everyone, rationing supplies as babies are born, or do we prescribe it to our most vulnerable, those *we* consider to be most in need? Perhaps we would offer it to those we consider to benefit the most from its provision. Does insurance pick up the tab? Should it be free? Offered for a fee? How do we decide who is worthy to receive this liquid gold? Could donor milk be experienced by mothers as more of an *un-doing*?

Dis-covering breast milk is more than a “medicine” that heals or the simple scientific knowledge that it reveals through growth and development statistics; it emerges as more than a dose-response relationship. It was a way for these mothers to *mother* in the absence of all other things motherly. What sway might the offering of another mother’s breast milk have on a mother already struggling to find her way into

mothering? Regarding breast milk as a mere resource in terms of what it can do for babies, potentially places NICU professionals in positions to strive toward mastering not only the numbers of mothers providing breast milk, but the length of time mothers provide breast milk to their babies, and the amounts of breast milk individual babies receive. The probability for the exploitation of breast milk here is apparent, and mothers are left feeling the pressure to perform. In considering what breast milk may offer to the baby, we should place a high value on what providing breast milk offers to the mother who does so for her own baby, and for those whose babies would potentially receive another mother's milk.

Taking the position of recognizing the possibilities that breast milk can offer to mothers, and changing attitudes, might allow for living a more fully developed pedagogic relationship with mothers and their babies in the NICU. Highly technological environments demand constant calculations, and increase the chances of failure to exist in ways that are inherently human. Their breast milk revealed these women as mothers, and allowed their potential to be actualized through the work of their *doing*. There is more than one way of relating to the world.

### **Living in the Tension of Hospitality**

The mother guides helped to uncover the tension of hospitality that existed in the NICU not only for themselves, but also for those closest to their babies in the NICU, the nurses. In speaking with these mothers in the comfort of their homes with their babies, I became a guest and a tension existed for me, as well. Perhaps I was more of a wanderer, putting down shallow, more temporary roots, but roots nonetheless. In their revealing to me, mothers became vulnerable, and I as wanderer,

walked the footpath between asking not enough and too much. Settling in to the silence of being with, was most difficult. The word wanderer stems from the West German root *wend-*, meaning “to turn” (Harper, 2001/2012). Turning towards mothers in my wandering allowed for tightly sealed doors to be dis-closed to me, even in my own uneasiness.

In asking nurses to reach out to mothers in welcome and listen to them, we essentially refuse to allow mothers to take this difficult journey alone. As mothers opened their doors in welcome, they surprised even themselves, as they realized they hadn't “told this whole story to anyone, not even my husband knows all this” (Wenda), and that “now that I look back, I know that I did everything I could” (Yesenia). Diana Anhalt (2012) draws me here to her poem, *Taking Root*.

#### Taking Root

In third grade, I punctured a sweet potato's  
middle with toothpicks, suspended it halfway  
in a cup of water until sprout-like whiskers

swam along its bottom. On day nine leaves  
crowned it. I scooped out soil with my hands  
and buried it up to its neck. I am no stranger

to roots. I've laid down my own in places  
where corn and tomatoes grow in vacant lots,  
where cilantro and basil thrive on window sills  
and in cities balanced on ancestor's bones.

Roots are hardy travelers, adaptable:  
they float on water, cohere to wood,  
burrow deep beneath foundations,  
buckle floorboards.

(p. 25)

How, then, can we support nurses in an expectation that they scoop *out soil* with their hands and immerse mothers in the richness and support the humus and disintegrated

rock offers? Rogers (1979) offers his ideas of the actualizing tendencies of human beings and he, too, uses the metaphor of the potato:

...in my boyhood the potato bin in which we stored our winter supply of potatoes was in the basement, several feet below a small basement window. The conditions were unfavourable, but the potatoes would begin to sprout – pale white sprouts, so unlike the healthy green shoots they send up when planted in the soil in the spring. But these sad, spindly sprouts would grow two or three feet in length as they reached toward the light of the window. They were, in their bizarre, futile growth, a sort of desperate expression of the directional tendency I have been describing. They would never...reach their full potentiality. But under the most adverse circumstances, they were striving to become. (Rogers, 1979, p. 99)

It seems difficult to live in the tension of hospitality that exists in the NICU for us all.

The nurses as hosts, myself as wanderer, and mothers as guests attempting to tend to their babies.

### **Nurturing the Nurses**

#### The Guest House

This being human is a guest house.  
Every morning a new arrival.

A joy, a depression, a meanness,  
some momentary awareness comes  
as an unexpected visitor.

Welcome and entertain them all!  
Even if they're a crowd of sorrows,  
who violently sweep your house empty  
of its furniture, still,  
treat each guest honorably.  
He may be clearing you out for some new delight.

The dark thought, the shame, the malice,  
meet them at the door laughing, and invite them in.

Be grateful for whoever comes,  
because each has been sent as a guide from beyond.  
(Rumi, 2006, p. 228)

Jalal ad-Din Muhammad Rumi, a 13<sup>th</sup> century Persian poet, wrote “The Guest House.” This poem reverberates, deeply, the innate vulnerability of hospitality. The unveiling of the insights gained through this study and the recognition of these understandings, gives nurses a more awesome responsibility. In this light, caring for the nurses is illuminated as the opening of oneself to others continuously, and is very hard work.

Levinas (1969) presents us with the idea that the home is an intimate place, a place where one is able to come outside of oneself and exist in comfort, lending to the idea that the real home is a “rootless” wandering mode of being. As we continue to move along in thought, the real home exists in us, and at times we decide to put down roots. Sometimes we attempt to do so at times when we are struggling with who we are and in difficult, unfavorable, places. What possibilities exist in supporting mothers settle into the NICU, and feel the comfort in being themselves?

The face I welcome makes me pass from phenomenon to being in another sense: in discourse I expose myself to the questioning of the Other, and this urgency of the response - acuteness of the present - engenders me for the responsibility; as responsible I am brought to my final reality. (Levinas, 1969, p. 178)

The sharp edges of NICU machinery become less threatening when draped in the culture of hospitality. It seems assisting mothers in putting down roots in the NICU can be best achieved in the face of hospitality. As the Zulu greeting, *Sawubona* (I see you), and its grateful response *Ngikhona* (I am here) communicates, we come into being through the welcoming of the other. Nurses must see mothers, so that mothers can be seen as present, and respond as being there.

The mothers who shared their stories with me spoke quite sincerely of the nurses who cared for their babies in the NICU, in terms of what they saw as their strengths, as well as limitations. As ways are considered to support nurses in being comfortable with mothers laying down roots among the wires of the NICU, new pedagogical practices might be envisioned to welcome the understanding they surface, even as they “buckle floorboards” of the NICU.

### **A Beautifully Blurred Vista**

I realize that my choice of phenomenology has buckled more than one floorboard as well, but I would like to think that it has taken root, as these stories have taken root in me.

There is a way between voice and presence  
where information flows.

In disciplined silence it opens.  
With wandering talk it closes.  
(Rumi, 2004, p. 32)

Through this experience, I find myself more fully able to embrace this “way between voice and presence.” I appreciate the importance of silence more and am learning to stop talking, to stop trying to *make* people feel better with my words, stop trying to *make* people understand what I feel they should know, and instead be there to dis-cover together what our being together shows us. What does all of this mean for me in my work with children “at-risk”? How does it call for me to move along in thought, to act? Through this study, I am called to re-cognize that as we *do* for children, they exist in-the-world. This seemingly simple and quite obvious statement swirls in complication. Whatever their world may be, the only true way to support them seems to work within that world alongside them. As we bring children into



hospitals, clinics, and schools and provide them with our *treatments*, even when necessary, are we supporting them within their worlds? Do we consider their lives beyond even an envired NICU? My hope is that I can urge professionals to envision a NICU that cares for mothers as it cares for babies, with intent, diligence, and compassion; and that these ideas may take root.

In coming to this end, my view of the children I serve has undergone some refocusing, and gone from my clear and measurable assistance in them becoming something better than they are, to the less distinct idea of them being already enough. This more hazy perception illuminates my role as educator, the roles of nurses and doctors, our roles as fellow human beings, in supporting children in becoming who they already are. Living this in its strangely complicated simplicity we can allow ourselves to journey with children in their resilience and support them in becoming their very best selves, as opposed to consuming ourselves with the limitations of risk.

As I continue, in bittersweet wander, through the lives of children, my purpose there is more blurred than ever. It is this haziness that keeps me focused, continually questioning whether my nomadic ways leave those left with something worthy of their welcoming. The river's crisp, bubbling flow that is always there, yet always already on its way, speaks the essence of my work in the lives of children. I have always already found my place at home, and this is brought forth in my journeying.

Locality and journeying, however, in which the poetic essence of the rivers is announced, relate to becoming homely in what is one's own. And this is so in the distinctive sense that one's own, finding one's own, and appropriating what one has found as one's own, is not that which is most self-evident or easiest but remains what is most difficult. As what is most difficult, it is taken into poetic care...This *coming to be* at home in one's own in itself entails that

human beings are initially, and for a long time, and initially forever, not at home. And this in turn entails that human beings fail to recognize, that they deny, and perhaps even have to deny and flee what belongs to the home. Coming to be at home is thus a passage through the foreign.  
(Heidegger, 1942/1996, p. 49)

### **Sharing Skylines: Transformations of Mother Guides**

Out beyond ideas of wrongdoing and rightdoing,  
there is a field. I'll meet you there.

When the soul lies down in that grass,  
the world is too full to talk about.  
Ideas, language, even the phrase each other  
doesn't make any sense.  
(Rumi, 2006, p. 313)

Mothers expressed their own transformations that occurred through their participation in the study. They expressed their gratitude for having someone who cared enough to listen to their stories. Through this clearing where things show themselves, where they are unconcealed, invites us not only to look at our limits, but opens up to show what can be done.

In order to see the world and grasp it...we must break with our familiar acceptance of it. (Merleau-Ponty, 1945/2004, p. 70)

Through their sharing, mothers seemed able to imagine how their providing breast milk for their babies planted the seeds of forgiveness, belonging, and connectivity. They realized that the telling of their *doing* made it known to others and somehow more real. They seemed to leave our conversations with a renewed view of themselves, a view that presented them having done their very best.

## Appendix A

### Eligibility Checklist

The Poetics of Bodily Being: The Lived Experience of Breastfeeding an Infant “Out of Reach” in the NICU

#### Inclusion Criteria

Yes	No	Criteria
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Mother of infant born at VLBW (<1500 g) infant

VLBW infant received expressed breast milk (exclusively or mixed with formula) during his/her stay in the NICU when on full enteral feedings.

VLBW infant has been discharged from the NICU and is currently residing with his/her mother.

No more than 6 months have passed since the infant’s birth.

Mother is a fluent English speaker.

#### Exclusion Criteria

Yes	No	Criteria
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Non-English speakers.

For use during screening of mothers:

Participant Name: \_\_\_\_\_ Date of Screening: \_\_\_\_\_

Participant Contact Information: \_\_\_\_\_

Reviewed and mother meets requirements for participation in study:  YES  NO

## Appendix B

### RESEARCH CONSENT FORM

**Protocol Title:** Breastfeeding in the NICU

**Study No.:** HP-00048277

**Principal Investigator:** Brenda Hussey-Gardner, PhD, 410-328-8782

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### ABOUT THIS CONSENT FORM

Please read this form carefully. It tells you information about a research study. A member of our research team will also talk to you about participating in this study. People who agree to take part in research studies are called “participants.” This term will be used throughout this consent form. If you have any questions about the research or about this form, please ask us. Taking part in this research study is up to you. If you decide to take part in this research study, you must sign this form to show that you want to take part. We will give you a signed copy of this form to keep.

### PURPOSE OF STUDY

We are asking you to take part in this research study because you are a mother who provided breast milk to your baby born preterm and at very low birth weight (< 1500 grams at birth) in the neonatal intensive care unit (NICU). We plan to enroll twenty mothers and their babies in this study.

The American Academy of Pediatrics Section on Breastfeeding emphasizes the benefits of human milk feeding for preterm infants. The purpose of this study is to understand the experience of providing breast milk to babies born preterm and at very low birth weight while they are staying in the NICU.

### PROCEDURES

The study will consist of (2-3) 60 to 90-minute conversations with you and your entries into a reflective journal. You will be provided with this reflective journal. It is simply a notebook where you can share any thoughts that may come to mind after your first conversation with the researcher and can include words, drawings, photographs or anything else you want to include that can be attached to the paper.

**Conversation 1.** After informed consent, you will be contacted by research staff to schedule a date and time for the first conversation. After a date and time has been agreed upon, you will receive a reminder phone call the day before the interview. The interviews will be conducted in your home or another place of your choosing. The

interview will be voice recorded for accuracy. The recording will then be transcribed and identified by a number. Once transcribed, the recording will be destroyed. At the end of Conversation 1 you will be left with a journal where you can write down any thoughts, ideas, or questions related to your breastfeeding experience.

**Conversation 2.** After the first conversation is transcribed, a researcher will identify ideas related to breastfeeding in the NICU. After these ideas are identified, the researcher will call you to schedule conversation 2 to clarify any questions and discuss them to be sure that your comments were properly interpreted. Conversation 2 will be recorded, transcribed in the same it was for Conversation 1.

**Possible Conversation 3.** This final conversation will be scheduled with you in order to clarify or further explore ideas that came up during previous conversations or in your reflective journal if necessary.

### **POTENTIAL RISKS/DISCOMFORTS**

There is the potential risk of loss of confidentiality. To help prevent this, we will transport all study information in a locked briefcase and store it in a locked file cabinet in a locked office. We will erase all recorded interviews once transcribed. Furthermore, we will password protect all electronic data.

There is also the potential emotional risk to you as you discuss your experience providing breast milk for your baby while in the NICU. We will provide you with support as needed, by way of discussion and a handout with the names and telephone numbers of individuals and agencies equipped to come to your assistance.

### **POTENTIAL BENEFITS**

You will have the chance to talk about your experience providing breast milk in the NICU during our conversations and you may further reflect on your experiences through our conversations and your journal entries. You may receive a great satisfaction knowing that your experience is being discovered in order to bring a deeper understanding of this experience to yourself, other mothers, NICU professionals and other interested individuals.

### **ALTERNATIVES TO PARTICIPATION**

This is not a treatment study. Your alternative is not to take part. If you choose not to take part, your family's care at University of Maryland, Baltimore will not be affected.

**COSTS TO PARTICIPANTS**

It will not cost you anything to take part in this study.

**PAYMENT TO PARTICIPANTS**

You will not be paid to participate in this study.

**CONFIDENTIALITY**

Only researchers involved in this study will have access to personally identifiable information. To protect your healthcare information, we will transport all study data in a locked briefcase and store it in a locked file cabinet within a locked office. We will erase all digitally voice-recorded conversations once transcribed. Furthermore, we will password protect all electronic data.

The data from the study may be published or used to teach others. However, you will not be identified by name. Everyone using study information will work to keep your personal information confidential. Your personal information will not be given out unless required by law.

**RIGHT TO WITHDRAW**

Your participation in this study is voluntary. You do not have to take part in this research. You are free to withdraw your consent at anytime. Refusal to take part or to stop taking part in the study will involve no penalty or loss of benefits to which you are otherwise entitled. If you decide to stop taking part, if you have questions, concerns, or complaints, or if you need to report a medical injury related to the research, please contact the investigator Dr. Brenda Hussey-Gardner at 410-328-8782.

There are no adverse consequences (physical, social, economic, legal, or psychological) of a participant's decision to withdraw from the research. If you take part in this research study and want to drop out, then you should call Dr. Brenda Hussey-Gardner at 410-328- 8782.

**UNIVERSITY STATEMENT CONCERNING RESEARCH RISKS**

The University is committed to providing participants in its research all rights due them under State and federal law. You give up none of your legal rights by signing this consent form or by participating in the research project. Please call the

Institutional Review Board (IRB) if you have questions about your rights as a research participant.

The research described in this consent form has been classified as minimal risk by the IRB of the University of Maryland, Baltimore (UMB). The IRB is a group of scientists, physicians, experts, and other persons. The IRB's membership includes persons who are not affiliated with UMB and persons who do not conduct research projects. The IRB's decision that the research is minimal risk does not mean that the research is risk-free. You are assuming risks of injury as a result of research participation, as discussed in the consent form.

If you are harmed as a result of the negligence of a researcher, you can make a claim for compensation. If you have questions, concerns, complaints, or believe you have been harmed through participation in this research study as a result of researcher negligence, you can contact members of the IRB or the staff of the Human Research Protections Office (HRPO) to ask questions, discuss problems or concerns, obtain information, or offer input about your rights as a research participant. The contact information for the IRB and the HRPO is:

University of Maryland School of Medicine  
Human Research Protections Office  
BioPark I  
800 W. Baltimore Street, Suite 100  
Baltimore, MD 21201

410-706-5037

Signing this consent form indicates that you have read this consent form (or have had it read to you), that your questions have been answered to your satisfaction, and that you voluntarily agree to participate in this research study. You will receive a copy of this signed consent form.

If you agree to participate in this study, please sign your name below.

\_\_\_\_\_  
Participant's Signature

Date: \_\_\_\_\_

\_\_\_\_\_  
Investigator or Designee Obtaining Consent  
Signature

Date: \_\_\_\_\_



### Appendix C

- Would you tell me about your pregnancy and \_\_\_\_\_'s birth?
- How did you first come to the idea of providing breast milk for \_\_\_\_\_?
- What was this experience like for you, of providing breast milk to your baby in this distant early relationship?
- What is the process you went through in providing your breast milk for \_\_\_\_\_ in the NICU?
- Would you tell me about your experience in the NICU? Are there any moments that stand out?
- Will you tell me about time spent with \_\_\_\_\_ in the NICU? What was that like?
- Do you remember the first time you provided breast milk to \_\_\_\_\_?
- Would you tell me more about your feeding experience with \_\_\_\_\_? How has the experience affected you?
- What was the most challenging part of feeding your baby in the NICU?

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