

# **Mapping Identity and Connection**

***How First-Time Mothers Make Sense of Premature Birth***

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A thesis submitted in partial fulfilment of the requirements  
for the degree of Doctor of Philosophy  
in Social Work by

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**2017**

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## Acknowledgements

I appreciatively acknowledge the University of Canterbury where I have studied for the past five years. The university generously provided me with a doctoral scholarship that enabled me to take up this research.

I am overwhelmingly grateful to my supervisors, Professor Kate van Heugten and Dr Patricia Champion. It is not an exaggeration to say they are the finest, most intelligent, and most caring supervisors anyone could ever hope to have. I could never have done this without them.

I extend my deepest thanks and love to my family, Joel, Abby, and Eli. Not only did they put up with the demands of my studies, they supported me wholeheartedly every step of the way.

Lastly, I am indebted to the mothers and babies who invited me into their lives in the hope of creating a more understanding world. I hope I have adequately honoured their stories. I dedicate this project to them.

## Abstract

First time motherhood in the context of premature birth is a specific experience of motherhood that has been relatively unexplored in the literature. This research examined the phenomena of meaning-making, identity formation, and relationship creation by first time mothers following “low risk” premature births.

Low risk premature births are moderate and late preterm births associated with a lack of serious, persistent medical concern alongside well understood and effective medical responses. The vast majority of premature births in New Zealand occur in this category and, as with elsewhere in the world, such births are on the rise. While understudied, this subset of premature infants carry significantly more risk factors than their full term peers.

Women who become mothers for the first time via the experience of premature birth must negotiate associated stresses, separations, and medical uncertainties in order to come to understand their lived experiences and evolve their identities as mothers. As with their low risk infants, exploration of the processes and perceptions of this group of mothers is under-investigated.

The research employed the qualitative methodology of interpretative phenomenological analysis (IPA) to analyse semi-structured interviews with 15 participant mothers. Findings were generated in response to research questions that focussed on how participants made meaning of the event of premature birth, the relationship with their infants, and their nascent identities as mothers. Three unifying superordinate themes emerged and centred upon the mothers’ unique perspectives of their maternal experience (“Little things are big things”), the maternal distress associated with premature birth (“Maternal experience”), the particular

obstacles mothers faced, and the avenues they pursued in an attempt to create a sense of themselves as mothers (“How do I become a mother?”).

Findings demonstrated that the identification of mothers and babies as low risk, created a paradoxical situation in which the perception that the babies were healthy and the mothers where healthy and competent actually increased the overall risk for the dyad. Furthermore, the findings suggested that mothers made meaning from within an ecological framework that was dyadic in nature. When mothers were considered outside of this dyadic maternal context—or when their infants were—surplus suffering occurred.

Findings have important implications for approaches to psychosocial interventions in neonatal intensive care units (NICUs), including psychological support and social work practice. When professionals are better able to see mothers' needs where they have been previously concealed, mothers and their infants can be better served. Similarly, when professionals can understand, embrace, and respond to mothers from an awareness of dyadic ecology—what this thesis terms the “dyad-in-context”—approaches to support, advocacy, and treatment can move beyond compartmentalised medicalised approaches to more relational, responsive, authentic ways of being with mothers and their infants.

# Chapter I: Introduction

## I.1 Introduction

The timeline of my professional life can be divided in two phases: before-earthquakes and after-earthquakes. The 2010 and 2011 Canterbury earthquakes represent a turning point for me, one that came with a bit of a plot twist. Prior to the quakes I was maintaining a private practice and expanding the work of the training centre that I co-founded to teach and apply the principles of attachment theory. After the quakes, things changed. Like so many Cantabrians, my home, family, and work life was altered. Once my children were settled into a new school and we found a safe place to live, I began to re-evaluate my professional goals. I was surprised to discover that I did not want to reignite the past. Instead of growth and influence, I found myself wanting to focus on smaller, more meaningful endeavours that were closer to home. After conversation and reflection, I awoke one morning and wondered about the notion of a PhD. The more room I afforded the idea, the more it gained traction. I enrolled at the university in February of 2012, almost exactly a year after the major 2011 quake. This chapter outlines the PhD project I decided to undertake.

## I.2 Conception and plan

In *Alice in Wonderland* (Carroll & Tenniel, 1998), there is a scene in which Alice speaks with the Mock Turtle. When the turtle asks about her adventures, Alice replies, “I could tell you my adventures—beginning from this morning, but it's no use going back to yesterday, because I was a different person then” (p. 123).

Alice’s fictional sentiments quite closely reflect my real-life dissertation experience. The research—which explores the meaning making experiences of first-time mothers and their

premature infants—was an exploration of adventure and change, both for my participants and myself. Before I began my research I would have characterised myself as a clinician primarily interested in quantitative data. By the end, I was not only committed to a qualitative methodology, but I could no longer discuss ideas without inclusion of a qualitative perspective and could no longer contemplate my identity as a clinician without adding a researcher’s mindset.

When I first began to conceptualise my research project, I had little comfort with qualitative findings and minimal knowledge about premature birth. I was interested in helping people and in using research to do so, but my coalface experience told me that it was hard to build a bridge between the two. In practice, people appeared to vary from generalisable results and advocacy based on statistical data which often meant championing group rights while obscuring the unique voices of individuals who comprised the group.

Social work theorists have struggled with this same dilemma. As Abramovitz (1998) noted:

The profession of social work has the potential both to meet individual needs and to engage in social change. However, the profession's position between the individual and society often forces practitioners to choose between adjusting people and programs to circumstances or challenging the status quo (p. 512).

Perhaps due to my clinical social work training, my first inclination was to seek to “do something” to help solve the assumed problems facing the mothers I wanted to focus on and I initially leaned toward designing an intervention that could be quantitatively assessed. I realised that this was replicating the dichotomy between action and individual

attention that Abramovitz was referencing. When I moved from the desire to create a response to the problem to an acknowledgement that I needed to first to understand things from the maternal point of view, it was as if formerly invisible options suddenly came into view. I wanted to learn more about the maternal experience surrounding premature birth within the context of a methodological and analytical framework that could discern and illuminate the experience in a way that could augment the field. Given that social work focuses on individual client lives without losing sight of context and environment (Smart & Smart, 2006), I wanted to construct research that gave a voice to individual mothers while holding in mind the world in which they lived.

I had not actually thought much about prematurity prior to my enrolment in the PhD programme. I have two children of my own, but both were full term babies. In fact, my first baby was 2 weeks overdue. My clinical work with parents had occasionally seen me face-to-face with prematurely born children and their mothers, but this was not usual. The first time I went inside a neonatal intensive care unit (NICU) was just as I was embarking on this research. However, I have had a longstanding interest in the psychological journey of mothers and a commitment to recognition of struggles mothers experience that typically fly below the clinical radar. Both personally and professionally, I have noticed an absence of dialogue around the day-to-day experience of mothers. Much of what mothers (and those in a mothering role) are doing, thinking about, and struggling with gets little discussion. If concerns do not reach an acknowledged level of pathology, the literature seems mostly aimed at the provision of advice, not the broadening of dialogue or understanding.

Before applying for enrolment at the university, I had lengthy discussion over several months with Dr Patricia Champion (who became one of my thesis supervisors). As an

expert in the field of premature birth and an innovator in the provision of scientifically-informed parent-child clinical intervention, Patricia alerted me to the ways in which this low risk cohort of premature infants was now so commonplace and medically stable as to be omitted from many streams of available support. Patricia expressed great concern about the way such mothers and infants were being overlooked and suggested it was a mischaracterisation of the realities; in other words, there was real risk present, but it was not being recognised.

My reading of the literature regarding first time mothers and low risk premature infants mirrored Patricia's concerns. The existing data was scant but it consistently concluded that low risk premature infants—be that premature babies born at higher birth weights or quite close to term—carried significantly more risk factors than their full term peers. Meanwhile, the absence of attention combined with the presence of adversity also reflected and invigorated my persistent professional concern for neglected and discounted experiences of mothers trying their best to do well. It appeared likely that this relative invisibility in both the medical world and the published findings signalled a gap in attention, comprehension, and support for mothers of premature babies. This further bolstered my aim to explore the topic in a way that could shed light on the maternal experience from the mothers' vantage point.

Through a process of reading, reflection, and discussion, I arrived at a plan to conduct a qualitative study using the methodology of interpretative phenomenological analysis (IPA) (see Chapter V for further discussion). The use of face-to-face interviews as the data gathering method facilitated not only a prioritising of maternal experience and voice, but the bridge between respect for individual reality alongside a social work framework of advocacy and care.

### I.3 Aims and significance

The aims of my study reflect my previously described aspiration to explore, support, and illuminate the overlooked, day-to-day lived experiences of “average” mothers. Broadly speaking, my research aims were to discern and give voice to the meaning-making experiences of first time mothers giving birth to low risk premature babies. Specifically, I was interested in how mothers construct a maternal identity while managing prematurity-related stressors and novice motherhood, as well as how they come to know their babies and understand the interpersonal relational processes that unfold. Aims were operationalised through the interview process; interview questions inquired about the birth experience, the psychological and emotional experience of identifying as a mother, and the process of coming to be in relationship with one’s baby.

The aims were closely tied to the significance of the study. There are many first time mothers who give birth to premature infants, and low risk premature babies—those born late enough and weighing enough so that there are no serious, persistent medical concerns—make up the majority of preterm births. Nonetheless, there is almost no data on this particular cross section of mothers and a corresponding belief that neither mother nor baby is negatively affected by the experience in any longstanding way (see Chapter III Literature Review for further information). This relatively inattentive stance is at odds with what literature does exist, all of which uniformly suggests that these dyads carry risks; in fact they likely have unique risk factors and risk profiles that make a strong case for acknowledgement, scrutiny, advocacy, and response.

For example, after I completed data collection, analysis of findings, and the writing of the majority of the chapters, an epidemiological review of premature birth was published, focussing on late occurring preterm births (Gill & Boyle, 2017). The evidence reviewed

challenges even updated notions about risk, stating that babies born as late as 38 weeks gestation present with measurable increased risk and severity of adverse outcomes, from neonatal illnesses through to neurodevelopmental and educational difficulties and even adult health problems. Study authors suggested that birth is now best understood as a continuum; while babies born near term (before 39 weeks) may not evince the more obvious and intense problems that much earlier born infants do, they nonetheless cannot be considered like full term births either. The authors concluded by describing these late born infants—like the majority in my study—as a “previously understudied population” (Gill & Boyle, 2017, p. 197). Thus, there is significance in research like mine that seeks to augment the knowledge base.

Furthermore, the research significance extends specifically to the absence of maternal voice, something that appears to be so removed from the literature that its omission is not usually noticed. As the field moves to respond to the realisation that later term, low risk infants have been understudied, I believe there could follow a realisation that the mothers of these infants are also understudied. This project is a small contribution to remedying that problem.

#### I.4 Structure of the thesis

The thesis is divided into 10 chapters, of which this is the first. Chapter II is an exploration of the background and contextual factors framing the research participants. This includes an overview of information about premature birth, including premature birth in New Zealand and the specific factors surrounding late term, low risk prematurity. Next, the chapter outlines policies governing and influencing mothers and their prematurely born infants, with mention of infant and family rights, NICU and hospital policies, and governmental frameworks designed to implement support. Lastly, the

chapter discusses the impact of neonatal social work, its structure, influence and connection to the participants' experiences.

In the third chapter, an extensive literature review is presented. The specific and unique cross-sectional identity of my research participants—first time mothers of low risk premature infants—has not been previously investigated. As a result, the relevant literature draws from a broad range of literary domains, with germane bodies of data extracted and curated according to their applicability. The literature review thus includes the data on prematurity (including low risk prematurity) and its relative risks and outcomes, factors influencing maternal identity, motherhood as it relates to premature birth, first time motherhood, the psychoneurobiology of mother-infant bonding, and influences on motherhood from within medical settings, especially the NICU.

In chapter four, I introduce the most salient popular academic theories and provide a review of them individually as well as of how they interrelate. The chapter will include discussion of theories related to the general psychological and emotional experience of motherhood, first time motherhood, construction of maternal identity and the meaning of becoming a mother, the lived experience of dyadic connection, and the meaning of premature birth. In general, three key areas will be explored, namely how women develop into mothers and make meaning of that development, how relationships between mothers and their babies are understood, and how the distinct events of prematurity influence the previous two tasks.

Chapter five covers an explanation of the methodology—interpretative phenomenological analysis (IPA)—that I employed. In this chapter I describe my personal journey with exploring methodological options and coming to understand what I wanted from the research. I then explain the philosophical tenets underpinning IPA, the role of the

researcher and the creation of research questions to align with the methodological and research aims. Next I discuss the practical steps I took to design, create and implement the research, with attention to the interviewing process and the participant mothers. Lastly, I clarify the multi-step process involved in IPA analysis and how that was applied to my research data. Finally, I point out ethical considerations and potential limitations of my findings.

The next three chapters—Chapters 6, 7, and 8—comprise my findings chapters. Each chapter presents thorough exploration and discussion of one of each of the three superordinate themes that arose through analysis, along with a breakdown of its composite subthemes. Chapter VI looks at a theme related to events outside the mother, while chapter VII focuses on things inside (or within) the mother, and chapter VIII takes stock of events between the mother and her baby. Chapter VI is concerned with the first superordinate theme of “Little things are big things” and concentrates on the participants’ reality, that the things that were most influential and meaningful for mothers were almost exclusively things that were absent, discounted, or invisible to the medical culture. Chapter VII addresses the second superordinate theme of “Maternal distress”. It reveals the persistent occurrence of painful and difficult emotions and reactions for participant mothers, while also validating the existence of such distress as normal despite a prevailing belief that mothers of low risk babies experience mostly mild responses. Finally, chapter VIII describes the third and last superordinate theme of “How do I become a mother?” This chapter hones in on what was occurring between participant mothers and their babies, as well as interactions occurring between the mothers and the NICU, and between different aspects of each mother’s sense of self. In the absence of conditions of normal, healthy, full term birth, mothers faced disruption to the typical processes underpinning the establishment of mother-infant connection. The superordinate theme of chapter VIII looks

at the reality of mothers developing maternal identities, narratives, and relationships via an unpredictable and untraveled path.

In chapter IX, I offer my discussion about the research analysis and findings, advancing my own thinking about how superordinate themes interconnect with analysis, as well as postulation as to the larger meanings contained in the findings. In this chapter I will suggest a revision to ecological theory and dyadic work, or what I have termed “dyad-in-context”, that seeks to explain the interrelationship between the three superordinate themes and the meaning-making experience of participant mothers. I further outline the IPA-driven analytical process involved in this level of interpretation and location of the findings within their larger context. This is a process driven by the researcher’s goal of making meaning out of the participants’ meaning-making. In the discussion chapter, I create a framework for looking at the superordinate themes. I further the participants’ narratives by looking for what connects them, what emerges from their significant experiences, and what is missing in the current understanding as reflected in the literature.

The final chapter, chapter X, examines the importance and implications of the research. I will provide a critical consideration of what findings suggest in terms of contribution to the field of maternal care, prematurity, and social work practice. I aim to offer additional phenomenological, theoretical, and ecological information to existing understandings and to make relevant recommendations for improvement of sensitivity, awareness, and responses in light of participants’ experiences. I acknowledge limitations of my research and offer suggestions for future research endeavours.

## I.5 Conclusion

In this chapter, I have provided an introduction to my thesis. My hope was to give insight

into my relevant personal processes and professional history so that my research is not only well-situated in the literature and methodology, but also connected to its importance in my life. I arrived at the decision to pursue this thesis through a somewhat winding pathway that has been punctuated by externally-generated and unanticipated turning points. Nonetheless, once decided, the thesis has been an endeavour of great value to me and, I hope, to the participants and ultimately the field of social work.

In the next chapter, I will move on to setting the stage for participants' stories as I establish the background framework within which participants were located. Chapter II (Background and Context) will address ecological and environmental factors at play, including the realities of premature birth, the specifics of such birth in New Zealand, policies and support systems influencing mothers and their premature infants, the construction of infant and family rights relevant to participant experience, and the influence of social work intervention and support.

## Chapter II: Background and Context

### II.1 Introduction

On first consideration, undertaking research on first time mothers of low risk premature infants might appear to have a very specific and narrow focus. Beneath the experiences of participant mothers, however, was a fabric of medical realities, policies, procedures, and practice standards for dealing with premature birth and caring for infants in neonatal intensive care units (NICUs). These background issues provided a context in which each participant mother operated, a general backdrop foundation upon which individual experience was built.

According to very recent neuroscientific thinking, the human mind is understood as embodied and relational system that regulates the flow of information. As Siegel (2016) wrote, the mind is “our interpersonal connections and embodied lives, subjective experiences, inner essence, sense of purpose and meaning, and consciousness” (p. 15). This is a modern twist on well-established ecological theory (Bronfenbrenner, 1979), a realisation that the context we are embedded in affects not only how we think, but who we become and how we make meaning of our world. As such, examination of this contextual milieu is essential to understanding the seen and unseen forces that exerted influence on the meaning-making and experiences of participant mothers.

Aligned with both modern neuroscience and contextual ecological systems theory, in this chapter I will outline the background influences and issues, offering a discussion of their relevance for my research and its participants. This includes factors of premature birth, medical and societal policies, and the impact of social work professionals.

## II.2 A snapshot of premature birth in New Zealand

In July of 2014, the New Zealand online news source, *stuff.co.nz*, published a blog post by a woman called Moata Tamaira who gave birth prematurely. She was 37 weeks pregnant and delivered her baby—her first—under urgent medical circumstances at Christchurch Women's Hospital. She titled her blog post *When your baby is in jail* (Tamaira, 2014). In the post, she wrote

When your baby is in NICU it's kind of like they're in jail except you have no idea when they'll be eligible for parole. The social worker I spoke to said that no one understands about NICU unless they've been through it. It can be a highly stressful environment for new parents . . . which is why they have social workers.

The blog post generated 74 comments, an apparently high number for this weekly blog column. The comments were evenly divided between commenters who completely identified with the distress and difficulty of having a baby in a NICU and those who angrily criticised Tamaira for writing anything negative about the amazing work done to save her baby. The blog post and the comments point to many of the themes and tensions that surfaced for my participants.

In defence of her experience, Tamaira responded with the comments,

To see where the "injustice" to the staff is in this post when not a single word of is negative about the staff. I'm writing from the point of view of a new parent with an unwell baby, and what that feels like. If any nurses are "offended" about me being honest about having a terrible time then they'll just have to find a way to cope with that, I'm afraid.

Not only did the blog post illustrate another voice in the New Zealand conversation, it explicitly referred to the role of the social worker, identifying social work in the larger context of mother-baby experience, both as a source of helpful information and essential support.

While the blog asserts that no one can understand the NICU experience without enduring it, I nonetheless hope that there are ways to provide real insight into the experiences of premature birth and NICU stays. Providing such insight is of course an aim of this research.

In order to help illuminate the context in which my research has taken place, this chapter concerns the background and context that influences the experiences of mothers with babies in NICU. I cover the following: the international context of premature birth, including the United States, United Kingdom, and Australia; statistics of premature birth in New Zealand; social, political, and medical issues surrounding premature birth in New Zealand, as well as trends from other nations; policy issues in New Zealand and Australia that govern premature birth and maternity care; the specific role of medical social work, both at large and in New Zealand; neonatal and maternal medical and philosophical frameworks in New Zealand; and the specific role of social work in NICU units in New Zealand. (It should be noted that examinations of New Zealand often include Australia as well because the two countries are grouped together, both as the result of joint medical affiliations and research ventures, and due to worldwide statistical analysis that bands them as one. I will specify where New Zealand-only data exists.)

## II.3 The statistical picture

### II.3.1 Premature birth around the world

The World Health Organisation (WHO) has defined premature birth as all births occurring before 37 full weeks gestation (Kramer et al., 2012; Setiawan, 2004). Worldwide, premature birth is the single largest cause of perinatal and neonatal infant mortality and morbidity, as well as the leading cause of death in children under the age of five (World Health, 2015). Complications of preterm birth are responsible for 35% of the world's 3.1 million deaths per year (Blencowe et al., 2013). More than one million prematurely born babies die each year (Lawn, Gravett, Nunes, Rubens, & Stanton, 2010). Data is not routinely collected in many countries and standard definitions of prematurity are lacking worldwide, among researchers and clinicians alike (Kramer et al., 2012). It is estimated that approximately 14.9 million babies were born preterm in 2010 (the most recent published statistics available). In poorer countries, the idea of preterm birth has often gone unrecorded due to insufficient record keeping, with birthweight as the focus in medical records (Kramer et al., 2012). In countries of all income bands, there is inconsistency in the inclusion or exclusion of stillbirth within the preterm statistics. Additionally, some preterm births are spontaneous whereas many others are induced for medical reasons (Blencowe et al., 2013), creating two very distinct categories. Roughly 40% of preterm births are idiopathic, but of the other 60%, approximately 30% are due to early rupture of membranes and the rest due to medically indicated or elective premature deliveries (Beck et al., 2010). However, preterm birth continues to be defined by time, not by its distinct characteristics (Kramer et al., 2012).

Distinctions are critical both in prevention and treatment according to each mother's situation, yet are not currently represented in the data. Delineating the two categories would

help clarify reasons and responses in countries where there are high rates of Caesarean section. Achieving a specific breakdown between moderately, very, and extremely preterm births would also be illuminating (Lawn et al., 2010). Researchers have suggested that improving data collection and moving to consistent definitions will help in the development of better understandings of the causes of preterm birth. In addition, improving access to effective medical care will likely help with the response to the needs of prematurely born infants (Beck et al., 2010). In 2014, iNeo was established. iNeo is a partnership association of national neonatal networks that includes Australia and New Zealand, Canada, Israel, Japan, Spain, Sweden, Switzerland, and the United Kingdom. Such collaboration of networks working toward accurate evaluation of premature infancy worldwide is seen as a step toward better understanding (P. S. Shah et al., 2014)

In Western countries such as France and the United States, nearly 40% of preterm births are provider-initiated and this rate of provider initiated preterm births appears to be on a steady increase in countries in which policies utilise Caesarean sections for cases of poor foetal growth (Blencowe et al., 2012). Similarly, the increased medical technology available in high-income countries means that infants born prematurely have higher rates of survival (Blencowe et al., 2012). For example, 95% of babies born between 28 and 32 weeks survive in high-income countries as compared with only 30% in low income ones. Overall, prematurity rates correspond to financial health, with low-income countries having the highest rates (11.8%) and high-income countries having the lowest (9.4%). Hence, social issues such as financial wealth and access to advanced medical treatment become key factors in the picture.

High levels of income do not protect a country from relatively high rates of premature birth, nor do more affluent countries report declining rates over time. Despite medical advances,

preterm birth is increasing in almost every country where data is available. Only three countries of the 65 with estimated trends over the past 20 years have shown an overall decline. They are Croatia, Ecuador, and Estonia (Blencowe et al., 2012). The United States, for example, is in the top ten countries with the highest estimated preterm births (Blencowe et al., 2013). Reasons for increases are again theorised as being different depending on each country's risk factors. In high-income countries, it is speculated that potential reasons for the increase are infertility treatment, multiple pregnancies, maternal age, and changes in obstetric practices such as non-emergency inductions and Caesarean deliveries before full term (World Health, 2012). In low-income countries, the increases are more likely due to infections, malaria, human immunodeficiency virus (HIV), very young maternal age, and poor medical care.

### *II.3.2 Worldwide low-risk prematurity*

Late preterm birth, typically defined as premature birth occurring from 34 weeks gestation up until 37 weeks gestation, is the fastest growing category of prematurity in the world and represents roughly 75% of all preterm births (Y. Dong & Yu, 2011). The category of late preterm birth applied to the birth situation for the vast majority of the mothers in my research sample. Compared with infants born at term, these babies have higher risks of morbidity, mortality and enduring medical problems (Y. Dong & Yu, 2011; Kramer et al., 2000). Recently, researchers have begun to look at both absolute and relative risks for this group of premature infants. Despite low absolute risks of death, late preterm infants have appreciable relative risks for mortality across a variety of categories, from infection and sudden infant death syndrome to abuse and maltreatment (Kramer et al., 2000). From a public health standpoint, there is a larger impact from this mild to moderate birth premature cohort than from infants born between 28 and 31 weeks gestation for all causes of death (Kramer et al.,

2000). Both the WHO and the American Academy of Pediatrics have called for more attention, investigation, and follow up of these late preterm babies (Raju, Higgins, Stark, & Leveno, 2006).

### *II.3.3 The New Zealand picture*

In 1994, The Australian and New Zealand Neonatal Network (ANZNN) was established (Donoghue & Henderson-Smart, 2009). The network's goal was to create a bi-national coalition of neonatal units that allowed for auditing care, providing feedback, monitoring clinical progress and advances in technology, and publishing results. With fewer than 150 neonatologists across both countries, the network serves as a forum for clinicians to aggregate and share research and knowledge, as well as providing unified expert opinion to the field (Donoghue & Henderson-Smart, 2009). As of 2014, there are 29 Level III NICUs represented in ANZNN, with New Zealand reporting approximately 60,000 total live births per year and 3,500 of those births eligible for ANZNN recording (P. S. Shah et al., 2014). Currently, the network only collects data on infants born at less than 32 weeks gestation or for infants weighing less than 1500g at birth. According to ANZNN's annual report (Chow, 2015), Level III NICUs in New Zealand exist at Christchurch Women's Hospital (38 beds), Dunedin Hospital (16 beds), Middlemore Hospital (30 beds), National Women's Health at Auckland City Hospital (46 beds), Waikato Hospital (41 beds), and Wellington Women's Hospital (40 beds). There are also 14 Level II nurseries in New Zealand, with a total of 132 beds available. This accounts for all the Level II and III units in the country.

For the year 2013, statistics for premature births showed that there were 3,501 babies born before 32 weeks (36%) and 6,220 babies born at 32 weeks or more (64%) in Australia and New Zealand combined. In New Zealand alone, 1,834 infants met the ANZNN registration criteria and represented 3.1% of all live births in New Zealand in 2013 (Chow, 2015).

Maternal ethnicity breakdown for all births was reported as 52.6% European, 18.8% Māori, 13.5% Pacific Islander, and 12.9% Asian, with 1.3% unspecified. This compares with 2013 general census figures of 74% European, 14.9% Māori, 7.4% Pacific, 11.8% Asian, and 2.9% other (Statistics, 2013). (People were able to identify with more than one ethnic group, so numbers do not add to 100.) Additionally, male babies were overrepresented among the ANZNN registrants with a figure of 58.3% (Chow, 2015).

In common with trends across the world, New Zealand and Australia's greatest proportion of premature births occurs in the lower risk categories of moderate and late preterm birth. Moderate preterm is typically defined as 32 to 34 weeks gestation and late preterm as 34 to less than 37 weeks; worldwide these categories comprise roughly 80% of preterm births, with about 70% falling in the late preterm category (Cheong & Doyle, 2012). All trends, both in Australia and New Zealand and worldwide, indicate that late preterm birth is rising (Cheong & Doyle, 2012).

The ANZNN also reports on median length of stay according to gestational age. For babies born between 30 and 37 weeks gestation (which matches the age range for the participants in my sample), length of stay ranged from 11 to 38 days (Chow, 2015). Of course, this sample only included babies who weigh less than 1500g at birth if they were over 32 weeks gestation, so is skewed lower than it would be if it included all birth weights, as my sample did. In other words, many of the babies in my sample presented with less medical acuity than those tracked by ANZNN. Similarly, the survival rates for the registered babies that would match my research ranged from 96% to 97.7% (Chow, 2015). Statistically, none of the mothers in my sample faced the likely death of an infant. The length of stay and survival rate statistics are the only data collected by ANZNN that appear to shed potential light on the maternal experience. Using this data, insights about maternal experience can only be inferred

via the knowledge that length of stay for the infant almost always means that there will be a time after maternal discharge that the mother is at home and the baby remains in NICU. The specifics of this time separated, however, would vary from case to case and are not currently collected or recorded outside of individual, confidential medical records.

#### *II.3.3.1 Low risk and late preterm birth in New Zealand*

The Auckland District Health Board prepares an annual report for the National Women's Hospital. According to the 2014 report (the latest available), 759 babies were born prematurely in 2014, with 554 of those born between 32 and 36 weeks gestation (Auckland District Health Board, 2014). This gestational range represents 14 of the 15 participants in my study. There were 910 admissions to NICU during the year, with an average occupancy of 95%. Babies born between 32 and 36 weeks made up 36.4% of NICU occupants, as compared with 14.7% for babies born at earlier gestations. Nearly half of NICU admissions were not due to prematurity. In terms of length of stay, babies in the 32 to 36 week category logged 4362 baby-days (occupancy) in the total of 14070 baby-days for all babies admitted. It is also possible to extrapolate the total number of NICU admissions for the entire gestational range of my research, babies born between 30 and 36 weeks. In the year 2014 in Auckland, admissions in that range registered 337, out of a total of 809 NICU admissions. There were two social workers on the NICU, for a total of a 0.6 full time equivalent position. No data is collected on maternal length of stay in the hospital, nor on visitation patterns in the NICU.

According to one of Auckland's consultant neonatologists, the late preterm infants are "great impostors" because they look deceptively like full term infants but typically have much greater needs (Rowley, 2014). He suggested that reasons for the increase in late preterm births in New Zealand have to do with increased reproductive technology, advances in surveillance and interventions in pregnancy, increased rates of foetal monitoring and

induction, and a relaxed approach to the risks of late preterm birth (including allowing Caesarean sections to be performed before 40 weeks gestation for reasons of convenience) (Rowley, 2014). Finally, using 2013 New Zealand figures, he surmised that the financial cost of a baby born at 35 weeks gestation who had a six-day stay in NICU was roughly \$19,900.

#### *II.3.3.2 New Zealand in comparison with other nations*

A small number of studies have also undertaken comparisons between neonatal care in New Zealand and care in other countries. A 2015 study examined the outcomes for preterm infants cared for in Australia, New Zealand, and Canada, collecting data from 9995 ANZNN infants and 7141 Canadian Neonatal Network (CNN) infants (Hossain et al., 2015). Rates of survival were similar across the two networks.

Another study conducted a qualitative and quantitative analysis of two NICUs, one in Japan (Tokyo) and one in New Zealand (Christchurch), examining the sources of parental stress, the cultural NICU norms, and how this influenced family care and nursing support (Ichijima, Kirk, & Hornblow, 2011). Chosen cities were regarded as representative of the medical care of each country. Parent and staff interviews as well as parental questionnaires were used to evaluate the information from 121 parents. Large differences in visitation practices were noted, with New Zealand mothers spending an average of 43 hours per week visiting their infants in NICU as compared with Japanese mothers who averaged 10 hours per week. Researchers concluded that because the Breastfeeding Friendly Hospital Initiative (BFHI) is fundamental to the NICU regulations in New Zealand, this was a factor in the variance in degree of parental involvement. The Christchurch NICU was also operating much more in line with the principles of family-centred care than the Toyko NICU, hence aligning Christchurch's operational ways with a philosophy that supports parental participation and inclusion.

#### *II.3.4 Context of ethnicity and socioeconomic status*

Around the world, poverty, lower incomes, and minority ethnic status are all risk factors for increased rates of premature birth (Beck et al., 2010; Blencowe et al., 2013; Blencowe et al., 2012; Culhane & Goldenberg, 2011; World Health, 2012, 2015). For example, in the United States, African American women have a 18.3% rate of premature birth as compared with non-Hispanic white women whose rate is 11.5% (Culhane & Goldenberg, 2011). The specific reasons for the statistical disparity are speculated to be multi-layered and complex, with socioeconomic status being one of them.

##### *II.3.4.1 Ethnicity and socioeconomic issues in New Zealand*

In New Zealand, some researchers have attempted to collect data regarding the relationship between socioeconomic status and premature birth. Over a 20 year period beginning in 1980, birth registration data was linked to the family's corresponding New Zealand Deprivation Index (E. D. Craig, Thompson, & Mitchell, 2002). Over the two decades of monitoring, premature births rose in New Zealand from 4.3% of total births to 5.9% by the end of 1999. However, the rate for those living in the most affluent areas rose by 71.9% whereas the rate for those living in the most deprived areas rose by only 3.5%. Hence, by the end of data collection, the influence of socioeconomic conditions had disappeared, challenging the existing assumptions about wealth and risk of prematurity. Researchers have attempted to speculate as to possible reasons for the differing rates and increases. Possible mechanisms suggested include: the increasing reliance on ultrasound technology and the use of ultrasound for pregnancy dating; an increased use of obstetric surveillance for high-risk pregnancies (possibly resulting in lower rates of infant death/stillbirth but higher rates of prematurity); increasing rates of assisted conception and fertility treatments; stress, and anxiety on the part of mothers; and maternal workforce participation and workloads (E. D. Craig et al., 2002). In

the case of the latter, collected statistical data suggests that there was a marked increase in the numbers of hours per week that women worked over the two decades, but it is unclear exactly how this corresponds to socioeconomic status. However, previous research has shown associations between the number of hours worked and preterm deliveries (Newman et al., 2001). The study authors concluded that no single hypothesis nor factor is sufficient to explain the trends and their magnitude.

#### [\*\*II.3.4.1.1 Long term study of birth outcomes and ethnicity in New Zealand\*\*](#)

In 2004, New Zealand researchers published a four-part series of articles drawing on the fields of paediatrics, obstetrics and gynaecology, epidemiology, biostatistics, and Māori and Pacific health (E. D. Craig, Mitchell, Stewart, Mantell, & Ekeroma, 2004; Ekeroma, Craig, Stewart, Mantell, & Mitchell, 2004; Mantell, Craig, Stewart, Ekeroma, & Mitchell, 2004). The research series examined ethnicity and birth outcome, including trends in premature birth, from 1980 until 2001. Seeking to better understand the particular New Zealand picture, researchers explained that trend analysis alone is insufficient to fully make sense of the health outcomes for each ethnicity; careful data collection and analysis combined with specific interpretation and connection to context is required (E. D. Craig, Mantell, Ekeroma, Stewart, & Mitchell, 2004).

In New Zealand, all births occurring at or beyond 20 weeks gestation must be notified by the hospital (or midwife) within 5 working days of delivery; parents must also complete a Birth Registration Form. Once both forms are received by Internal Affairs, data is merged into a single entry. This process is thought to accurately capture 99.9% of births (E. D. Craig, Mantell, et al., 2004). This data includes information such as gestational age, weight, and sex of the baby as well as maternal age and ethnicity. Additionally, the New Zealand Deprivation Index (Salmond, Crampton, King, & Waldegrave, 2006; Salmond, Crampton, & Sutton,

1998) was used in conjunction with this data to connect the birth-related information to socioeconomic status. The New Zealand Deprivation Index is based on the same theory as national census collection and is validated against representative sample survey data collected in response to 28 deprivation-related questions (Salmond et al., 2006; Salmond et al., 1998); it is a significant tool for measuring socioeconomic deprivation in individuals.

According to the first report (E. D. Craig, Mantell, et al., 2004), rates of preterm birth rose by 30% for European/other women and declined by 7% for Māori women and 4% for Pacific women. There was little variation in the mean New Zealand Deprivation Index scores associated with maternal ethnicity over that time. Risk of preterm birth was highest among Indian and Māori women and lowest among Pacific and “other” non-European minority group women. Risk was also elevated for teenage mothers, women over the age of 35, and women living in the most deprived areas. However, for Pacific women there was no association between level of deprivation and risk of prematurity.

In parts two through four of the research series, each ethnic group’s outcomes were examined and interpreted by a team of analysts led by an expert in the ethnic group studied. Part two focused on the birth outcome experiences of Māori women in New Zealand (Mantell et al., 2004). In the first half of the studied timespan, from 1980-1994, Māori women had the highest preterm birth rates of any ethnic group. From 1995 until 2001, this inequality was offset both by a non-significant 7% decline in preterm rates and a 30% increase for European women. Despite teen pregnancy being a risk factor for preterm birth and there being high rates of teen pregnancy among Māori women, there was no evidence that teen pregnancy conferred additional risk of preterm birth for Māori mothers. As the analysts pointed out, the statistics did not suggest any real improvement in health outcomes for Māori women since the closing of the ethnicity gap was largely a result of the significant rise in the rates of

preterm birth in European mothers. They further speculated that the relative lower rates of obstetric interventions in Māori women, such as Caesarean sections and induction of labour, may have had something to do with the increased incidence of preterm birth in European women. As with other research examining socioeconomic status and its links to preterm birth in New Zealand (E. D. Craig et al., 2002), there was little impact from the New Zealand Deprivation Index deciles on the rates of preterm birth among Māori women; however, a gradient effect was noted, showing that risk increased with deprivation. Researchers concluded that the higher rates of “small for gestational age” deliveries among Māori women, a rate that is 40% higher than their European counterparts, needed to be a main cause for policy concern and focus.

Part three of this four-part series of New Zealand birth studies focused on the outcomes for Pacific women and, again, was written and analysed by a team of experts and headed by a doctor with Pacific expertise and heritage (Ekeroma et al., 2004). Pacific women had the lowest rates of both preterm birth and small for gestational age birth when compared with Māori and European women. Their preterm birth rates also experienced a 4% non-significant decline over the study period. Despite reported underutilisation of primary health services, Pacific women still appeared to fare better in their pregnancy outcomes than their Māori and European counterparts. This was all despite the fact that according to birth registration data, Pacific women had higher co-morbidities, were more socioeconomically disadvantaged (46% live in the most deprived areas), and had lower rates of utilisation of health care. Pacific women had high rates of teen pregnancy but the lowest rates of smoking (19% versus 25% in European/other women and 48% in Māori women). It was suggested by the researchers that the low incidence of smoking may be partially responsible for the lack of connection between socioeconomic status with preterm birth, as rates of smoking are a statistically close proxy for deprivation (Salmond et al., 2006). Alternative hypotheses focused on the links between

stress and foetal development. Other research found that immigrant communities have lower rates of preterm birth as compared with nationals, speculating that there is a buffering level of emotional and social support within immigrant communities (Guendelman et al., 1999).

Following that logic, New Zealand researchers suggested that it is possible Pacific women have stronger social networks alongside cultural systems that provide both psychological and emotional support. According to the researchers, unpublished data from an Auckland hospital suggests that when Pacific women have hidden pregnancies (and hence receive no family support) their birth outcomes are poorer.

The last part of the research series focused primarily on European women (E. D. Craig, Mitchell, et al., 2004) and followed the same structure for the analysis as the previous two. The progressive and consistent rise in preterm birth for European women over the two decades studied was the primary concern, particularly as the rise was confined to this ethnic group. Researchers suggested that the increase in obstetric interventions is partially behind the rise in preterm births. New Zealand does not collect data on ultrasound use patterns, but it is possible that changes in its utilisation were implicated in the increase. While not fully supported by the New Zealand literature, study authors also questioned if non-clinical factors may have been influencing clinicians to intervene more in the pregnancy and delivery of Europeans. It was noted that a trend toward inducing infants even one week earlier over the duration of the study period would have been sufficient to account for the data changes seen. As this cannot yet be proven, researchers advised remaining vigilant about potential other reasons for an increase in spontaneous preterm delivery among the European ethnic group. Maternal age was also a potential factor as the proportion of women over 35 giving birth rose from 4.7% to 12.1% in European women during the study time.

By way of comparison, Australia has collected some similar data on its population. In the country at large in 2001, 7.8% of babies were born prematurely, 6.1% being born between 32 and less than 37 weeks gestation (Laws & Sullivan, 2004). In 2013, the rates of overall prematurity were at 8.2% (Donoghue, Lincoln, Morgan, & Beard, 2013). Unlike New Zealand, increasing socioeconomic advantage is associated with increasing risk of having a premature baby. This is true even after adjusting for maternal age, ethnicity, and smoking (Donoghue et al., 2013).

## **II.4 Policies regarding prematurity**

### *II.4.1 Worldwide policy regarding prematurity*

There is not a great deal of data available on policies governing the care of premature birth, premature babies, or mothers of premature infants. Policies appear to not only vary by country, but also by hospital. Existing research indicates that inconsistencies abound and the focus of publications is typically on recommendations (Vogel, Oladapo, Manu, Gürmezoglu, & Bahl, 2015; World Health, 2015). There is a wealth of information on best medical practices regarding the many specific medical variables and scenarios faced in premature birth, delivery, and care but I am not reviewing those as they are not pertinent to the aims of this chapter. Within the worldwide data, researchers have examined policies regarding parental involvement in NICUs (Pallás-Alonso et al., 2012), parental presence during clinical bedside rounds (Abdel-Latif, Boswell, Broom, Smith, & Davis, 2015), kangaroo care (H. Moore, 2015), visitation (Cuttini et al., 1999; Latva, Lehtonen, Salmelin, & Tamminen, 2007), and family-centred care models (Keller et al., 2010).

In research on parental involvement, a study of 362 NICUs in eight different European countries looked at variables such as access to reclining chairs at the baby's cot-side, policies

regarding encouragement of parental participation, and the use of kangaroo care (Pallás-Alonso et al., 2012). Researchers found that each variable was common across the countries, yet rates of use varied wildly and inconsistently, with policies governing these practices also being inconsistent or non-existent. For example, almost every NICU reported use of kangaroo care; for some use was restricted to parent request or medical needs, whereas in other cases skin-to-skin contact was not employed even while employing the kangaroo care position. Other research focussing specifically on the use of kangaroo care in neonatal units concluded that without standardised policies in effect, inconsistency was always the case (H. Moore, 2015). Visitation policies also varied greatly from unit to unit, with some countries giving 24-hour access to parents (and in some cases siblings and grandparents as well), and other countries restricting access to limited hours of visitation and providing no access for siblings (Cuttini et al., 1999; Keller et al., 2010). Additionally, most NICUs do not have policies regarding whether parents should be present during bedside medical rounds, yet research has indicated that when parents are included, 95% of parents and 90% of nursing staff recommend implementation of policies to mandate their inclusion (Abdel-Latif et al., 2015).

With worldwide inconsistencies across policies, definitions, and data collection methods, it becomes difficult to draw conclusions about NICU practices and to begin to define what best practice is (Vogel et al., 2015; World Health, 2015). At present it seems that most policy recommendations focus solely on medical issues. In terms of policies affecting mothers and involving mother-infant interaction, only kangaroo mother care related policies consistently surface, with current international recommendations being for continuous, skin-to-skin, prolonged contact (Vogel et al., 2015; World Health, 2015).

The only policy recommendations I could find that addressed multiple aspects of maternal life, were recommendations made for the physical, architectural, and construction design of neonatal units (Shepley, 2014). In the book, *Design for Pediatric and Neonatal Critical Care* by Shepley (2014), prominent designers, architects, and researchers considered concepts of mother-infant relationship development and parental involvement in NICUs through the lens of building design. Recommendations blended suggestions for the layout and practicalities of the physical space with the needs of mothers and infants; they included the following: sufficient sleeping space for mothers on the unit and adequate space for sibling care, the ability for mothers and fathers to stay on the unit at all times, the need for privacy and quiet for infants and their parents, and the use of natural light and nature itself to enhance and support the NICU space.

#### *II.4.2 Policy in New Zealand*

There are a number of published documents, practice guidelines, and policy statements that direct service delivery for New Zealand-born premature infants and their families. The majority of this information is not specifically written for cases of premature birth but contains relevant material influencing care. In this section I will outline the pertinent policies and guidelines, including NICU health facility guidelines, clinical practice around preterm birth, standards of care for young people and adolescents, protocols for neonatal palliative care, breastfeeding codes for maternity care in NICU, mother-infant health recommendations, and NICU-specific patient information. After this section on policy, I will discuss the documented rights that are applicable to premature birth as well as New-Zealand specific legal frameworks and policies that govern issues around maternity and premature infant care.

The Australasian Health Facilities Guidelines which govern New Zealand and Australia (Australian Health Infrastructure Alliance, 2014), were developed via consultation with both

experts and consumers, and serve to facilitate planning within any intensive care, neonatal, or special care nursery. While not mandatory and largely aspirational, they appear to reflect the current thinking in neonatal care in Australia and New Zealand. According to the guidelines, the model of care for newborns in neonatal units should be multidisciplinary and is described as a “care-by-parent” model (p. 5). Within a care-by-parent model, parents are given unfettered access to their child and are understood as active participants in their child’s care. The model encompasses provision of a range of services and support, typically providing rooming-in options for parents when the infant is critically ill, as well as when preparing to transition home. Services also try to include specialists in the areas of lactation, discharge planning, and home support. According to the guidelines, parents must be accommodated on the unit to be close by their newborn, however, no specific definition of “close by” is offered, nor is it suggested that the opportunity to sleep on site should be available for most parents.

The guidelines state that NICUs should be both “baby-centred” and “family-centred” (Australian Health Infrastructure Alliance, 2014, p. 6). Baby-centred is defined as requiring the creation of an environment that includes: best-practice care from full life support to convalescent care; efforts to manage noise, light, and temperature control in order to best support babies; support of a care-by-parents model; facilitation of kangaroo care; and procedures that minimise any risk of adverse occurrences, especially infection.

Family-centred is defined as acknowledgement of the pivotal role of parents and other family members as a part of the newborn’s care team. It stipulates the following: creation of a welcoming environment that provides sufficient space; nearby live-in accommodation, and privacy for parents; the encouragement of physical contact and breastfeeding; counselling and emotional support; and communication with staff. In terms of staff, it is suggested that role delineation and composition will be unit-dependent and this may include social workers.

The New Zealand-specific *Clinical Practice Guidelines for Care around Preterm Birth* (Ministry of Health, 2000), developed in conjunction with government, rank recommendations based on the strength of available evidence. While mostly medical in nature, the guidelines also devote space to some social, emotional, and relational issues, making suggestions generally based on behaviours assessed as most highly valued and to be encouraged. In alignment with the Australasian Health Facilities' suggestion that NICUs should embrace a family-centred model, the *Clinical Practice Guidelines* find that encouragement of mothers to provide caregiving is supported by the strongest level (level one) evidence in the research literature.

Breastfeeding and mother-infant bonding are other mother-related behaviours identified in several policy documents. As well as the aforementioned Australasian Health Facilities and New Zealand Clinical Practice Guidelines, the Baby Friendly Hospital Initiative (BFHI) certification process and the Ministry of Health practice guidelines for the postnatal period echo the importance of breastfeeding and mother-infant contact and connection. In the Ministry of Health document, *Observation of mother and baby in the immediate postnatal period* (Ministry of Health, 2012) (developed by the New Zealand College of Midwives, the Royal Australian and New Zealand College of Obstetricians and Gynaecologists, and the Ministry of Health), the antenatal period immediately following birth is thought to be a critical time for support of the physiological processes of motherhood, alongside the promotion of skin-to-skin contact, and breastfeeding. While primarily embracing a medical focus, the guidelines do highlight the importance of maternal wellbeing, however, there are no details given specifying how to support mothers, or how to address the difficulties that occur for mothers separated from their babies due to premature birth and NICU stays.

The Baby Friendly Hospital Initiative (BFHI) certification guidelines were launched by the World Health Organisation and UNICEF in 1991 (UNICEF & WHO) and function in almost every maternity care centre in New Zealand. Further to the initial BFHI framework, there now exists a BFHI certification specifically for neonatal wards, called Neo-BFHI (Nyqvist, 2015). As with the Ministry of Health recommendations, the Neo-BFHI guidelines (Nyqvist, 2015) state that the postnatal period is highly valued; mothers should be treated with sensitivity, empathy, and respect for their maternal role. They are to be supported to make informed decisions regarding feeding and are to receive focussed individualised support. Furthermore, the guidelines state that all mothers should be recognised as vulnerable, with first time mothers being classified as “particularly vulnerable” (p. 10). The initial BFHI guidelines identified 10 key steps in practice; the encouragement of kangaroo care and continuous skin-to-skin contact is one. In the neo-BFHI guidelines (2015) mother-infant bonding is given greater definition than in other documentation. It is specified as follows:

7a The breastfeeding policy states that there are no restrictions on the mothers' presence in the neonatal ward.

7b Mothers and infants are allowed to be together in the neonatal ward without restrictions, unless there are justifiable reasons for being separated.

7c The neonatal ward provides practical opportunities for mothers' unrestricted presence day and night.

7.1 The breastfeeding policy confirms that:

- the neonatal ward is open to mothers 24h/7d;

- the mothers' presence beside their infants is unrestricted, even during emergency situations and medical rounds.

## 7.2 Observation of the neonatal ward confirms that:

- the ward is open to mothers 24h/7d ;
- the mothers' presence beside their infants is unrestricted, even during emergency situations and medical rounds (pp. 35-36).

Alongside the neo-BFHI framework, The Royal Australasian College of Physicians (RACP), Paediatrics & Child Health Division, led the creation of guidelines for the standards of care for children in health services (2008). According to these standards, parents must have facilities that enable the ability for them to remain nearby their child (for example a comfortable chair or portable bed) and must also have facilities for breastfeeding and breast milk storage. The authors noted that allowing parents to stay with their children reduces stress for both child and parent. Currently, however, no NICU in New Zealand has provisions for accommodating mothers (or fathers) 24 hours a day in the NICU unless they are willing to sleep in a chair sitting up; there are no beds for adults in NICUs. Mothers do have 24 hour seven day access to their infants but not necessarily the provision of practical opportunities for unrestricted presence. Because the neo-BFHI and BFHI guidelines are aimed at breastfeeding, the rationale throughout the document is almost exclusively concerned with facilitating breastfeeding and improving breastfeeding rates. This could possibly mean that once a hospital does not have BFHI certification or when a mother is not breastfeeding, the focus on mothers being with their infants whenever they choose becomes minimised.

While pertinent to all NICU families, New Zealand also has practice guidelines developed for neonatal palliative care which echo the suggestions and mandates of the previous documents

that call for support of breastfeeding and put parents at the centre of infant care (Gifford, 2015). Developed by the New Zealand Nurses Organisation and the Neonatal Nurses College Aotearoa, the guidelines state: “it is important to remember that the best person to make decisions for the baby is the parents, family or whānau as they will know what feels right for their baby” (p. 5). Whilst medical treatment remains a feature of palliative care—especially the provision of pain management and administering of life-sustaining measures—it appears that once a medical assessment indicates that a baby’s life cannot be saved, thinking may be more relaxed around the appropriate amount of parental authority. The guidelines state that parents should be acknowledged as the primary carer and must be involved in all decisions involving their baby. It remains unspecified exactly how parents would be supported to know what feels right for their babies. The process of getting to know one’s infant can be disturbed by NICU procedures, separations, and interventions. This is potentially more likely for parents of very unwell babies facing death.

#### *II.4.3 Infant and family rights in New Zealand*

Distinct from policy documents are the documented rights that apply to infants in NICUs and form part of the backdrop to maternal experiences. The rights of infants and children in health settings have indeed been addressed in New Zealand. New Zealand is a signatory to the United Nations Convention on the Rights of the Child; inspired by that document and following on from its principles, a New Zealand charter was thus written (Paediatric Society New Zealand, 2007). The New Zealand charter encompasses the rights outlined by the United Nations and adds a New Zealand specific adaptation, including the Treaty of Waitangi/te Tiriti o Waitangi (New Zealand’s founding bicultural treaty, signed by Māori and representatives of the British Crown in 1840). It is based not only on the United Nations Convention, but also the New Zealand Code of Health and Disability Services Consumers’

Rights, the Australian Charter of Healthcare Rights and the Charter of the European Association for Children in Hospital. The charter was co-written as a consensus statement of the Paediatric Society of New Zealand and Children's Hospitals Australasia and represents an important statement of rights that are applicable to premature infants and their mothers.

The charter is a package of eleven rights. Together they have a stated aim of ensuring that all children receive appropriate and acceptable health care. Three general principles underpin the charter (Paediatric Society New Zealand, 2007):

The first is the primary consideration of the child's or young person's best interests.

The second is hearing and taking seriously all children and young people. The third is the recognition that the family/whānau is the fundamental group in children's and young people's lives (p. 6).

Within the charter, the eleven rights of children focus on a requirement to have their needs met, their best interests put forward, their voices heard, their participation mandated, their connection to family upheld, and their guarantee of receiving quality care, consideration, and communication. Additionally, the charter states that infants require special consideration of their specific needs, including services that provide support and information for their parents.

A few of the rights hold specific relevance for my research. In terms of Right 1—that which defines a child's best interests—the charter stipulates that this refers to overall wellbeing or hauora, a holistic concept that equally and inseparably encompasses “physical (Taha Tinana), spiritual (Taha Wairua), family (Taha Whānau) and mental (Taha Hinengaro)” wellbeing (p. 9). Children have the right to choose someone they wish to have with them at all times, unless this places them or someone else at risk; furthermore, any assessment of what constitutes a child's best interest must be a collaborative process that includes the child, the

parents, and healthcare professionals. In other words, a child is more than just the medical condition that places him or her in hospital, and such a holistic view necessitates being seen *in relationship* with parents and family.

In Right 2, attention to the specific needs and expressions of infants is directly addressed. Interpreting this in infant-appropriate terms is vital. The document states, “Health service providers must be attentive to the many bodily ways in which children and young people express their views. Expression begins at birth and can include cries, gestures, posture, verbal communication, changes in physiological parameters and interactions with others, particularly parents” (p. 10). When it comes to premature infants and their mothers, these more subtle forms of communication are the mainstay of interactive communication. Often mothers (and fathers) are reacting to a change in facial expression, gaze aversion, flinching, or even the body temperature of their infants. How parents respond and regulate these responses is a core feature of relationship-building and in ensuring infants are not overwhelmed by stress (Feldman & Eidelman, 2003; Hofer, 1994b; Perry, Pollard, Blakley, Baker, & Vigilante, 1995; A. N. Schore, 2000). In order to protect infant rights, communication on this level must be understood and assimilated by health professionals.

Right 5 concerns the right of every child to be nurtured by their parents and to have family supported by complementary medical care services. This right identifies the dual reality that both the child and the parent need each other as well as requiring other support. The document also states that parents should be encouraged to stay with their child. Despite 24 hour a day visitation in New Zealand NICUs, fulfilment of this right appears to be focussed primarily on daytime interaction, with a lack of provisions for overnight stays. The lack of parental presence at night is unlikely to compromise medical care; it does, however, fail to fulfil the full meaning of this right of infants and also has implications for other aspects of

infant wellbeing. To make this right a practical reality suggests a requirement of some fundamental changes to both NICU policy and philosophy.

Right 7—an infant’s participation in decision-making—echoes right 2 and suggests again that health professionals must heed nonverbal cues and communication of infants. How infants communicate their needs in terms of medical decisions is also discussed in Right 8.

The right to be kept safe from harm—the 8<sup>th</sup> right—addresses the role of adequate pain relief in infants. Parents are to be supported to hold, comfort, and/or breastfeed babies during painful procedures, and timely pain management is essential. Children must also be treated with sensitivity and in ways that respond to them as individuals. The document does not define what kind and sensitive treatment means, but it is logical to assume rough handling, the administration of procedures, needles, or tubes without warning, and failure to address infants directly and with kindness would all be excluded from the definition. The reality of infant handling practices in New Zealand NICUs have been explored in research from the Christchurch NICU (Murdoch & Darlow, 1984); infants were handled an average of 18% of time over a 24 hour period, with parental handling accounting for about one-third of total handling. Infants received an average of 234 handling procedures over the course of a full day, with many procedures having undesirable consequences (defined as medical events such as drop in oxygen saturation or bradycardia) for the infant. The research did not look at the variables that would be included for sufficient fulfilment of right 8, yet points to the centrality of handling in the infant experience.

The United Nations charter and the New Zealand-specific follow-on document do not necessarily correspond to legal rights under New Zealand law. They nevertheless create a framework for thinking about infant rights and the rights of family who care for them; they also form a template of New Zealand philosophy regarding the treatment and care of children

and clearly embed children within a larger context of parents and family systems. To advance the accepted belief in the importance of children's rights beyond philosophy and into practical application, the notion of participation must be addressed (Atwool, 2006). Believing in a child's rights and creating a way for them to participate in carrying out those rights are not equivalent processes. When discussing barriers to children's participation in decision-making regarding their care placements in New Zealand, analysis uncovers a great hidden obstacle: theories of child development (Atwool, 2006). Because child development theories often portray children as becoming developed (as opposed to already developed or fully competent), adults are assumed to reasonably speak for the child and the child's interests. This of course minimises a child's ability to be participate (Atwool, 2006) and perhaps even extinguishes the opportunity for an invitation to do so.

#### *II.4.4 Legal frameworks and policies*

Beyond the health policies and rights documents, there exists a New Zealand-specific legal framework that institutes government policy and law surrounding economic and employment issues influencing maternity care, maternity leave, and infant health. Central to the issues that affected the mothers participating in my research was the entitlement of paid parental leave. According to international research, recovery from childbirth can take 6 months or longer (Callister & Galtry, 2006), and paid parental leave is associated with fewer low birthweight babies, fewer infant deaths, higher rates of breastfeeding, longer parental lifespan, and improved mental health (Burtle & Bezruchka, 2016) with statistically significant associations between job-protected paid parental leave and reduced infant mortality (D. Patton, Costich, & Lidströmer, 2017). Antenatal leave is also associated with reduced stress for mothers and a reduction in premature births (Burtle & Bezruchka, 2016). Without economic policies that allow for paid antenatal and postnatal maternity leave, mothers face loss of earnings,

depreciation of skills, loss of job training and advancement, as well as further economic losses as a result of time out of the work force (Callister & Galtry, 2006).

New Zealand was one of the last in the Organisation for Economic Cooperation and Development (OECD) to create national legislation for paid parental leave (Ravenswood & Kennedy, 2012). The Maternity Leave and Employment Protection Act was introduced in 1980, changing to the Parental Leave and Employment Protection Act of 1987 and then becoming the Parental Leave and Employment Protection (Paid Parental Leave) Amendment Act of 2002. In creating the 2002 amendment, the amount of time needed for bonding between a mother and baby was debated, with a final decision that 12 weeks paid leave was adequate (Ravenswood & Kennedy, 2012). Of note, in the original 1980 legislation, unpaid leave had been extended to 26 weeks because that amount of time had been seen as required for bonding.

According to the Inland Revenue Department (2016), paid parental leave is payment for loss of income for parents who take leave from work to care for their newborn child. From 2016, parental leave became payable for up to 18 weeks. Notably, if one's baby arrives early, IRD states parents qualify for additional pre-term child payments for the period of time after their baby is born up until 37 weeks gestation. According to comparison data collected from 41 developed countries, New Zealand stands out as one of the six countries offering the shortest leave periods (along with Greece, Israel, the Netherlands, Spain, and Switzerland) (Burtle & Bezruchka, 2016). By contrast, Sweden provides 480 days paid parental leave (Callister & Galtry, 2006). Countries also vary by the amount of leave offered at full pay, amount of job protection, and other benefits offered.

The paid parental leave system is part of the intricate context of the maternal environment. For mothers without access to paid leave or for those requiring antenatal leave, their ability to

manage their health and that of their premature infant will be directly impacted. Even with access to paid leave, the disruption of prematurity and its corollaries of separations and stress may mean that 18 weeks is insufficient for mothers and infants to overcome the initial adversity and to have proper bonding time.

## II.5 Neonatal social work in New Zealand and around the world

There is a relatively limited amount of published information regarding the role of social workers in neonatal and maternal health. Outside of general social work texts covering medical social work (Beder, 2013), not a lot has been written about the particulars of social workers employed specifically within mother-infant health. Auslander (2001) asked a team of expert clinicians and academics from around the world to report back on the key achievements of social work within health care. Findings included three accomplishments relevant to neonatal social work: “establishing the place (importance, status) of the social worker as an integral part of the health care team, both as practitioner and as researcher, together with other medical and paramedical staff” (p. 208), “recognizing the importance of families in health care and introducing practices that reflect this. Ensuring that a family orientation in health care is maintained” (p. 208), and “recognition on the part of the profession, of social work in health care as a specialization within the profession” (p. 209). More recently, a history of health social work in New Zealand was published to help elucidate the origins of social work practice in health care from the 1940s up to the present day (Beddoe & Deeney, 2012). As the disease model was replaced by the biopsychosocial model for social workers around the world (Auslander, 2001), social workers in New Zealand increasingly gained a respected place within multidisciplinary health teams (Beddoe & Deeney, 2016). In 2007, District Health Boards in New Zealand employed 1139 social workers (Beddoe & Deeney, 2016). Registration is currently non-mandatory, but over time,

New Zealand social workers have secured professional identity alongside educational and professional standardisation. Recent trends show more and more social workers in managerial and supervisory positions within healthcare (Beddoe & Deeney, 2016), indicating better valuing of social work expertise within the health sector.

Also applicable to New Zealand social work, literature from outside New Zealand has addressed the role of social workers in mother-infant health. Social workers on neonatal units have an integral role to play in the bioethical realm of practice (Silverman, 1992). Because complex and problematic ethical decisions are often part of the landscape for families in NICU care, social workers can help ensure clinical effectiveness through their liaison role with parents and their commitment to patient and parent advocacy. As part of an interdisciplinary team, social workers can provide a unique ability to anticipate, understand, and give therapeutic direction in times of crisis (Silverman, 1992), thus performing both a clinical and organisational leadership roles.

The field of infant mental health has also contributed to both publication and reflection upon the importance of social workers in parent-infant health. According to infant mental health principles, “an at-risk infant is in a partnership with a mother . . . thus the primary goal for infant mental health workers is to promote the well-being of mothers and to strengthen families” (Bonkowski & Yanos, 1992, p. 144). As the writers pointed out, concern for the wellbeing of infants and their families is rooted in the history of social work evolution and practice. Neonatal social workers are doing front-line work with mothers and infants, often having contact with the mothers before birth. In New Zealand social workers are typically the first point of contact for maternal assessment and family wellbeing. The implications of an infant mental health paradigm for neonatal social work includes application of knowledge from the field of infant development, including the fundamental nature of relational

development in the context of both infant and maternal health (Bonkowski & Yanos, 1992).

This is in line with the previously-discussed children's rights and health guidelines currently in place in New Zealand.

Finally, social work theorists have put forward key principles that can be utilised for effective social work practice within neonatal settings. One suggested practice is infant observation: taking the time and allowing the uninterrupted quiet space to observe and learn from watching mothers and infants interact (Briggs, 1999). Mother-infant observation supports reflective practice and effective decision-making for social workers, moving them from rote or reactive stances to ones that are embedded in the unique understandings and needs that arise for each dyad (Briggs, 1999). Additionally, the use of narrative in social work practice has been highlighted as a potentially useful tool for modern social workers (Riessman & Quinney, 2005). Narrative is grounded in simple daily practices for neonatal social workers such as assessment interviews and case consultations; these practices can then be augmented by an understanding of "stories" as a source of meaning and personal expression, instead of just for gathering facts. The ability to better understand clients in such an in-depth way has also been found to improve social worker satisfaction and quality (Riessman & Quinney, 2005) and could represent a useful expansion of neonatal social work practice.

In addition to research and theory, social workers also operate under a Code of Ethics determined by the membership body, Aotearoa New Zealand Association of Social Workers (ANZASW), and a Code of Conduct determined by the registration body, Social Workers Registration Board (SWRB). Both codes discuss commitment to supporting the rights, capacities, dignity, participation, and self-determination of all clients, regardless of age. The code of conduct pays special attention to children and young people, stating that social

workers must seek the views and opinions of children and explain things to them in terms they can understand.

Both codes also address the role of advocacy, with the Code of Ethics stating that challenging unjust policies and practices is the duty of the social worker. Such an advocacy role has potential applicability to NICU and hospital policy that can interfere with infant and maternal wellbeing. Similarly, the Code of Conduct notes that all people are deemed competent unless declared incompetent via legal proceedings and demands that social workers must treat them as competent. This appears to include infants as well, though again the mechanisms for decoding infant competence and relating it to practical social worker responses is not determined. The Code of Ethics names the United Nations Convention on the Rights of the Child as one of its foundational documents, so this offers another way forward for social workers to operationalise their ethical duties in the realm of infants in NICU.

#### *II.5.1 Social work in the New Zealand NICUs*

In addition to the research and ethical frameworks, I was able to have email correspondence and in-person discussions with various practitioners on the ground in NICUs in Christchurch, Wellington, and Auckland, all of whom agreed to be cited in my research. In Christchurch, I was fortunate enough to be able to interview the senior social worker. In Wellington, I was in discussion with a researcher who also supervises some of the social work staff. In Auckland, I received information from a senior neonatologist. The most specific and in-depth information I have gathered regarding social work came from Christchurch so I will focus initially on that.

Toward the end of 2015, I was able to spend a couple of hours with the senior social worker at the Christchurch Women's Hospital Neonatal Unit (N. Johnson, personal communication,

28 October 2015). Johnson explained to me the general job description and day-to-day role of social workers in the NICU. In Christchurch, the social work office was based on the ward. The social workers (of whom there were three at the time of interview), responded to door knocks from parents as well as conducting assessments on almost every family. Almost every baby was referred to the social workers, typically by the night nurse. Social workers enquired about practical matters such as need for accommodation and transportation, as well as medical history, and how mothers were coping emotionally. The social work team triaged cases, with critically ill infants and complex cases taking priority. Social workers made referrals to psychiatry for more serious mental health concerns, but these needed to be signed off by a medical consultant as well.

Social work was actually officially named “Social Work and Counselling Service” and social workers were tasked with providing counselling to parents. This was confirmed by an official NICU pamphlet stating that social workers can provide support, debriefing, and a listening ear as well as help with birth trauma, anger management, family breakdown, and abuse (Canterbury District Health Board, 2009). Counselling by social workers was not done cot-side due to privacy issues and social workers wore plain clothes, not scrubs, or white coats. Assessment included questions about family violence, addiction, mental health history, family circumstances, and coping strategies. All discussion with social workers was voluntary and not all mothers wanted to talk, with mothers often reporting that they were “fine”. With high caseloads and high acuity in many cases, low risk cases were not usually prioritised. Johnson described advocacy as a central part of the social workers’ role.

The advocacy role was sometimes required to support parents as they negotiate the medical system and interactions with medical staff. Sometimes social workers would even help parents write complaints. At the time of interview, recent changes in the Christchurch

Hospital social work department meant that social workers were required to rotate off service placements every 12 months in an effort for them to gain professional diversity and further job exposure. The requisite rotation appeared to have opened the possibility that social workers without particular interest in neonatal issues would be employed within the NICU; another concern was the amount of time required to learn the role before a social worker can be familiar and up to speed.

In the Wellington NICU, my discussions were with a researcher who had supervised some of the social work staff (L. Zwimpfer, personal communications, 10 April 2015 and 27 March 2016). Zwimpfer confirmed that Wellington social work staff did not experience mandatory rotation and that many of the social workers stayed for years, though turnover could be an issue. As in Christchurch, according to Zwimpfer, social workers in Wellington were the first port of call if a family needed additional psychological support. Similarly, they also had huge caseloads and intense workloads that meant they did not always have the time to offer the depth of support required.

Finally, in addition to providing me with a general medical understanding of the low risk premature infants in New Zealand NICUs, one of Auckland's NICU doctors reflected on the role of social work on the NICU from his perspective (S. Rowley, personal communications, 24 September 2014 and 2 October 2015). According to Rowley, any baby needing to spend time away from parents (which he said was every baby in NICU) should have social work input. However, because of insufficient social work resource and the intensity of work and caseloads, often only those identified early as needing extra support (for example if there were serious concerns about child welfare) and those with very preterm or very sick infants gained access to social work services. Referrals were discussed at weekly multidisciplinary team meetings. The Auckland unit also employed a family liaison nurse who offered general

support for the rest of the families alongside support via psychiatric referral, as is the case in Wellington and Christchurch. Like in the two other units, referrals for psychiatric services were usually made only in cases of significant mental health concerns. Rowley confirmed that, like in Wellington, there was no mandatory rotation policy in place for social workers in Auckland, although he said he found merit in many aspects of such a policy, especially as it could help to avoid burnout for staff.

While it is impossible to draw a complete picture of social work services on neonatal units throughout New Zealand, the interviews and conversations I was able to have were strongly indicative of a social work role that was guided by acuity, replete with high intensity work, and focused mostly on the medically complex cases. Such a response may make sense in a context of scarce resources and parallels the overall medical response. For first time mothers with low risk premature babies, such as those in my study, however, social work services may fall short of being able to sensitively respond to and understand their experiences. This approach also does not appear to fully match the aspirational New Zealand policy goals and guidelines discussed earlier in this chapter.

## II.6 Conclusion

In this chapter I have outlined the most salient background considerations on my research. I have considered the backdrop of premature birth—both overall and specifically low risk—and the picture of mothers giving birth prematurely in New Zealand. Included was a summary of the effects of ethnicity and socioeconomic status on premature birth and their interplay with risk. Larger frameworks of governmental, hospital, and social policies were provided to help position participant mothers in the social and economic realities they were living in, as well as suggesting ways in which national and medical schemes can impact

mothers and infants throughout the prematurity journey. Lastly, unique contributions and conditions arising from NICUs and social workers employed within them were discussed.

In the next chapter I will move on from the foundational context discussed in this chapter in order to examine the literature surrounding the relevant issues, themes and topics pertaining to research participants. This will include the terminology of prematurity, the data on prematurity and low risk prematurity, meaning-making, and motherhood, first time motherhood, mother-infant bonding, and motherhood within medical settings.

## Chapter III: Literature Review

### III.1 Introduction

This chapter reviews the literature pertaining to the process of mothers making sense of premature birth. As participants in my research were first time, low risk mothers with infants also categorised as low risk, the chapter considers a relatively broad array of issues germane to their experience.

Rather than providing an exhaustive account from each of these fields, my literature review is limited to a focus on the specific categories that are pertinent to my research, confining it largely to the empirical, non-theoretical texts. A separate review of theory is independently included in the following chapter. Inclusion criteria for this review began to be defined in the proposal stages of the research project and criteria were updated and refined as necessary, seeking out literature germane to the research questions. Background and foundational issues underpinning the research are included alongside topics that were reviewed after completion of the interview and analysis process, following the emergence of findings. I used PubMed, Google Scholar, the university's library and databases, such as PsycInfo, as search engines. I discussed database and search engine choices with University of Canterbury library advisors to make sure they were considered comprehensive. I also used a variety of key words and search terms, including motherhood, first time motherhood, meaning making, maternal identity, prematurity, low risk prematurity, late preterm birth, NICU and motherhood, maternal stress, mother-infant relationship, neonatal care, social work and motherhood, social work and prematurity, medical social work, preterm birth, maternal separation, medical culture, neonatal culture, mother-infant touch, nursing identity, nursing culture, NICU nursing, understanding prematurity diagnosis, infant neuroscience and brain development,

epigenetics and infant development, infant identity development, physiology of motherhood, and mother-infant bonding. Searches produced publications and articles that had helpful bibliographies and reference lists; this led to further research and I followed many of those leads.

Simultaneously, I was also in contact with several researchers in the field to seek consultation with regard to my specific questions and to request guidance regarding further publications to examine. This included researchers in the field of neonatal intensive care unit (NICU) nursing, neonatal medical care, maternal experience in NICU, and mother-infant bonding. Finally, one of my supervisors, Dr Patricia Champion, is an expert in prematurity and parental rapport, and she also recommended relevant researchers, projects, and publications. At the conclusion of this series of consultations and inquiries, I sought to determine what was most pertinent to include; this chapter is an account of those relevant items.

My research has a specific focus: first time mothers and low risk prematurity. This is a unique subset of mothers and of premature birth and, as far as I am aware, there is no other published research that focuses expressly on this group of mothers. Nonetheless, aspects of participants' experiences can be located across a broad swathe of relevant subjects and themes.

To begin, I will define and clarify the terminology regarding prematurity. Literature is then organised and reviewed according to arising themes and subthemes. Main themes include prematurity and low risk prematurity; meaning making and the process of becoming a mother; mother-infant bonding and the process of forming a relationship; and mothering in the context of the NICU, including the contribution of social work. The mother-infant relationship issues have been placed first in the order, rather than those related to the individual maternal experience; this has been done for ease of understanding the literature.

Some of the maternal identity and meaning-making data derives foundational principles from the fields of affective neuroscience and dyadic theories of development. With broader, relational findings reported on first, the more inner realm of the individual mother's experience becomes easier to understand. Put together, the three sections represent the layers of maternal experience as reflected in the available literature. I also point out gaps in the literature where they appear to exist.

### III.2 Terminology

At present, terminology surrounding prematurity, including its designations and classifications, is both inconsistent and confusing. For many decades before the invention of the incubator, premature babies were grouped within a larger medical category of early born and vulnerable infants called, simply, weaklings (Baker, 2000). While we now have a sophisticated understanding of the specifics of prematurity, terminology remains inconsistent. At present, nomenclature includes "premature" which typically means born before 37 weeks; "very premature", which means born before 32 weeks; "low birth weight", which is under 2500g; "very low birth weight", which is under 1500g; and "extremely low birth weight", which is under 1,000g. (Browne, 2003). "Late preterm" birth has replaced the older terminology of "near term" and is generally used for infants born from 34 weeks gestation and later (Engle, Tomashek, & Wallman, 2007), though some categorise it more narrowly and others more widely. Only in recent years has the significance of the late preterm and low risk populations come into focus (Browne, 2003).

Babies today who are born at 32 weeks gestational age or later are described as relatively low risk, as are babies who are not very low birth weight (Bakewell-Sachs, 2007). In general, gestational age is most closely correlated with risk; the earlier a baby is born, the more vulnerable the baby is likely to be due to the additive risks from neurobiological immaturity

and physiological vulnerability (Wolke, 2016). Birth weight is also a fairly good—though imperfect—proxy for gestational age.

In research where mothers are the focus of study, the research typically includes mothers of infants from across several categories of prematurity, with various gestational ages and birth weights. Sometimes findings relate specifically to mothers with babies from discrete classifications, but generally they do not. Understanding this is important when reading the research and summaries offered here. The larger backdrop of prematurity will be discussed as a way of highlighting the issues facing mothers and their prematurely born infants, understanding that within the research are variables and factors pertaining to my participants.

### **III.3 Mothers in connection to their infants: Developing a relationship**

Components of the mother-infant relationship development are spread across fields of study, including neonatology, affective neuroscience, psychology, maternal health, neuroendocrinology, and epigenetics. As a result, much of the literature exists in silos. I have endeavoured to draw this together in this review; relevant findings are grouped around categories and themes that arose from my review of the characteristic vulnerabilities and attributes of the first time mother and her low risk premature infant.

#### *III.3.1 Prematurity*

Most of our understanding of prematurity is derived from the study of groups of premature infants and their individual levels of functioning; much of the literature is not about relationships in premature infancy. Even so, mothers must make meaning of prematurity in order to bond. It is therefore useful to take account of what is known about premature babies.

### *III.3.1.1 Prematurity: Infant experience*

Being born prematurely is considered both a medical concern and a global obstetrical, medical, and educational challenge (C. George, Solomon, Cassidy, & Shaver, 2008; Reisz, Jacobvitz, & George, 2015; Solomon & George, 1996). The vulnerability of preterm infants exists across cognitive, socio-emotional, educational, and relational domains (Constable et al., 2008; Peterson et al., 2003). Even without severe medical complications or extreme early birth, prematurity is associated with this diversity of risk factors in the literature (Browne, 2003). These risk factors include neurological immaturity that impacts the development of vagal tone, sleep-wake cycling, emotional regulation and stress response, attention regulation, and motor and feeding functions (Feldman, 2006; Feldman, Rosenthal, & Eidelman, 2014; Feldman, Weller, Leckman, Kuint, & Eidelman, 1999; Siegel, 1999), create potential deficits across brain development, cognition, motor function, and emotional behaviour (Butler & Als, 2008; Minde, 2000). This immaturity also decreases social capacities (Feldman et al., 1999; Minde, 2000; Minde, Whitelaw, Brown, & Fitzhardinge, 1983); decreased social capacity correlates with decreased social responsiveness, time in alert states, and clarity of signalling, all potentially leading to the perception of premature infants as less rewarding social partners (D. H. Davis & Thoman, 1988; L. Davis, Edwards, Mohay, & Wollin, 2003; Feldman et al., 1999; Minde et al., 1983). Physical symptomatology in prematurely born children include higher rates of cerebral palsy, sensory deficits, feeding difficulties, and respiratory illnesses compared with children born at term (Beck et al., 2010). This also includes a high relative risk for death during infancy, even if prematurity is mild or moderate (Kramer et al., 2000).

Many prematurely born infants also show long-term effects. Compared with full term babies, children born prematurely are more likely to have developmental delays, with a gap that often

widens as they age (Butler & Als, 2008; Minde, 2000); this includes increased risks of lifelong disability and extreme impairment (Moster, Lie, & Markestad, 2008). One third of very preterm children show disorganized attachment (measured at approximately one year of age), with underlying neurodevelopmental problems associated with their growth (Wolke, Eryigit-Madzwamuse, & Gutbrod, 2013) and at 26 years old, adults who were once very preterm infants report higher levels of introversion, autistic features, and social difficulties (Eryigit-Madzwamuse, Strauss, Baumann, Bartmann, & Wolke, 2015). Even relatively healthy, low risk premature infants evidence higher rates of impaired cognitive and neurological functioning as children (Eckerman, Oehler, Hannan, & Molitor, 1995; Malatesta et al., 1989). Study authors have suggested that many of these alterations are due to a combination of the effects of early birth on brain development, the stressors experienced in the NICU environment, and the changes to the infant-parent relationship as a result of the prematurity and illness.

### *III.3.1.2 Prematurity: Maternal experience*

Mothers who give birth prematurely have greater rates of anxiety, depression, unresolved grief, and trauma (Browne, 2003; Cox, Hopkins, & Hans, 2000; Dall’Oglio et al., 2010; Feldman et al., 2009; Goldberg, Lojkasek, Gartner, & Corter, 1989; Poehlmann & Fiese, 2001; P. E. Shah, Clements, & Poehlmann, 2011; Wille, 1991) as compared with women who birth at full term. For example, in one study of 100 mothers who gave birth to premature babies, 75% of participants were assessed as having high risk of anxiety disorders and one-third as having high risk of depression, both of which findings correlated with experiences of trauma surrounding the birth (Eutrope et al., 2014). This suggests that risk for the mother is at least partially located in how she experiences the birth, not the age or weight of the baby. Since mothers who have premature births universally evaluate this as a stressful and

emotionally demanding experience (Muller-Nix et al., 2004), vulnerability for mothers is high.

Further to the stress of premature birth, mothers must negotiate unique processes in order to make sense of what is unfolding. Two unique processes—resolution of the diagnosis and navigating maternal grief—will be discussed in the next section.

#### [III.3.1.2.1 Prematurity: Mothers and resolution of the diagnosis](#)

In order for mothers to make sense of their experience they must wrestle with what prematurity means. In the literature, this skill is referred to as resolution of the diagnosis. Resolution of the diagnosis is defined as a process of sense-making in which a parent integrates understanding about their baby's condition and what it means for the child, themselves, and for their relationship (Pianta et al, 1996; Milshtein, Yirmiya, Oppenheim, Koren-Karie, & Levi, 2010; Oppenheim, Koren-Karie, Dolev, & Yirmiya, 2009). How a mother perceives her baby and her own emotional experience influences how she relates to her baby and the stability of their relationship (C. George & Solomon, 1999; Lyons-Ruth et al., 1998; Solomon & George, 1996). If a mother can make sense of her baby's diagnosis in her own mind, she can more easily and authentically relate to her child in the present without being inhibited by old worries and without getting stuck in the past (Pianta et al, 1996; Oppenheim et al., 2009).

The importance of resolving the diagnosis of prematurity is echoed in the finding that how the mother constructs an internal mental model of her child is most predictive of later attachment security between preterm infants and their mothers (Cox et al., 2000) as well as the suggestion that maternal factors are likely to be even more influential in creating infant

attachment than are infant risk factors (Goldberg et al., 1989). Meaning making of the diagnosis of prematurity appears to be a critical factor in a mother's wellbeing.

### *III.3.1.2.2 Prematurity: Mothers and grief*

Mothers typically also face feelings of grief and loss when dealing with premature birth, with some mothers experiencing a sense of unresolved grief and others resolving it more easily (P. E. Shah et al., 2011). How a mother manages her grief has implications for the quality of her relationship with her baby (Marvin & Pianta, 1996), again reflecting the impact of the maternal process on the bond.

New perspectives on parental grief covered in a 2004 review of the literature by Davies (2004) suggested that parents resolve grief through continuation of their bond with a child after death, as opposed to older models that emphasised breaking the bond with the dead child and putting one's focus on moving on. Such a theory of grief resolution appears to have relevance for parents dealing with other kinds of losses associated with premature birth. Theories regarding grief will be more fully discussed in the next chapter.

In summary, the literature suggests that mothers and infants both face increased individual risk factors associated with preterm birth. The vulnerabilities they face are varied and specific to their situations and gestational age, and are profound inputs into the meaning-making endeavours of these mothers.

### *III.3.2 Low risk prematurity*

There is a subset of the prematurity literature that focuses on low risk categorisations. As previously discussed, low risk prematurity is not a specific medical designation but includes

late preterm birth as well as slightly earlier births that are absent of significant medical complications.

### *III.3.2.1 Low risk prematurity: Background*

Since 1990, rates of prematurity have steadily increased and babies have been medically supported to survive at earlier and earlier gestational ages (Dall’Oglio et al., 2010). As babies have survived earlier and earlier premature birth, the focus of medical intervention and concern has shifted toward the most fragile infants. Low risk categories of premature birth represent roughly three-quarters of the entire premature population (and approximately 9% of total births) (Cheong & Doyle, 2012). The extant data on premature infants born at 30 weeks gestation or later indicates these babies present with a less intense but similar risk profile as the infants designated as high risk (Feldman & Eidelman, 2007).

### *III.3.2.2 Low-risk prematurity: The infant experience*

Evidence spanning the fields of neonatology, paediatrics, neuroscience, psychology, and medical epidemiology creates a picture of both short- and long-term risks associated with low risk categories of preterm birth. Short-term risks include higher rates of mortality, morbidity, neurodevelopmental and socioemotional deficits, problems with thermoregulation, hypoglycaemia, respiratory distress, hyperbilirubinemia, sepsis, apnoea, feeding difficulties, and jaundice (Engle et al., 2007; Hack et al., 2005; Morse, Zheng, Tang, & Roth, 2009; Petrini, 2009; Rickards, Kelly, Doyle, & Callanan, 2001; Shapiro-Mendoza et al., 2008). Many times these difficulties do not manifest until 2 to 3 days after birth, often occurring after discharge from hospital (Rowley, 2014); this is a potential reason for another short-term risk factor, the higher than normal rates of hospital re-admission (Engle et al., 2007).

Long-term risk factors are also revealed when comparing low risk prematurely born infants with full term babies and assessing them as children 2 to 4 years later. These risk factors include significantly lower scores on cognitive and neuropsychological abilities (Bakewell-Sachs, 2007; Dall’Oglio et al., 2010), increased problems with issues of perception, motor integration, memory and attention (P. E. Shah, Robbins, Coelho, & Poehlmann, 2013), significantly higher risk of delayed social development (S. Johnson et al., 2015), and higher rates of autism (Guy et al., 2015). Some research has further suggested that challenges faced in infancy likely persist into adolescence and adulthood (Caravale, Tozzi, Albino, & Vicari, 2005).

In 2013, a study was undertaken comparing very premature infants, born at less than 30 weeks, with moderate preterm infants (born between 30 and 33 weeks), and also late-term premature infants (born between 34 and 37 weeks) (P. E. Shah et al., 2013). The researchers examined cognitive skills and child behaviour problems at 36 months, as well as maternal parenting interactions, neonatal health risk, family risk factors and maternal mental health. There were no differences in cognitive skills, however, it was the *late* term premature infants who manifested the most externalising, aggressive, and oppositional behaviour, leading researchers to conclude, “Our results suggest that late preterm infants, previously thought to be a low-risk population, may be at risk for behavioural difficulties” (P. E. Shah et al., 2013, p. 11). Study authors noted that this is a finding contrary to expectations and that further research is needed to explicate it.

### *III.3.2.3 The unique profile of low-risk prematurity*

In a medical context, late preterm babies are typically viewed by doctors as similar to full-term newborns; late preterm babies are sometimes referred to by neonatologists as great imitators since they “masquerade” as full term infants (Wang, 2004, p. 374). Late preterm

babies are often treated by caregivers and health professionals as though they were developmentally mature (Bakewell-Sachs, 2007; Engle et al., 2007). Late preterm babies are seen as more similar to full term babies than their early preterm counterparts and are typically discharged between 4 and 12 days after birth (Ellis & Boyce, 2008; Pulver, Denney, Silver, & Young, 2010). This unintentional confusion about late preterm infants is one potential explanation for the increased risk findings around the lowest risk prematurely born babies.

Creation of a unique risk profile partially through mechanisms of invisibility and similarity to other groups, sets low risk premature births apart while simultaneously leaving gaps in the literature that occur precisely because the vulnerabilities are concealed. Investigation into the experience and trajectories of low risk premature infants and their mothers has not been conducted with the depth that has been afforded to higher risk infants. As a result, the research regarding babies designated as low risk is still emerging. I was unable to find any published studies that focussed solely on low risk premature infants and first time mothers.

#### *III.3.2.4 Low risk prematurity: The maternal experience*

Like their infants, mothers of low risk prematurely born infants also have a distinctive experience. When comparing the emotional responses of mothers of late preterm infants with mothers of full term babies, mothers of the preterm babies have statistically higher rates of emotional distress, higher levels of post traumatic symptoms, and more worry (Barratt, 1996; Brandon et al., 2011), as well as more depression, anxiety, and a higher likelihood of viewing their infant's mood as negative (Voegtle, Stifter, & Family Life Project, 2010).

Additionally, mothers of late preterm infants report greater difficulties with breastfeeding when they are experiencing other distress (Zanardo et al., 2011) and are they show lower levels of maternal responsiveness and warmth with their infants when the babies are 20 months old (Brandon et al., 2011). Researchers interviewing mothers have reported that

whereas full term mothers describe difficulties with early motherhood as transient, mothers of premature infants encounter difficulties in a more persistent way, with lingering effects posing potential problems for the mother-baby relationship (Brandon et al., 2011).

#### *III.3.2.4.1 The unique profile of mothers of low-risk premature infants*

According to Engle et al. (2007), health professionals often assume that mothers of later born, healthier preterm infants do not experience significant distress because their infants are at low risk of morbidity and mortality (Engle et al., 2007). In the NICU, stays are typically short for low risk premature infants and their mothers do not become NICU “veterans” as mothers of more unwell babies often do (Sargent, 2009). Furthermore, the longer a mother is a part of the NICU, the less she reports the need for information from staff since her understanding and comfort grows with time (Sargent, 2009). As a result, the compounding factors of short stays, lack of familiarity with the NICU, and the assessment by professionals of not requiring support, leaves mothers of low risk babies with increased vulnerability. Again, as with the infants, the vulnerability appears to arise largely due to oversight.

#### *III.3.2.5 Low risk prematurity in conclusion*

Low risk prematurity, albeit a subset of all premature births, appears to be a discrete category with particular strengths and unique vulnerabilities that do not necessarily parallel those of higher risk births and thus requires honed attention to the implications for mothers, their infants, and their burgeoning relationship with one another.

### *III.3.3 The impact of prematurity on the developing mother-infant relationship*

#### *III.3.3.1 Relational risk factors*

When infants are born prematurely, the relatively immature capacities of the infant combined with the stressors of premature birth for the mother can negatively impact the mother-baby relationship. In general, research findings have suggested that premature mother-baby pairs interact in less attuned, less affectionate ways as compared with full-term dyads (Poehlmann & Fiese, 2001). Many families who have experienced premature birth report difficulties between the mother and child throughout the childhood years (Dall’Oglio et al., 2010) and children born prematurely are at higher risk for abuse and neglect from within their families (Taylor, 2012).

Underlying neurodevelopmental problems associated with premature birth appear to be linked to a variety of social relationship problems in infancy and childhood. Prematurely born infants evidence higher rates of disorganised attachment, with one third of very premature infants meeting that criteria (Wolke et al., 2013). Mothers of premature infants typically display less looking, vocalising, touch, and contact, elements usually required for healthy attachment (Feldman et al., 1999). However, a 2015 meta-analysis of 34 studies examining only the variable of maternal sensitivity found that mothers of preterm children do not display lower levels of sensitivity than mothers of full-term children (Bilgin & Wolke, 2015). This finding correlates with data showing that social-emotional problems often occur even when parenting is evaluated as sensitive (Bilgin & Wolke, 2015; Wolke et al., 2013), emphasising the importance of distinguishing between risk factors associated with the mother as opposed to risk factors present due to a child’s immature neurological development.

When given support that alleviates their stress, mothers demonstrate increased levels of sensitivity with their prematurely-born children at 12 months of age (Ravn et al., 2011). Of particular relevance to my participant mothers was the finding that first time mothers were most likely to benefit from such interventions (Ravn et al., 2011).

It therefore appears that the environment created within the relationship influences both the mother and the baby and, in reverse, the mother and the baby individually influence the kind and quality of the relationship. Simultaneously, all three—mother, premature infant and dyad—are impacted by the larger context in which they find themselves.

#### *III.3.3.2 The relational backdrop*

How a mother and her premature baby develop is reliant on the transactions between the unique contexts and the biobehavioural regulatory systems in the mother and in the environment after birth (Halfon, Russ, & Regalado, 2005). As Halfon et al. (2007, p. 7) pointed out, health is not a static concept but is an “adaptive process”. This suggests that each mother will come to understand her experience and define her relationship with her baby in response to multiple layers of influence acting upon them both. These main influences will derive from how they bond, how they respond to stress, and how their biology is affected by their environment, thus leveraging epigenetic forces. It is therefore reasonable to assume that greater understanding of these underpinning scientific concepts will provide a foundation for what is happening on a micro level between each mother and her infant, including participant mothers in my research.

#### *III.3.3.3 The science of mother-infant bonding*

Researchers in the field of parent-infant relationships are interested in potential mechanisms in bonding that may be biologically-determined or evolutionarily-programmed. Investigation

into hormonal, neuroendocrinological, and neurological response systems have suggested a mammalian recognition system in which both mother and infant can selectively respond to, influence, and prefer each other immediately from birth (Curley & Champagne, 2015; R. Feldman, 2011; Feldman et al., 1999; Feldman, Weller, Zagoory-Sharon, & Levine, 2007; Leuner & Sabihi, 2016), even on the basis of non-visual cues such as smell, cry, or taste (Sarro, Sullivan, & Barr, 2014). Breastfeeding, skin-to-skin contact, mutual gazing, and affectionate touch increase oxytocin in both mother and infant, as well as showing associations with improved maternal wellbeing, reduction in maternal anxiety, and improved maternal energy and health (Feldman & Eidelman, 2007; Feldman, Gordon, Schneiderman, Weisman, & Zagoory-Sharon, 2010; I. Gordon, Zagoory-Sharon, Leckman, & Feldman, 2010; Strathearn, Fonagy, Amico, & Montague, 2009; Uvnäs-Moberg, 1996, 1998; Uvnäs-Moberg, 1997; Winberg, 2005). These maternal behaviours form a system of “hidden regulators” (Hofer, 1994b, p. 193) stemming from the mother which guide infant development. Hidden regulators are understood as effects that emerge from being in physical contact with the mother; effects that then regulate the physiological processes in the infant, including body temperature, heart rate, growth hormone, oxygen consumption, sleep cycles, and feeding (Hofer, 1994b). In their absence, infants tend to show dysregulated responses, including increased heart rate, increased cortisol, decreased body weight, disturbances of sleep, metabolism, cardiovascular systems and endocrinology, as well as decreased immune function (Hofer, 1994a, 1994b). It turns out that simple contact between mothers and their babies underpins a vital part of healthy infant development.

It is not just infants who are being shaped by their mothers’ biological and hormonal responses. Examination of the neurological changes in mothers have revealed that mothers are affected as they adapt to maternal care, including experiencing neurogenesis (the generation of new brain cells) (Leuner & Sabihi, 2016). The ability of the mother’s brain to

change in response to mothering is termed “maternal neuroplasticity” (Leuner & Sabihi, 2016, p. 1). According to Curley and Champagne (2015), this parallels the neurological changes and developments that are influenced directly by the mother’s care for her infant.

#### III.3.3.3.1 The science of touch

Touch is one aspect of mother-infant bonding that has been heavily researched and has broad applicability to premature birth. Touch in its various forms, including skin-to-skin contact, is well documented in the literature as a potent factor in mother and infant experience (Ferber, Feldman, & Makhoul, 2008; Mori, Khanna, Pledge, & Nakayama, 2010). To date, skin-to-skin contact between mothers and infants has been researched in over 34 studies, with results collated in a Cochrane Review in 2012 (E. R. Moore, Anderson, Bergman, & Dowswell, 2012). Results across studies consistently showed that babies who received skin-to-skin contact had more maternal interaction and less crying than babies receiving usual hospital care; mothers were more likely to breastfeed in the first 4 months, and tended to breastfeed longer; and babies were more likely to have a good early relationship with their mothers, although this was noted as difficult to assess.

In terms of skin-to-skin contact specific to prematurity, studies have reported extensive benefits for infants, mothers, and their bond (Bystrova et al., 2003; Feldman & Eidelman, 2003; Feldman, Eidelman, Sirota, & Weller, 2002; Feldman et al., 2014; Feldman, Weller, Sirota, & Eidelman, 2002, 2003; Flacking, Thomson, Ekenberg, Lowegren, & Wallin, 2013; Tallandini & Scalembra, 2006). Mothers who experience uninterrupted connection with their infants and skin-to-skin contact report lower levels of stress and greater feelings of competence (Flacking et al., 2013), show more positive touch (Feldman, Eidelman, et al., 2002), experience lower levels of maternal anxiety (Feldman et al., 2014), and have infants who are more neurodevelopmentally mature (Feldman & Eidelman, 2003). Gains appear to

be maintained with age. At 10 years of age, preterm-born children who received early skin-to-skin contact have better cognitive results, a more robust stress response, and improved sleep (Feldman et al., 2014). Mother-preterm infant skin-to-skin contact has been shown to increase the amount of loving touch of the baby by both mothers and fathers, along with closer proximity of spouses and increased mutual looking and triadic play between all three, thus having a positive effect on mother, baby, father, and all dyadic relationships, as well as that of the family (Feldman et al., 2003). (Note: to date, research on parental relationships with preterm infants has been predominantly focussed on heteronormative families. Results such as those shown by Feldman et al. (2003) are likely to also be relevant to non-heteronormative couples, but more research is needed to establish this.) Findings in the field of mother-infant touch suggest short and long term benefits for mothers, babies and their relationship, with clear relevance to the participant mothers in my research who were looking for ways to deal with their stress and develop bonds with their infants.

### [\*\*III.3.3.3.2 How they respond to stress: The science of stress and vulnerability\*\*](#)

Research across the domains of neuroscience and psychology has reported that stressors which interfere with healthy relationship development in early life are associated with long term difficulties, including insecure attachment, anxiety, depression, addiction, mental impairment, and physical illness (Chapman et al., 2004; M. Dong et al., 2004; Dube et al., 2001; Edwards, Holden, Felitti, & Anda, 2003; A. N. Schore, 2000, 2001a, 2001b, 2010; J. R. Schore & Schore, 2008).

The ability of the person to respond to stress involves the neurological, neuroendocrine, and immune systems and is a product of an interactive, complex model of stress called allostatic load (McEwen, 1998). When the systems are challenged in a way that a person can surmount and recover from, a body can become even stronger as a result; but if the systems are

overwhelmed (through overuse, inability to shut off, or inadequate strength), the response is deleterious (DiCorcia & Tronick, 2011; McEwen, 1998, 2000, 2007). In this “quotidian resilience” model of human development (DiCorcia & Tronick, 2011, p. 1594), it is assumed that within typical, normal interactions between a mother and baby, stressful moments will naturally be produced. These events will activate the infant’s systems of stress response and will often require a caregiver’s assistance to effectively resolve it. When the stressors can be resolved, the infant’s capacity to cope with later, even greater, stress will be developed; if the stress is unresolved, the regulatory system remains increasingly vulnerable to future stressful triggers (DiCorcia & Tronick, 2011).

#### *III.3.3.2.1 The context of stress*

The allostatic load model is a context-sensitive model. A person’s potential for stress recovery and resilience is now understood to be a combination of how genetically-driven components interface with particular environments (Rutter, 2003). While maternal warmth is generally cited as buffering children against stress overwhelm, when children are living in high crime neighbourhoods, for example, maternal warmth is no longer sufficient to provide the resilient buffer (Jaffee, Caspi, Moffitt, Polo-Tomas, & Taylor, 2007). Similarly, children with low socioeconomic status present with significantly higher cortisol levels than children with high status; at the same time, cortisol levels in children from all socioeconomic backgrounds is significantly correlated with their mother’s depressive symptoms (Lupien, King, Meaney, & McEwen, 2000). In other words, mothers and infants are embedded in a complex and unique context of internal, external, environmental, and relational factors that determine the impact of stress at any given time.

Genetic research adds the knowledge that resilience and vulnerability are created, in part, by genetically-driven levels of individual environmental permeability (Ellis & Boyce, 2008). In

other words, the more biologically sensitive a person is to their context, the more they will be negatively impacted by stress in the environment; the same person will be more positively impacted by support.

In summary, the impact, meaning and trajectory of stressful events is directed by context. Therefore to understand how stressful events impact a mother, it becomes necessary to bear in mind the full context of individual, relational, and environmental factors in her life.

#### *III.3.3.2.2 How the environment impacts biology: The science of epigenetics*

The science of epigenetics proposes that life experiences can alter the form, structure, and expression of DNA, including the chemicals associated with it, the proteins connected to it, and how traits manifest in the organism (Buchen, 2010). Epigenetics is another framework for understanding the intricacies of how forces of nature and nurture interact, of how context shapes experience, and of how the unique dyadic and environmental influences may interact to impact mothers' meaning-making.

One major finding from within epigenetic study demonstrates that how babies are mothered directly guides how their brains develop stress-response pathways, both in infancy and in their adult lives (Champagne & Meaney, 2001; Meaney, 2001; Weaver et al., 2004). The better a mother cares for her infant, the fewer stress hormones are produced in the infant and the more the baby is able to be resilient in the face of future stress (Liu et al., 1997; Meaney, 2001). This finding holds true even when the mother is not the biological mother, suggesting that the stress response is largely influenced by maternal behaviour, not simple genetics (Champagne & Meaney, 2001; Francis, Diorio, Plotsky, & Meaney, 2002; Meaney, 2001; Warwick, 2005).

Some of the relevant research has been conducted with mammals other than humans. In such research, when circumstances interfere with the mother's ability to care for her infants—such as when mother rats are temporarily separated from their babies (called disturbing the nest)—mothers' bonding behaviours are impacted (Weaver et al., 2004). If the separation is short, mothers will step up their efforts to care for their infants as soon as they are reunited; however, if separation is too long, mothers disengage, showing signs of depression and anxiety and an inability to recover their maternal role (Buchen, 2010; Gunnar & Cheatham, 2003; Millstein & Holmes, 2007; Weaver et al., 2004). While epigenetic researchers have suggested that rodent findings have clear applicability to humans, it is likely important to be cautious in interpretation.

Efforts to match such research to human studies are limited but the data that exists suggests that human brains match what is seen in rats. (Meaney et al., 2009). I have been unable to locate literature that proposes what the “nest” might be for a human mother, including for mothers who are mothering within a hospital setting.

#### *III.3.3.2.3 The context of stress and earthquakes*

Because my research has been undertaken in New Zealand and the majority of participants lived and birthed in Christchurch, the context of the 2010 and 2011 earthquakes arise as a relevant and important ecological factor in maternal experience. Some participant mothers had given birth prior to any of the earthquakes, others after them; all of them lived with the impact of aftershocks and the requisite psychological and emotional adjustments that occurred, as well as having to negotiate the additional stressor of natural disaster while parenting their first child. The earthquakes injured nearly 7000 people, damaged more than 100,000 homes, caused massive upheaval in road, wastewater, electricity, and power delivery systems, and displaced many residents (Hargest-Slade & Gribble, 2015).

Eighteen months after the first earthquake, significant adverse impact on mental health was still being registered, with a substantial rise in major depressive disorder (Spittlehouse, Joyce, Vierck, Schluter, & Pearson, 2014). For mothers, the need to be close to one's child was heightened post-earthquake (Cowan, Bennett, Clarke, & Pease, 2013), a response to the frightening and uncertain times. Interviews with women in Christchurch after the quakes suggested that a woman's first role was to keep her family together and to support family members who required it; furthermore, much of the work women did on this front was unseen and invisible, yet very active (L. Gordon, 2013). This parallels research done in other countries that finds women are particularly vulnerable in natural disasters as they take on the mainstay of the caregiving burden and experience great anxiety about the wellbeing and safety of their children (Banford et al., 2016). Similarly, mothers who lived through the great earthquake in Japan that occurred just after those in Christchurch, experienced high levels of psychiatric distress when measured at 10 months, 16 months, 24 months, 36 months, and 48 months after the event (Sato, Oikawa, Hiwatashi, Sato, & Oyamada, 2016). While I could not find any New Zealand data of that duration, the findings from Japan suggest that the negative impact is ongoing and not abating even 4 years post-quake; this is a time period that covers all participant mothers.

#### *[III.3.4 Mothers in connection with their infants: Summary](#)*

A diverse and complex interplay of ecological factors and stress-related events underpins the bonding process between mothers and their premature infants. Each of the factors exerts unique pressures and has consequences particular to the specific dyad, varying in each moment, and showing change and growth over time. As this is all unfolding, the mother herself is also engaging in a change and growth process of personal meaning-making in developing her identity as a mother.

### **III.4 Mothers in relation to themselves**

How mothers make meaning of themselves as mothers is a central research question.

Participating mothers are all first-time mothers. However, as there is little existing research on first-time motherhood in cases of prematurity, related research examining first-time motherhood in general and all stages of motherhood in the context of prematurity was examined.

#### *III.4.1 First time mothers*

First-time mothers are often less prepared for parenthood than experienced mothers (L. George, 2005). They report less confidence in their role as mothers (Olafsen et al., 2007), often register higher levels of motivation for professional guidance (Bakermans-Kranenburg, Van IJzendoorn, & Juffer, 2003) and demonstrate greater uptake of interventions seeking to improve maternal sensitivity (Ravn et al., 2011). Longitudinal research has suggested that the degree of wellbeing and happiness surrounding the first experience with motherhood is predictive of whether a woman will go on to have more children (Margolis & Myrskylä, 2015).

The task of creating an initial maternal identity is a theme that arises across research with first-time mothers. Mothers identify a transition in their thinking and a process of both overwhelming change and constant learning that allows for profound reconstruction of who they are (Rogan, Shimed, Barclay, Everitt, & Wylli, 1997); they express initial ambivalence about their new role and a sense that their new identities are more relational than before having a child (J. Smith, 1999); and their narratives are full of discussion about the

challenges of new relationships, both with themselves and with their babies (T. Miller, 2007) with mothers assigning great meaning to the process of transformation. When inquiring into the psychological impact of the transformation, researchers have suggested that women experience a profound change in their self-concept, and that this change is within three key areas: control, support, and forming a family; mothers position this experience of change within a shift from an individual identity to one of being part of a family (Darvill, Skirton, & Farrand, 2010; Jackson, Ternestedt, & Schollin, 2003; Shin & White-Traut, 2007; Shin, 2004).

#### *III.4.2 Becoming a mother of a premature infant & maternal identity within the NICU*

Women who give birth prematurely face increased challenges when moving into the unknown territory of motherhood and maternal identity (Lupton & Fenwick, 2001; Nyström & Axelsson, 2002). There is a range of research which investigates the process of early motherhood as it takes place in the context of premature birth and within the NICU environment. Common themes emerge across multiple research studies, however, none of the studies focus solely on first-time mothers, nor do they focus on low-risk premature infants. Consistent themes include: diminished or distanced role of the mother (Holditch-Davis & Shandor Miles, 2000; Jed, 1999; Malakouti, Jebraeili, Valizadeh, & Babapour, 2013; Shin & White-Traut, 2007; Ward, 2001), difficulty with mother-infant separation (Brandon et al., 2011; Guillaume et al., 2013; Malakouti et al., 2013; Whittingham, Boyd, Sanders, & Colditz, 2014; Wigert, Hellström, & Berg, 2008; Wigert, Johansson, Berg, & Hellström, 2006), need for contact and to watch over baby (Erlandsson & Fagerberg, 2005; Hurst, 2001a, 2001b; Lupton & Fenwick, 2001; Spear, Leef, Epps, & Locke, 2002; Whitlow, 2003), mixed and painful feelings (Brandon et al., 2011; J. H. Fenwick, Barclay, & Schmied, 2002; Malakouti et al., 2013; Rossman et al., 2011; Rossman, Kratovil, Greene, Engstrom, &

Meier, 2013; Shin & White-Traut, 2007; Shin, 2004; Whittingham et al., 2014), and need for positive relationship with staff and fear of losing access to baby (Brandon et al., 2011; Fenwick, Barclay, & Schmied, 2001; Holditch-Davis & Shandor Miles, 2000; Hurst, 2001a, 2001b; Lupton & Fenwick, 2001; Wigert et al., 2008; Wigert et al., 2006). As all these studies suggest, difficulties, fears, worries, and additional pressures are characteristic features of the maternal experience of premature birth.

#### *III.4.2.1 Maternal identity and liminality*

Mothers attempting to establish a maternal identity within a NICU face a tension between medical priorities and maternal ones, with a medical culture of technology sometimes in opposition to the maternal culture of bonding (Macey, Harmon, & Easterbrooks, 1987). Qualitative research with mothers of premature babies in NICUs has uncovered the notion of liminality in maternal experience (Black, Holditch-Davis, & Miles, 2009). Liminality has arisen from the field of anthropology and suggests a threshold state where one is between phases; it was originally used to discuss rituals serving as rites of passage in which a person had begun the ritual but not yet completed it (Little, Jordens, Paul, Montgomery, & Philipson, 1998). Liminality for mothers in NICU implies occupying a psychic space in which a former identity as non-mother has been left behind but the identity of mother is not yet fully embodied. Other research findings have mirrored this sense of mothers feeling stuck between being a mother and not being one (Shin & White-Traut, 2007).

Researchers reporting on the experience of liminality in mothers have found noticeable differences between experienced and first-time mothers. Experienced mothers felt more competent in their mothering and had an established sense of maternal identity to draw upon, whereas first-time mothers expressed a sense that they were in the process of becoming a

mother. Researchers concluded that the preterm birth creates preterm motherhood in which first time mothers have a maternal identity that is yet to be claimed (Black et al., 2009).

#### *III.4.2.2 Maternal identity and claiming of the baby*

Related to the theme of liminality and unclaimed identity is the theme of the unclaimed baby. This is summarised in the phrase “from their baby to my baby” (Erlandsson & Fagerberg, 2005; Wigert et al., 2006); there are obstacles in making that shift within the NICU but there are also events that can help with it, such as a mother’s first holding of her baby (Aagaard & Hall, 2008).

The importance of embracing a position of “this is my baby” turns out to have confirmation elsewhere in the literature. Research from within the field of foster care has concluded that a parent’s commitment to a child in his or her care is critical. The more foster parents treat a child with the belief that this is “my child”, the more child wellbeing, parental enjoyment, and security of relationship all increase (Bernard & Dozier, 2011; Bick, Dozier, Bernard, Grasso, & Simons, 2013; Dozier & Lindhiem, 2006). While mothers of premature infants have a biological link to their babies through birth, the separation, stress, and NICU caregiving can interfere with the immediate development of a “this is my baby” position.

#### *III.4.2.3 Maternal identity in other medical contexts*

Themes arising in research with mothers who have had to parent within other hospital settings may also help elucidate the findings for mothers of premature babies. In research with mothers diagnosed with cancer, the biggest factor mothers considered in the many medical decisions they had to make was if they could maintain the bond with their child/ren (Campbell-Enns & Woodgate, 2013). Mothers considered themselves in context, and considered their own physical needs and the needs of their children as “inseparable

components” (Campbell-Enns & Woodgate, 2013, p. 265). Like the scientific literature that proposes the inextricability of mothers and infants in relationship, mothers themselves appear to reflect and represent this.

### *III.4.3 The physiological process of becoming a mother*

Becoming a mother and trying to construct maternal identity is not merely a psychological process. Physiological responses and mechanisms appear to partially underpin the formation of maternal identity, with caretaking behaviours by mothers linked to their physical proximity to, and separation from, their infants (Gunnar & Cheatham, 2003; Insel, 1997; Meaney, 2001).

For example, the responses of mothers of full term infants have been compared with those of mothers of infants born between 34 and 36 weeks gestation and those with very low birth weight babies born much earlier to see how they each managed separation from their babies (Feldman et al., 1999). Overall, mothers declined in their ability to manage distress and provide caretaking as the amount of separation increased. However, it was mothers of the low birth weight babies who had the highest levels of both distress and worry, and who also devoted the longest period of time to thinking about and talking to their infants, approximately 13 hours per day—nearly all their waking hours. In another study, the impact of being able to see one’s premature infant in the first hours after birth was evaluated a year post-birth (Mehler et al., 2011). Children whose mothers had been able to see them in the first 3 hours after birth had significantly higher rates of secure attachment than children whose mothers did not (76% security versus 41% security). First-born premature children had overall higher rates of insecurity. From this study, unique in the literature it seems, it is suggested that previous mothering experience helps attenuate the relational risks of premature birth and that separation affects the trajectory of maternal and bonding behaviour. One

suggested mechanism for this effect is the level of maternal oxytocin present, with data showing a correlation between the emergence of maternal caregiving and affection with the amount and stability of oxytocin in the mother's body (Feldman et al., 1999; I. Gordon et al., 2010; Parsons, Young, Murray, Stein, & Kringelbach, 2010).

#### *III.4.3.1 Stress for Mothers in NICU*

A subset of both physiology and psychology of the maternal meaning-making experience is the matter of stress. The most potent variable in maternal stress levels for mothers of premature babies is not the severity of infant illness but how the illness is perceived and the amount of support provided (Brooks, Rowley, Broadbent, & Petrie, 2012; L. Davis et al., 2003; Miles, Funk, & Carlson, 1993; Miles, 1989; Spear et al., 2002). Other factors such as level of maternal education, additional stressful life events, and infant temperament also appear to influence the amount of stress mothers may experience (Woodward et al., 2014) and therefore impact the formation of identity.

##### *III.4.3.1.1 Response to stress through experiential avoidance*

While there are many ways mothers can seek to manage stress, the pattern of experiential avoidance emerges in the literature. Experiential avoidance, a coping mechanism, is defined as an attempt to avoid or flee from feelings, thoughts, memories, or other difficult internal responses (Hayes, Wilson, Gifford, Follette, & Strosahl, 1996). There are positive correlations with experiential avoidance and maternal stress after discharge from hospital (Greco et al., 2005), with reduced maternal wellbeing and increased maternal psychological symptoms, such as depression and anxiety (T. Evans, Whittingham, & Boyd, 2012). Researchers suggest that experiential avoidance decreased a mother's overall sensitivity to her infant through her use of a response that involves emotionally shutting down (T. Evans et

al., 2012, p. 8); they believed mothers were well supported by NICU staff and they evaluated the use of experiential avoidance as an individual trait. However, it is possible that the concept of experiential avoidance as proposed by the researchers does not provide a holistic enough view of the context and also potentially pathologises a coping strategy that is required to endure the experience. It appears research investigating the notion of experiential avoidance examined within a broader, more contextual, non-judgmental framework has not been undertaken.

#### III.4.3.1.2 Hidden contextual factors of stress

There are a small number of other inputs into the stress response system of mothers that are somewhat hidden in the literature, awareness of which could contribute to a more contextually-driven, non-judgemental framework of understanding. One of these factors is the role of the father; another one is the role of ethnicity and culture.

Mothers talked mostly about their own experiences but the role of their male partners was a regular feature of discussion. For many, the father was the one who was with their infant straight after birth as most mothers were unable to stay with their babies; while mothers relied on their partners, it was also a source of emotional pain that they were not able to be the one with the baby. In 2014, Swedish researchers investigated the frequency with which fathers and mothers engaged in the initial bonding moments with their babies, moments such as first holding the infant, first touching the infant, first seeing the infant and being with the baby upon transfer to NICU (Baylis et al., 2014). While two-thirds of all parents did not have the opportunity to hold their baby immediately after birth, more fathers were able to touch the baby (61% vs 53%), nearly all fathers were able to see their baby (98% vs 67%) and fathers had a 22-29% chance of carrying the baby skin-to-skin into the NICU, while mothers had between a 0 and 5% chance of this happening. With fathers participating in active, direct, and

immediate contact at significantly higher rates than mothers, it is possible that creates unintentional psychological distress for mothers.

If a mother is Māori or Pacific Islander, Australian research has further suggested that her infant has an even higher risk of neonatal difficulties when compared with European and Asian infants of similar gestational age (with similar findings for Australian Aboriginal mothers) (Ruan, Abdel-Latif, Bajuk, Lui, & Oei, 2011). While all the mothers in my study were European, the influence of ethnicity is another hidden variable in the context of stressors faced by mothers in the NICU.

#### [\*\*III.4.3.1.3 The stress of separation\*\*](#)

In my review of the literature, separation emerged as one of the most often named stressors by mothers of premature infants as well as being the most identified source of stress for participant mothers. The notion of separation as stressful has a relatively long history.

Beginning in the 1970s, theorists began to discuss the implications for the mother-infant relationship created through separation (Klaus et al., 1972) expressing concern about the disruption of a sensitive period of bonding. During this time, standard NICU procedure was for the infant to be separated from the mother immediately after birth, with minimal contact for a period ranging from 3 to 12 weeks. Mothers reported negative effects on their commitment and self-confidence (Barnett, Leiderman, Grobstein, & Klaus, 1970) and disruption of normal maternal behaviour was regularly observed, especially in first time mothers (Leifer, Leiderman, Barnett, & Williams, 1972).

Early mother-child separation is a significant factor associated with postnatal depression (Righetti-Veltema, Conne-Perréard, Bousquet, & Manzano, 1998) and is understood as inducing a kind of grief reaction in humans (Shear & Shair, 2005). A mother's contact with

her baby is thought to protect her from the loss associated with the disruption of attachment bonds such as those commonly experienced in NICUs (Schen, 2005).

For women who give birth to late preterm babies, data suggests that the peak of emotional distress occurs at maternal discharge from hospital, while baby is still in the NICU (Brandon et al., 2011), and mothers consistently report physical separation as the most stressful event (Hughes & McCollum, 1994).

In one study of mostly first-time mothers with babies hospitalised for short stays in NICU, mothers reported significant emotional strain and experienced a lack of control even when infants were not seriously ill (Nyström & Axelsson, 2002). Even when mothers remain in hospital, researchers have found they experience separation stress (Obeidat, Bond, & Callister, 2009). When mothers whose babies are in NICU are housed on maternity wards together with intact mother-baby pairs, NICU mothers report experiencing high levels of distress (Heermann, Wilson, & Wilhelm, 2005). In cases of overnight separations when babies are in NICU and mothers are elsewhere, the long-term data suggests a dose-response effect between a diagnosis of separation anxiety disorder at age 6 and those children who had NICU stays in infancy (Karabel et al., 2012). One study, however, has suggested that first-time mothers may be less prone to the stressor of separation; the researchers reported more acceptance of the necessity for separation by first-time mothers, perhaps because of lack of previous experience and bonding (Arnold et al., 2013).

#### III.4.3.1.4 Separation and its future implications

In a landmark study of 176 mother-baby pairs randomised into four different experimental groups, mothers and babies who underwent a 2 hour post-birth separation measured lower levels of maternal sensitivity, infant self-regulation, and dyadic mutuality and reciprocity 1

year later (Bystrova et al., 2009). This matches findings suggesting that repeated separation produces misattuned physiology between mother and infant (Middlemiss, Granger, Goldberg, & Nathans, 2012) and creates physiological changes that may manifest as permanent alterations in neuronal functions and maternal behaviour (Kuhn & Schanberg, 1998; Zimmerberg, Rosenthal, & Stark, 2003).

#### III.4.3.1.5 Stress in summary

Stress comes in many different forms and has different trajectories, impacts, and meanings for every mother. Stress spans the biological and the psychological, as well as the environmental and relational aspects of experience. How mothers make sense of and respond to stressors in their prematurity journey has both obvious and subtle influences on their maternal meaning-making experience and the construction of maternal identity.

### III.5 Mothers in relationship with others: Medical and NICU contexts

Mothers must manage stressors that are part of the physical environment of the NICU, the psychosocial characteristics of the NICU, the uncertainties of their baby's health and wellbeing, and their emotional reactions and feelings of powerlessness (Weber, Harrison, & Steward, 2012). The NICU itself can bring about difficulties with mothers feeling comfortable and with how they establish a secure bond (Bialoskurski, Cox, & Hayes, 1999; Moon & Koo, 1999) and in addition there remain substantial differences between a NICU environment and that of a home. NICU birth involves routine overnight separation, the compromised health of the infant, and the medical management of care. Each mother must manage her reactions to these conditions (Mendelsohn, 2005). Nurses, social workers, and medical culture all play a part in the maternal meaning-making experience.

### *III.5.1 Mothers interacting with nurses*

It has been suggested that NICU nurses become mothers' first teachers about how to mother (Ewald, 2015). For first time mothers like the participants, this may be even more relevant.

#### *III.5.1.1 Mothers and nurses: Dyads and triads*

In reporting their findings from qualitative research with mothers, Fenwick et al. (2001) noted that mothers perceived that access to their infants must be via the nurses. As a result, the typical dyadic structure of the mother-baby relationship became a triadic structure between mother, nurse, and baby. Moreover, each member of the triad did not have equal influence, with mothers describing the triad in more linear fashion, from the nurse to the baby to the mother (Fenwick et al., 2001); nurses therefore had the potential to hinder connection between mother and infant (Bialoskurski et al., 1999).

#### *III.5.1.2 Mothers and the nursing culture*

The NICU culture emphasises high acuity and constant change, with an intensity of medical focus on the intense fragility of many infants (Cricco-Lizza, 2011). The NICU has been described as a hostile environment for parents who are under extreme pressure to navigate its challenges (Karabel et al., 2012). Mothers report distress at the loss of their expected caregiving role (Wielenga, Smit, & Unk, 2006) and report feeling the strain of attempting to parent in public (Shields, Kristensson-Hallström, & O'Callaghan, 2003).

In interviews with both mothers and nurses in Australia (Lupton & Fenwick, 2001), mothers reported that getting to know their child was a highly medicalised phenomenon that required them to engage in focussed observation of their child as well as pay close attention to everything medical that was occurring around them. Research in Sweden found that as a

mother experienced difficulties in establishing closeness with her child within NICU, maternal behaviour diminished (Wigert et al., 2006).

### III.5.1.2.1 Mothers and nurses: The influence of stress

The influence of nursing staff on maternal stress levels is not straightforward. Holditch-Davis and Shandor Miles (2000) noted that in some cases nurses could exert strong supportive influences and reduce stress for mothers, whereas in other cases they were experienced as sources of increased stress (Holditch-Davis & Shandor Miles, 2000). In other studies, mothers' experiences with nurses in the NICU were evaluated as supportive but after leaving the NICU for home, mothers felt unsupported and without sufficient knowledge to mother competently (Nicolaou, Rosewell, Marlow, & Glazebrook, 2009). The influence of interactions with nursing staff does not appear to hinge on the provision of information but seems to be centred on the quality of the relationship. For example, in a study by Koh et al. (2007), interventions to more effectively give mothers information about their infants had no effect on maternal wellbeing. Instead of depending on the provision of information, findings indicate it is the caring qualities and bridging support of nurses that reduce maternal stress (Guillaume et al., 2013). A systematic review of the literature by Cleveland (2008) examined 60 studies looking at the needs of parents in NICUs and found that these consistently underlined the importance of the quality of relationship between mothers and nurses.

### III.5.1.2.2 Mothers and nurses: Participation and communication

Good communication with nurses and a caring attitude of nursing staff toward both infants and mothers appears to assist mothers in managing stress levels, and in moving toward engagement in interaction with their infants (Guillaume et al., 2013; Pepper, Rempel, Austin, Ceci, & Henderson, 2012). In Guillaume et al.'s (2013) research, most mothers felt they needed

medical staff to welcome them into the NICU, especially on their first visit, as well as provide them with regular explanations about what was going on. Other researchers have similarly noted that an experience of empathy and shared understanding can be critical to the mothers' feelings of wellbeing and management of the NICU setting (Rossman et al., 2011).

### *III.5.2 Nursing culture and NICU culture: The larger context for mothers*

Just as mothers have reported finding themselves “parenting in public”, nurses have reported feeling like they were exposed and nursing in public (Wigert, Berg, & Hellström, 2007). NICU culture has everyday practice values that include reliance on a sisterhood of nurses, maximising infant potential, and confronting ongoing uncertainty, together with reliance on technology and tight control of actions (Cricco-Lizza, 2011). Nurses find themselves perpetually busy, under continual levels of stress, and with high reported levels of burnout due to sometimes-overwhelming stimuli, ethical, medical, and technological demands, high risk situation management, and unrelenting high patient needs (Marshall & Kasman, 1980).

#### *III.5.2.1 Nurses and emotional labour*

The NICU culture is noted to be an emotionally evocative environment for nurses in which they expend great amounts of “emotional labour” in their everyday work life (Cricco-Lizza, 2014). Nursing researchers Gray and Smith (2009) explained emotional labour according to Hochschild’s framework (Hochschild, 2003), defining it as “the induction or suppression of feeling in order to sustain an outward appearance that produces in others a sense of being cared for in a convivial safe place” (Gray & Smith, 2009, p. 253). In the case of NICU nurses, the situation has been similarly assessed, with emotional labour hidden behind a calm, capable deportment and tacitly accepted as a part of NICU culture (Cricco-Lizza, 2014). For NICU nurses in the United States, findings suggest that parental presence and the expression

by parents of intense emotion threatened nursing staff's ability to maintain their professional façade, with emotional contagion being a problem (Cricco-Lizza, 2014). Irish researchers echoed this, reporting that NICU staff endure stress, vicarious trauma, and compassion fatigue that can impede sensitivity and empathy within relationships (Twohig et al., 2016).

Nurses in Cricco-Lizza's (2014) research were without a release valve and struggled to make sense of "troubling emotions" when they arose (p. 625). Similarly, Wigert et al. (2007) showed nurses struggled if a child did not recover from a condition and felt guilty for not being able to enact a cure for the baby. Such findings highlight a potential parallel process whereby both nurses and mothers must at least partially disengage from their emotional experience in order to continue to function within the NICU setting.

In following up on the literature, I received personal communication from the United States researcher conducting much of the investigation into NICU nursing experience, Dr Roberta Cricco-Lizza. Cricco-Lizza (personal communications, June 2014) stated that from her research experience she believed that NICU nurses preferred to care for the sickest of the sick, finding themselves attracted to the complex levels of care alongside the learning and new research. Many identified with being a "super nurse" and that it was plausible that mothers of low-risk premature infants are naturally but unintentionally left out of potential support.

### *III.5.2.2 Nurses' perceptions of mothers*

When nurses are caring for critically ill children, it is the children—not their mothers or fathers—who take first priority in the attention of nurses, despite the fact that parents report needing care as well (Callery, 1997). While nurses are eager for parental care to be part of their role, others report feeling as if they were "baby sitting" parents (p. 995). Additionally,

parents who showed what was considered to be excessive anxiety were often labelled as irrational and difficult. Nurses themselves acknowledged that the baby in their care did not belong to them but they still found it difficult to not take over care of the baby and therefore sideline the parents (Callery, 1997). Nurses from infant special care units in Australia also expressed the need to keep mothers involved but not have them intrude or become difficult, as well as to encourage them to take frequent breaks (Lupton & Fenwick, 2001).

Other findings have suggested that mothers who express gratitude to nurses are spoken of as a reward of the job and mothers who are friendly and appreciative are labelled as good by the nurses (Wigert et al., 2007). When mothers are seen to be quiet and introverted, nurses find them difficult; when mothers are assessed as being loud, demanding, or rejecting of help, nurses either withdraw or end up in altercations (Lupton & Fenwick, 2001). Mothers who try to push their own ways forward and want to decide how their baby is cared for can be seen as tiresome, and relationships with these mothers can be strained (Wigert et al., 2007)

### *III.5.2.3 Perception of illness: Mothers and medical staff*

Finally, research suggests a possible clash of maternal versus medical culture when it comes to perception of illness (Brooks et al., 2012). New Zealand researchers have identified that mothers and clinicians hold very different perceptions of illness about the same baby, finding that the greatest difference in perceptions is for babies in NICU. Mothers in this research were more worried than clinicians about their babies and evaluated the babies' conditions as more serious. The mothers' perceptions of severity were "unrelated to objective measures" of illness severity or clinician ratings, motivating researchers to suggest the development of interventions to help address the "faulty" maternal perceptions of the mothers (Brooks et al., 2012, pp. 636-638). Of note, this study referred to "perceptions of the same baby" yet it can be argued that they are not really the same baby, as the baby in relationship with the mother

is a different baby than the baby being assessed on his or her own. It is possible that mothers' assessment process is based on very different criteria, including relational ones, but as far as I am aware, evaluation of what constitutes maternal perception of illness has not been undertaken.

Overall, the interactions and relationships with nurses, the nursing culture, and medical environment—both as individuals and as a system—have an influential and reciprocal effect on the experience of maternal identity and meaning-making.

#### *III.5.2.4 NICU design as a larger context*

Both mothers and nurses live within the larger NICU context. While some of that is metaphorical, thematic context, there is an element of physical context that underpins the larger ecology of experience: NICU design. All of the participant mothers interfaced with a traditionally designed NICU, one that had a design often referred to as a barn (Cone, Short, & Gutcher, 2010; White, 2016) due to the fact that infants are grouped together in an open-bay space. Investigations into the influence of such NICU design have found that its relative lack of privacy and individualised space result in diminishment of early parental bonding moments (Baylis et al., 2014), a reduction in hours of visitation and an increase in maternal stress (Pineda et al., 2012), a less conducive environment for breastfeeding and control of external stimuli (Cone et al., 2010), reduced understanding of infant cues by the parent (Flacking & Dykes, 2013), and a feeling of the parent as visitor (White, 2016). Nurses have also evaluated the barn design as more noisy, more threatening for parents, less inviting for parents, and worse for babies (Cone et al., 2010). The majority of these studies compared the open barn design with the newer trend toward single family rooms, a private and separate room for each dyad (and often fathers and siblings, too), which is consistently evaluated as better for mothers, babies, and mother-baby relationships.

Because participant mothers had only one experience—that of the barn design—it is impossible to tell how much this environmental context influenced their experience, yet it is evident from the research it could have had real impact.

### *III.5.3 The contribution of social work in prematurity care and the NICU*

Social workers are also part of the medical and psychosocial support system of care for mothers and their premature infants. There is not a great deal of literature that examines the specific role of social work in the NICU or with mothers of premature infants. A 1962 publication in a social work journal first appeared to address the role through an exploration of prevention interventions for families experiencing crises, of which premature birth was one (Rapoport, 1962). As premature birth in the early 1960s was associated with much more uniform rates of medical crises across birth demographics, crisis management was the focus for social workers. Crisis management was also the focus of another social work journal looking at the topic of perinatal social work and its role in responding to families experiencing a variety of antenatal and early postnatal medical illnesses (Noble & Hamilton, 1981). From this early literature, however, it appears that the field of social work and the base of information, knowledge, and theory surrounding social workers in the perinatal realms began to grow.

In a 1976 presidential address to the American Psychosomatic Society (Cobb, 1976), Dr Cobb made a plea for social support as a critical component for health and wellbeing and suggested this should be the function of social work. In a similar fashion, Harrison (1993) outlined the principles of family-centred neonatal care which have always included a central role of advocacy by social workers on behalf of parents and infants within NICU. Both suggested that social work as an integrated part of interdisciplinary care has become an expectation.

By the 1990s the term perinatal social work was commonly seen (Mahan, 1997) and the contribution of social work duly noted (Combs-Orme, 1988). The United States had also formed a professional organisation exclusively for social workers employed in perinatal health arenas, the National Association of Perinatal Social Workers (NAPSW). A few years later, in 1997, the field saw the publication of a book entirely devoted to the fundamentals of perinatal social work practice (this was republished in 2012 under a new name) (Lind & Bachman, 2012) with chapters addressing reproductive technology, obstetrics, postnatal depression, substance abuse, HIV, adolescent pregnancy, and premature birth. In the chapter devoted to prematurity and the NICU (Bachman & Lind, 1997), authors delineate the social work role as comprising assessment, interventions such as linking to resources, mediation, and advocacy, discharge planning, and team membership within an interdisciplinary medical staff. The same book included a chapter on social policy considerations, suggesting that perinatal social work is linked with the larger social policy issues surrounding infancy and birth and admonishing social workers to be a part of social action networking.

To date, social workers working within intensive care (including NICU) are typically one of the first professionals to interface with parents, usually providing family assessment within the first days of admission (Delva, Vanoost, Bijttebier, Lauwers, & Wilmer, 2002). NAPSW created a 15-standard template for social workers in the NICU based on the principle that “Every NICU should have social work services as an integral part of the health care delivery system. These services must be available to the infants and their families, as well as to the NICU staff and to professionals who will come into contact with the families around ongoing/follow-up services. The services are aimed at alleviating the stress of hospitalization, maximizing the potential for optimal growth and development, and maintaining gains made via an effective network of services” (NAPSW, 1998, p. 1).

Their provision of information and support with practical problems is critical, highlighting an ongoing role of social work support in the immediate stages of NICU care; this is a role that impacts short and long term NICU stays equally. NICU social workers provide direct services to families, specialist support to siblings (Levick et al., 2010), and advocacy for parents (Bachman & Lind, 1997). Paediatric social workers play a central role in crisis intervention and assessment (J. Miller, 2001).

Social workers themselves see their role within hospital settings, including NICU, as multifaceted, including professional themes of bouncer, janitor, glue, broker, fire fighter, juggler, and challenger (S. L. Craig & Muskat, 2013). For example, the broker role is linking with families to translate medical information and organise discharge planning; the fire fighter role is about crisis responses. Low risk premature admissions may suggest a reduced interaction with social workers and the possibility of mothers being overlooked, especially as low risk mothers may not be perceived as requiring crisis intervention, assessment, or advocacy to the same degree.

The topic of social work in relation to maternal support and prematurity remains under researched as compared with the body of evidence regarding nursing in these fields. Examinations of the experience, culture, and responses of social workers could likewise be helpful, both directly for the professionals and for the mothers and families who receive their care, as well as indirectly to build understanding of what best practice should be. My own discussions with NICU social work staff suggested they are very aware of many issues that affect mothers, including mothers of low risk premature infants, but the extant literature does not currently represent their thinking.

### III.6 Conclusion

Respecting the complexity of the literature is akin to respecting the complexity of development for each mother and her baby. There are layers of context and influence. Much of the literature is devoted to individual medical and physiological factors occurring for the baby and the mother, with less evidence devoted to the dyadic processes and the social and emotional health factors at play, a fact confirmed by research evaluation (Wolke, 2016).

In this chapter I have reviewed the pertinent research literature as it relates to maternal identity, mother-infant relationship, and maternal context. Adjacent to this literature is a body of theory that touches upon the same questions. Relevant theory also addresses the experience of first time mothers and their premature infants and offers a companion assemblage of writings to shed light on the research questions and findings. This theory will be reviewed in the following chapter.

## Chapter IV: Theory Review

### IV.1 Introduction

Many theories are relevant to an understanding of how first time mothers of premature infants develop a maternal identity and come to know themselves and their infants; there is not a single existing theoretical model that effectively encompasses the research questions. Given the individuality and complexity of such a multi-factorial, context-driven phenomenon, it is unlikely that a single theory would ever suffice. Instead, multiple theories can feasibly be woven together. A theoretical framework can begin to be constructed by examining and incorporating theories relevant to the individual themes that mark the experience for mothers. Through examination of existing related theories, maternal experience can be better understood and clarified. Gaps in current thinking, theorising, and research can also be identified.

The research questions necessitated examination of theory related to the general experience of motherhood, first time motherhood, construction of maternal identity, development of mother-infant connection, and premature birth. While much of this theory has overlap, it is most often written about discretely; in general, theory surrounding aspects of the research questions exists in silos of inquiry and publication. This allows understanding of individual theoretical meaning but can make it difficult to weave a sufficiently comprehensive picture to make sense of the research.

Because of the importance of holistically understanding the experiences of mothers in relationship with their children in their surrounding environments, this chapter concludes with a commentary on ecological theory. Ecological theory offers a means of overcoming silos in theorising and is an appropriate framework within which the whole of the research

can therefore be situated and understood. This chapter will discuss each of the distinct theories that are germane to maternal experience whilst also remembering the reality that they are interwoven in the lives of the research subjects.

The review spotlights popular theories pertinent to the research questions and will target three key areas, as well as offering a review of an umbrella theory that offers a link between them.

The first area will focus on how women develop as mothers, create maternal identities and infuse their experience with meaning. Popular theories related to what it is like to become a mother will be reviewed. The second area of focus will concentrate on how relationships between mothers and infants are created and how the dyadic nature of such relationships is understood. Here will be offered theories that are relevant to the mother's relationship with her infant, including how relationships unfold and how mothers come to understand their babies. Thirdly, I review theoretical literature concerning the unique factors, themes, and interpersonal mechanisms surrounding premature birth and how these affect the aforementioned individual and relational tasks. This area of theory centres on the uniqueness and challenges faced by mothers of premature infants and includes theories of grief, loss, and posttraumatic growth; ambiguous loss; relational uncertainty; and alloparenting. Finally, a review of ecological theory, a uniting theoretical framework, will be provided.

#### **IV.2 What is it like to become a mother?**

A great deal of what is written regarding maternal identity is located in the domains of feminist theory, socio-political context, economic history and policy, and the impact of culture (Chodorow, 1989; Glenn, Chang, & Forcey, 2016; Manne, 2005, 2008). For the purposes of this theory review, I will focus on the writings that address maternal identity as it pertains to women who are willingly becoming mothers and their journey of psychological

and emotional transformation. While there are important theories that address female identity construction, women's reproductive rights, cultural norms regarding motherhood, and feminist critiques of the role of women as mothers, I excluded these; they are not an integral part of the ecological context in which the research takes place and they were not mentioned by any participants.

Since the late 1800s and the emergence of the field of psychoanalysis, philosophers and researchers have been theorising about the role of the mother and how a woman adopts a maternal identity (Freud et al, 1953; Jung, 1936, 1959). Over time, writers became more interested in theorising based on observations of mothers' experiences, as opposed to the development of theories largely based on ideas about the unconscious processes potentially at play. Observation of mothers was naturally comingled with observation of infants and, of course, mothers and infants interacting. As such, theorists in the field of maternal identity are typically ones who have an interest in infants as well. Leaders in this field include Winnicott, Stern, and Rubin. Their professions include paediatrics, psychiatry, and maternal nursing.

In the 1930s—and continuing on until his death in 1971—paediatrician and psychoanalyst Donald Winnicott began writing about the world of mothers and maternal experience. His work became a partial foundation for later work in neuroscience and developmental psychology as it relates to individual and relational maturation. Winnicott was writing from within the world of psychoanalysis but, like John Bowlby's (1947, 1958) developing theories about infancy, he was breaking new ground while also breaking ties with the more pathology and fantasy based models of his training. Winnicott spoke of mothers as having a knowing, which is to be distinguished from the learning that takes place when mothers receive outside information from medical staff. The knowing, according to Winnicott, is an activation of

instinct and ability based solely on getting to know her infant under ordinary circumstances (Winnicott, 1992).

Mothers know and feel something that others do not and that is the vital importance of getting to know their babies as people, from the earliest possible moment (Winnicott, 1992). “No one”, said Winnicott in a text addressed to mothers, “who comes along to give you advice will ever know this as well as you know it yourself” (p. 20). Mothers achieve this potential not through some special or rigorous undertaking, but through “ordinary devotion”, in which ordinary women enter an ordinary phase, act naturally and then, months later, ordinarily recover (p. 10). During this time, a mother comes to understand her baby’s needs, tangible and emotional, obvious and subtle, and in the process comes to know herself as well. This is a time of focus on the infant, termed “primary maternal preoccupation” (Winnicott, 1965, p. 16). It is viewed as necessary to forge this new relationship, new understanding, and new identity, and something which would be considered strange and inappropriate at another time of life (Winnicott, 1956, 1960, 1970). This temporary yet highly sensitive time gives the mother opportunity to manage the baby’s needs as if they were her own (Harris, 2005). The aptness for this unique time following birth has a goodness of fit that comes to a natural conclusion, hence why women gradually cease their preoccupation without prompting or difficulty (Kim, Mayes, Feldman, Leckman, & Swain, 2013; Winnicott, 1992). This period is special, an adaptation of the mother’s identity at the beginning of the child’s life, and allows for the integration of new information and the creation of new meaning about herself and her world.

Nurse and scholar Rubin focussed on this immediate postpartum period as the centrepiece of most of her research and work (Rubin, 1984). Rubin was one of the first maternal nurse specialists in the world and the first to establish a professional research journal for the field.

Her work has been a foundation for practice, especially in the United States and countries adopting United States models of care. Through scores of observational studies and her work as a nurse and midwife, Rubin suggested that the postpartum period is the foundational time for women to transition into maternal mindsets and ways of being. Unlike other theorists, she observed the postnatal period to be “unbelievably cruel”, suggesting that this immediate period after birth can be full of physical and psychological hardships which are subsumed under the banner of normality and during which sufficient maternal support is rarely forthcoming (Rubin, 1975, p. 1684). Paradoxically, she also suggested it was a time of overlooked miracles, referring to the miraculous daily events around birth and new motherhood that go unnoticed due to their repeated occurrence. The transition from pregnancy, through birth, into motherhood is a concentrated time of reflection and reorganisation for a woman (Rubin, 1992). As such, moving from an individual identity into a maternal orientation revolves around a two-step process called taking-in and taking-hold (Rubin, 1984). Taking-in, the first process, is a brief, receptive time during which the mother takes in information about herself and her new life. Next is taking-hold during which this new information is processed and incorporated, prompting her to move forward.

Unlike Winnicott, Rubin observed this immediate first stage as one in which a mother is preoccupied with herself and her own needs, a time where she needs personal support and the ability to talk about the birth that has just occurred. This phase lasts only two to three days, after which begins the longer phase entitled taking-hold. During this second instalment of the transition process, the mother assumes responsibility for her newborn and puts her focus squarely on the baby, beginning to cement her new identity and allowing her to achieve attainment of her new role. Mothers, she suggested, need time to recover themselves before moving to restore their identity, one that now is hinged to plentiful new sensory awareness via interaction with her infant (Rubin, 1967, 1984).

Theorists from the nursing and midwifery worlds have aligned with these theories and named this postpartum period “the fourth trimester” in order to suggest the inextricable identities and experiences of mother and baby in the sensitive span of time after birth (Karp, 2004; Kitzinger, 1995; Matambanadzo, 2014). These theorists have all been instrumental in influencing practices such as rooming in and minimisation of mother-newborn separation in hospital.

Other theorists and researchers from within nursing have argued, however, that the idea of two discrete phases is no longer applicable to maternal experience, suggesting instead theories that purport a continuous identity transformation journey that sees mothers working in their own time and their own way to establish a new normal in their lives (Martell, 1996, 2001). Still others have worked to update and refine Rubin’s foundational theories, proposing that instead of maternal role attainment, the terminology of “becoming a mother” is more appropriate and reflects the continual evolution, growth, and development that occurs for women both in the immediate postpartum period and beyond (Mercer, 2004).

Stern was also very concerned with the unique time after birth and named it the “postpartum crucible” (Stern, 1995, p. 24), a time during which there is a reworking of a woman’s identity, never as powerful, extensive, or intense as with the first birth she goes through. According to Stern, a woman must navigate a change from seeing herself as a child of her own mother to a new view of herself as a mother of her child (Stern, 1995). This transformation includes a sense of loss as well as new challenges and vistas, including the balancing of the desire for altruism (putting the baby’s interests before her own) and narcissism (putting her own needs at the fore). This notion of a shift from individual identity to a relational one has been suggested and reiterated by other theorists as well (Bowlby, 1958; Ruddick, 1980; Winnicott, 1957). For example, one theorist labelled this new

reconfigured identity “matrescence” (Speier, 2001, p. 13) and another invented new terminology for the new relational love a mother invests in, calling it “preservative love”, a love that pushes beyond an individual way of thinking into one that places the preservation of life and relationship at the fore (Ruddick, 1980, p. 17). Philosopher Manne (2005) has also identified this identity shift through her journalistic investigation of motherhood, calling it a “threshold into a different world, with different values, a different universe” (p. 15).

For Stern, after the birth of a baby (especially the first child), the mother gains access to a psychic space that organises her newfound maternal compass and abandons old mental structures so that she can orient around the baby and her new role as a mother; he termed this “the motherhood constellation” (Stern, 1995, p. 171). This maternal constellation is something developed by the mother, neither something foisted upon her nor something automatic. According to Stern, it involves both internal and external discourses, as the mother engages imaginative mental conversation with herself, her baby, and her own mother. It is a reorganisation largely based on meaning and experience, suggesting that this process is influenced less by explicit external events than by how mothers construct the story and interpret those events that matter the most to them.

The idea that mothers create a sense of self through interpretation of events suggests a hermeneutic model of maternal identity and role construction; a hermeneutic model is one that focuses on the interpretation of the meaningful event and challenges that may arise from within it, locating the subject within the surrounding whole or environment in which the event unfolds. The construction of meaning and the development of a coherent narrative become hallmarks of this theoretical transformation, thus resting the theory underpinning maternal identity creation alongside general theories of meaning-making such as those that predicate interpretative phenomenological analysis (Larkin, Eatough, & Osborn, 2011;

Larkin & Thompson, 2012; Larkin, Watts, & Clifton, 2006; J. Smith, Flowers, & Osborn, 1997). This narrative, hermeneutic model is reiterated in theories of relational development and adult functioning (Fonagy, Steele, Steele, Moran, & Higgitt, 1991; Fonagy & Target, 1997; Hesse, 2008; Main & Hesse, 1990; Main, Hesse, & Goldwyn, 2008). In these adult development theories, which are further discussed in the literature review chapter (Chapter III), a mother's story of her past is predictive of her present mothering directly through her story's level of narrative coherence and her ability to derive healthy meaning from it.

Recently, researchers have further theorised that when obstacles exist that prevent a mother from being able to fully construct a new identity, such as when she feels she must keep certain feelings hidden or aspects unexpressed, an emotional barrier arises between her and her baby and this barrier may contribute to maternal depression (Welch, 2016). As with Winnicott's notion of ordinary devotion, mothers may move through the natural process of identity construction only when ordinary circumstances are at play. In other words, when confronted with extraordinary events, the straightforward path to identity construction will be impeded.

Stern and his wife/colleague Bruschweiler-Stern theorised that there are fundamental processes mothers engage in along their journey to a cohesive maternal identity and that these processes are entwined with interaction with their babies (Stern & Bruschweiler-Stern, 1998). They proposed that the mother's experience of becoming is interlaced with her experience of the infant. This idea of an interlaced becoming appears to be a feature of many theories of maternal identity. This maternal becoming is rooted in a "slow dance" that begins at birth (Stern & Bruschweiler-Stern, 1998, p. 193). It begins with the new mother gently touching the baby's feet and hands, the baby a familiar stranger. As the baby accepts the touch, the mother will move up the leg or arm, increasing in her assurance and using a corresponding

touch that will use all of her fingers, not just fingertips. She then moves from the periphery of the body to the centre, to the baby's belly and chest. Her hand will open and caress the baby with her palm. She may stay there a while and then, invariably, she will move up to the baby's head and cradle it in her hands, sometimes lightly touching the baby's face with her other hand or her own lips. This process, according to the Sterns, varies somewhat from mother to mother and is the mother's way of making this baby her own baby. In turn, this solidifies her sense of her own motherhood (Stern & Bruschweiler-Stern, 1998).

On the subject of women who give birth prematurely, this theory mirrors that of the recent postulations, suggesting that prematurity, along with its ensuing separation and disruption, often creates an inability to engage in such a maternal dance, thus leading to an emptiness and temporary inability to connect with, love, or protect the real baby. This has been named a "representational vacuum" (Stern, 1995, p. 39) and points to an out-of-sync development where external circumstances create abnormality. The emphasis on the external anomaly is important, as the theory is clear that it is not internal psychopathology within the mother that initiates the disruption.

One of the most cited theoretical pieces of Stern's thinking concerns the questions that must be answered by new mothers that give them access to the construction of a strong maternal identity and insights into the phenomena of their maternal journey. The first and most critical question mothers ask themselves is whether they have the capacity to support the life and growth of their baby. Inside the mother, this question is a simple one: can I keep this baby alive? (Stern, 1995; Stern & Bruschweiler-Stern, 1998). Specifically,

The baby must live and must thrive. This encounter with your primary responsibility as a parent finally gives psychological birth to your new identity. The first, unavoidable task of motherhood is to keep your baby alive . . . As a society we tend to forget this

obvious and stark reality, to take for granted the drama and import of the task, but it doesn't go unnoticed in a mother's heart (p. 93).

After this question of whether she can keep her baby alive, the mother must face other questions, such as whether she can love the baby, whether the baby can love her, and whether she can become who she needs to be to make this happen (Stern, 1995).

It is through decades of clinical work with mothers that Stern arrived at his theories; clinical work that included not only hours of observation and clinical support but extensive videotaping and reviewing, often in moment-by-moment analysis. To date, Stern's theories have received wide acceptance by those working in perinatal mental health, maternal mental health, and mother-infant care and have been built upon by many (Beebe et al., 2010; de Zulueta, 2013; Goleman, 1986; Lyons-Ruth et al., 1998; Palombo, Bendicsen, & Koch, 2009; Trevarthen, 2013; Tronick & Beeghly, 2011; Tronick et al., 1998). Whilst it is almost certain that there are professionals working with mothers and infants who discount or criticise Stern's theories, I have been unable to locate any published critiques in the extant literature.

The transition to motherhood is a process, not an event, moving from a known reality into an unknown one. It involves both personal and interpersonal change as a woman takes on maternal tasks and a maternal identity (Pridham & Chang, 1992). It is described as a transition that can vacillate, is unending, and proceeds on a unique and individual trajectory (Rogan et al., 1997). As such, it is part of the unique contextual construction of events and influences that surround and influence maternal experience.

#### **IV.3 Infant development, relationships and the world of the mother-infant dyad**

How mothers create and make sense of relationships with their baby is connected to how babies themselves develop. The process of infant development—of developing a sense of

self, beliefs about the world, a lexicon of emotion, psychological understanding, and a connection with others—is discussed widely in terms of theory. Whilst there is a significant body of physiological, neurological, and medical research to help explicate this mechanism, many of our understandings, paradigms, and insights are derived from theory. For the purposes of theoretical review, I will focus on theories of infant development that concentrate on the world of relationships.

There is a large literature, both theoretical and scientific, that explicates individual human development from infancy onwards. This includes general theories and information from the fields of psychological development, genetics, epigenetics, physiology, neuroscience, temperament, cognition, and disability, as well as social theories around the role of culture, environment, economics, gender, religion, and family. Each of these contributions helps explain aspects of human development and no picture would be complete without consideration of them all. Because my research focuses on the maternal experience and how mothers come to know and connect with their infants, I am highlighting only those scholars working on theories of relational development. The review thus seeks to elucidate the ways of thinking about infant relationships and relational identity; this is not to suggest that this is either the sole or most important component of maturation but it is simply the most applicable and salient theory given the context of my research, as well as the most relevant contexts for the maternal ecology.

#### *IV.3.1 Theories of mother-infant bonding and human development*

Just as Winnicott was breaking with psychoanalytic thinking of the day by honing in on how mothers themselves were navigating the process of creating maternal identity, he was also part of a contingent of mental health scholars in the 1950s who were equally interested in how infants develop. Unlike the Freudian postulations that Western clinicians of the time

were trained in, Winnicott observed that newborns were immediately part of a dyadic system, acting and reacting within the context of their immediate maternal environment. These scholars were departing from the notion of individual, unconscious processes governing infant identity and preferring direct observation of mothers and infants together over ideas of fantasy complexes, dreams, and thwarted sexual desires (Freud et al, 1953). Winnicott was still squarely of the psychodynamic tradition in that he cared about unconscious processes at work yet he was also highly practical and believed that mothers had an inherent capacity for competence and value, as did infants. Alongside Winnicott in the field were psychiatrist Bowlby, also in the United Kingdom, and psychologist and primatologist Harlow in the United States, as well as countless colleagues and researchers working in similar laboratories and clinics. As well as pushing against a psychoanalytic model, these three theorists were also developing theories about infant needs that extended beyond the other existing model of the day: behaviourism. Behaviourism was led in large part by American psychologists Watson and his student, Skinner and professed that what was going on inside a person—their feelings and meanings—were largely irrelevant to the outcomes of their lives (Skinner, 1985). Instead, children were often seen as experimental subjects that could (and should) be trained according to desired behaviour (L. D. Smith & Woodward, 1996). According to Watson, love and affection were mostly unnecessary and once a child's character had been spoiled by bad handling in the form of things like hugs and kisses, the damage may not be repairable (Watson, 1928). Behaviourism's influence was huge, and Skinner has been judged the most influential psychologist of the 20<sup>th</sup> century (Hagg bloom et al., 2002). The new and revised theories of Bowlby, Winnicott, and Harlow served as a scientific bridging, combining the internal psychological world of experience and meaning with external, observable phenomena. In doing so, they created theories of infant development that continue to

underpin thinking today and assisted in the development of a foundation for the more recent disciplines of affective neuroscience and developmental psychology.

Winnicott is known for this view of the baby existing only within a relationship, often paraphrased by saying there is no such thing as a baby (Winnicott, 1987). That statement has become a central metaphor for comprehending infant mental health, anchoring the notion of relationships beneath all infant mental health work. Babies, relational theorists suggest, develop their sense of selves and the world through their primary relationships and, in fact, cannot survive without them. Winnicott's preeminent contributions to infant theory revolved around the notions of good-enough mothering and the concept of holding (Winnicott, 1965, 1960). Winnicott believed that babies "were human from the beginning" (Winnicott, 1992, p. 79) not empty vessels nor unformed creatures. Infants are, instead, engaged in immediate and emotionally charged interaction with their mothers from birth and develop within the context of this reciprocal communication. He believed that the foundations of infant health are laid down by a good-enough mother who is providing ordinary loving care of her baby (Winnicott, 1957, 1992). This good-enough care is created by the mother's ability to hold the infant both physically and (more importantly) emotionally. This then initiates an environment in which the baby can be true to any needs, impulses, and feelings, all in the presence of a mother who is consistent, caring, and appropriate. The mother engages in real-time adaptation to her baby's needs as the infant comes to know him or herself incrementally and sensitively through the process of being known by the mother (Winnicott, 1960).

A contemporary of Winnicott, yet working independently, was British psychiatrist and psychoanalyst Bowlby. Bowlby developed attachment theory to explain the way in which human infants and parents form deep, lifelong relationships that ensure the protection of the infant and the survival of the species (Bowlby, 1956, 1958). Influenced by evolutionary

theories of Darwin (1872) and the ethological theories of Hinde (1970, 1983), Bowlby engaged in decades of work with young children, including young boys described as juvenile delinquents. In doing so, he started to piece together a theory based on his observations of children and the consequences of their early parenting histories (Bowlby, 1947). More so than Winnicott, Bowlby's work moved into case studies, research projects, clinical examination, and documentation such that a more comprehensive evidence base came to augment the theoretical suppositions.

In studying children and families, Bowlby recognised that the absence of warm parenting in the early years functioned as a psychological loss that changed the course of life (Bowlby, 1969). Contrary to the behaviourist point of view that children did not require anything but proper training, and the psychoanalytic perspective that babies only bonded because they were being fed, Bowlby posited that emotional connection underpins a child's ability to grow, develop, and become a well adjusted and loving adult (Bowlby, 1958, 1969; Cassidy & Shaver, 2016).

From these hypotheses, the field of attachment theory was born. Attachment theory postulates that all humans develop an internal working model of self and other that guides current and future relational interactions, shapes the individual's view of themselves, and predicts relationship quality and mental health (Bowlby, 1958, 1969). In 1965, Bowlby's student, Ainsworth, developed the categories of attachment, outlining the different forms of emotion regulation, responsiveness, and dyadic communication that comprise both secure and insecure patterns of relating and bonding between a mother and her child (Ainsworth, 1969). Ainsworth employed rigorous and extensive field work in both Africa and the United States, documenting moment-to-moment interactions, responses, and individual maternal and child variables in order to develop this categorical catalogue (Ainsworth, 1979; Bell &

Ainsworth, 1972). Her original work has been updated to account for the effects of intergenerational trauma and the uniqueness of changes that can be made in adulthood, but has stood the test of time in terms of scientific method and validity (Ainsworth, 1978; Main, Kaplan, & Cassidy, 1985; J. R. Schore & Schore, 2008), and has continued to be refined as more recent research and critical analyses have come to light.

Early critics of attachment theory suggested that temperament was at work in distinguishing between the types of attachment patterns (Kagan, 1994), but cortisol research with the studied infants (Gunnar, Brodersen, Nachmias, Buss, & Rigatuso, 1996) and later research through, for example, twin studies (Fearon et al., 2006) combined with the inclusion of temperament, genetics, and neuroscience within modern attachment theory have mostly put those concerns to rest (Gander & Buchheim, 2015; Raby, Cicchetti, Carlson, Egeland, & Andrew Collins, 2013; Raby, Roisman, & Booth-LaForce, 2015). Other critics of attachment theory have proposed theoretical objections to the theory's relevance, especially as it applies to non-Western cultures such as Japan or indigenous traditional cultures of Africa, citing concerns about how concepts like maternal sensitivity are constructed as well as how cultural values and norms influence definitions of interpersonal health and infant competence (Gottlieb, Otto, & Keller, 2014; Otto, 2014; Rothbaum, Weisz, Pott, Miyake, & Morelli, 2000). While two separate meta-analyses of cross-cultural attachment studies confirm the validity of the theory (van IJzendoorn, Bakermans-Kranenburg, & Sagi-Schwartz, 2006; Van IJzendoorn & Kroonenberg, 1988), current thinking in the field recommends the research and assessment of attachment only via a combination of the existing, validated measures with indigenous measures of attachment devised from within each specific culture (Behrens, 2016).

To grasp the applications of attachment theory, it must be understood as a theory of relationships. Human infants come to be known and to know others through unique early

parenting relationships constructed from before birth. The quality of these relationships, their consistency, reliability, attunement, and capacity for care, love, and appropriate soothing all influence how the infant develops (Cassidy & Shaver, 2016; C. George et al., 2008). The baby is both giver and receiver, even while the onus of care is unidirectional. Bowlby described two baseline positions in the dyadic interaction, that of a secure base and a complementary safe haven. The theory explains that infants exist in relation to their primary caregivers and are constructing and defining their world in a continuous exchange. Within this reciprocity are two poles of experience: an exploratory mode (secure base) in which babies are using the security of the relationship to discover their world, and a comfort-seeking mode (safe haven) in which they are returning to the safety of the relationship for calming, soothing, or regulation of emotion (J. R. Schore & Schore, 2008; Waters & Cummings, 2000). The internal processes and meaning derived from the relational interplay will be unique for each infant, and each dyad.

As babies have repeated experiences within their primary relationships, internal representations will be created that will influence future relational development and individual identity (Lyons-Ruth et al., 1998). The attachment frameworks created both impact the future as well as remaining susceptible to other influences throughout the lifespan (Bowlby, 1958; J. R. Schore & Schore, 2008). According to the theory and its relevant research base, the effects are potentially profound in adulthood as the baby-now-parent seeks to raise his or her own child (Hesse, 2008; Main & Hesse, 1990).

Criticisms of attachment theory do not generally seek to discount the robustness of the theoretical concepts but, instead, argue about how significant the contributions of early relationships may be (Bretherton, 1985; J. R. Schore & Schore, 2008). How much impact relationships have on an individual human appears to depend on a plethora of factors, all

interwoven with specific complexity that is highly personal; yet there is scholarly agreement that relationships do matter and that the basic tenets of attachment theory hold up to scrutiny. Additionally, scholars continue to discuss the emergent complexities, nuances, and research that guide the adaptation and updating of the original attachment theory in the face of evolving understandings from fields such as neuroscience and affect regulation (DiCoccia & Tronick, 2011; Tronick & Beeghly, 2011; Weber et al., 2012). One critical theoretical proposal to advance and revise the original theory of attachment submits that although the initial mother-child relationship has an “undeniable influence on other relationships” (Tronick, 2003, p. 482), each relationship a child constructs over its lifetime is not only unique, but also dynamically changing all the time. This results in an ongoing reworking of each relationship as the child grows and evolves, allowing for great degrees of relationship change and a wide variety of relationship options, not simply a recapitulation of the original relationship template (Tronick, 2003).

#### *IV.3.2 Theories of relationship derived from primate research*

While Bowlby and his colleagues within the psychoanalytic world were seeking to push their field into observable theoretical stances that held meaning for babies, concurrent theory was being developed in the United States that sought to move the field of psychology beyond a sole focus on behaviour into consideration of infant experience. This work was led by Harlow, a psychologist and monkey researcher. One of Harlow’s students and his colleagues (Suomi, Van der Horst, & Van der Veer, 2008) summarised it like this:

His initial experiment with surrogate monkey mothers all but demolished two of the most prominent contemporary theories at the same time. First of all, it knocked the socks off of the classic psychoanalytic view of how infants establish their initial relationships with caregivers, namely through oral gratification associated with

nursing. It also clearly contradicted the prevailing psychological theory of primary and secondary drive reduction, which had at its heart the idea that an infant's desire to be with its caregivers stems from the reduction of the primary drive of hunger through feeding, i.e., this desire for the caregiver represents a secondary drive. Thus, both the prevailing psychoanalytic and behavioural views at the time held that relationships between parents and infants developed initially as a consequence of nursing. And Harlow's surrogate research, in which he demonstrated convincingly that rhesus monkey infants overwhelmingly preferred to be with cloth-covered surrogates that provided no source of milk to wire-covered surrogates that provided them with all the milk they could ever drink, showed that neither of those views could be correct. Bowlby of course spent much of his entire career fighting the classic orthodox psychoanalytic view (p. 358).

As that historical summary indicates, Harlow's work with infant monkeys was groundbreaking as it developed a theory that contradicted thinking at the time. By employing a primate research design that allowed for the kind of experimentation deemed unethical for humans, Harlow established compelling grounds for a human theory based on an applicable and comparable monkey model. In his most famous experiments, alluded to above, in which motherless monkey infants prefer their soft cloth-constructed mothers over the milk-producing wire mothers, Harlow began to put forward the notion of infant love (Harlow, 1958; Harlow & Harlow, 1966; Harlow & Zimmerman, 1959). Prior to this time, the field of mental health did not entertain the notion of love as a need, desire, or capacity of an infant. Harlow admonished his peers that they were failing in their mission by viewing love as an improper topic for exploration and research, calling it a "wondrous state" that "pervades our entire lives" and thus demanded rigorous study (Harlow, 1958, p. 673).

Harlow's theory began with a postulation that the absence of a real mother was more than the absence of flesh and blood, more than missing access to feeding and milk; it was an absence of relationship, of socialisation, and of affection. These losses, believed Harlow, had an immediate and long-term impact on the health and wellbeing of the developing infant monkeys. Like Ainsworth (1979), Harlow (1958) conducted meticulous observational experiments and administered many different permutations of conditions so as to test different sorts of separation, different ages, and different living arrangements. He also went beyond the focus on the sole importance of the mother, where Bowlby's focus largely remained, and developed data and theory about the role of peers and fathers in the healthy development of infants (Vicedo, 2009, 2010). Harlow recognised that the competency of mothers varied and the ingredients influencing an infant's development were multifactorial and complex. Both he and Bowlby—who knew each other and were mutually supportive of the other's work—continued to advance the concept of infant affective needs and the importance of early relationships as central components of maturation.

As can be expected, there was criticism from many in the face of Harlow's work and the new theories he suggested. In a review of the literature referencing his work, however, I was not able to find any rejection of his theories or findings, barring those from animal rights groups objecting to the use of primates for such experimentation. Just as Bowlby's work has been both foundational and also requiring fine-tuning, expansion, and revision, Harlow's work (Harlow, 1958; Harlow & Harlow, 1966; Harlow & Zimmerman, 1959) also forms the basis for current thinking about infant development and their basic needs for relationships, connection, loving affection, and the kind of care required for healthy growth (Blum, 2011). In light of today's knowledge about psychological growth and development, Harlow's theories are no longer groundbreaking but mostly seen as common sense. Yet these theories and understandings of human development continue to guide our understandings of how our

earliest relationships are formed. They have direct relevance for comprehending how mothers come to create connection with their babies and for grasping the meaning of these early experiences for both mother and infant.

It is the mother's focus to come to know her infant, since it is through knowing her baby that she steps into her role as mother, able to provide the care that her baby requires and able to do this in a way that another cannot do. The need for familiarity and intimacy with her baby suggests that mothers enter into a world where they attempt to understand things from their infant's point of view, to learn what it is like to be an infant; in doing so, they employ the relationship to sculpt and edify their own identity as mother while supporting their infant in the process.

#### *IV.3.3 What is it like to be an infant?*

Various facets of the literature together paint a nuanced picture of how infants develop within the context of their early and ongoing experiences. Infants are not passive recipients of relationships, but are active communicators and meaning-makers.

“What is it like to be the infant?” is a question that the research rarely addresses. Most research, instead, documents the effects of events, circumstances, and interactions on the infant and deduces the infant's experience from there (Trevarthen, 2011). According to infant theorist Trevarthan, babies start building an understanding of themselves through interaction, cooperation, imitation, and communication, using the entire physiological and biobehavioural experience to construct an intersubjective reality (Damasio, 1999; Trevarthen, 2011; Trevarthen & Aitken, 2001). These first primary relationships have been described as “the emotional cocoon from which the infant's social and emotional self develops” (Rosenblum, Dayton, & McDonough, 2006, p. 109). Unlike adults, babies will live their experiences

through the feeling of what happens, through a felt sense in the body and “whole organism maps” (Damasio, 1999, p. 180). According to such infant development theory, parents communicate with their infants “through gazing, smiling, gentle touch, soft voice, and behavioural synchrony. Even if the parents use words, which of course they do, the meanings of the words are not understood by the child, except through accompanying paralinguistic cues, facial expressions, patterns of touch and so on” (Schachner, Shaver, & Mikulincer, 2005, p. 146). In other words, a baby is using his or her entire physiology and all available feeling states to understand the world. Emotions are consequently understood as flows of energy and information that initiate orientation, appraisal, and arousal and become the shared focus within relationships, thereby directing how an infant comes to know his or her own mind, as well as the mind of another (Siegel, 2001). From their first days and weeks of life, infants are understood to be able to convey three primary emotions: distress, positivity (or joy), and interest (Rosenblum, Dayton, & Muzik, 2009).

According to Tronick and Beeghly (2011), the systems that guide psychological growth, communication, and meaning for the infant are dyadic, mutually regulated, and based on an exchange of information between parent and infant. The interplay between infant and parent has been described as messy and includes missteps, tries and retries, reconnection, disconnection, and reconnection (Tronick & Beeghly, 2011). The ability and opportunity to repair interactive errors is not only normal, but seen as essential for growth, the groundwork for new learning and understandings, allowing for implicit relational knowledge to emerge. Scholars and clinicians at the Boston Change Process Study Group label this error-ridden relational process “interactive sloppiness” (Bruschweiler-Stern et al., 2002, p. 1056). Sloppiness in this case is not pejorative but instead denotes a dynamic, nonlinear, unpredictable, and vital affective exchange that changes with input from each dyad member.

According to theory, babies are open biological systems (Tronick, 2005). Their understandings increase in both coherence and complexity as they assimilate and synthesise new information from active engagement in the world alongside the construction of new meanings derived from within relationships (J. T. Davis, 2015). Sometimes infants manufacture meaning in ways that go wrong and

may lead down aberrant developmental pathways. Some infants may come to make meaning of themselves as helpless and hopeless and they may become apathetic, depressed and withdrawn. Others seem to feel threatened by the world and may become hypervigilant and anxious or hyperactive and perseverative . . . When these aberrant or atypical forms of meaning-making persist, they can distort how infants master age-appropriate developmental tasks, such as developing self-regulation, forming attachments with caregivers or establishing autonomy (J. T. Davis, 2015, p. 107).

Theorist Tronick (1989) explained that infants make sense of themselves through reciprocal exchanges with their parent during which each member of the dyad has the potential to expand the consciousness of the other. These “dyadic states of consciousness” (Beebe & Lachmann, 2015, p. 334) in which the infant takes in meaning from the mother (and vice versa) create a powerful subjective experience. This is understood as a co-creative process in which the infant is influencing the adult while simultaneously being influenced by the adult (Tronick, 2003). As such, early experiences are both predictive paradigms and unpredictable notions due to the ongoing potential for novel exchanges of information and revised meanings.

Other theory has emerged from research that delved deeper into how the baby navigates these communicative transactions through microanalysis of face to face video sessions (Beebe et

al., 2010). Through taking a more intensive look at how babies engage in self- and other-understanding, the researchers suggested that not only is meaning being constructed through a dyadic, mutually-influencing process, but the infant also engages in self-correction via an innate and intrinsic ability to detect patterns, perceive time, and generate expectancies, thus capturing another's inner feeling state and also adjusting their own. Thus infants become known through an energetic combination of self-assessment, other-assessment, and relationship-assessment, all of which are undergoing continual flux, building on past expectation and new information (Beebe et al., 2010). These dialogues were termed "narratives of vitality" (Trevarthen & Delafield-Butt, 2013, p. 186). According to this theory, the infant narratives respond to the beat of human vitality present in relationship from the moment of birth and are of a musical nature, combining time-regulated rhythms and ebb-and-flow cycles organised in sequences that create narrative structure. The narrative arises through a unique psychobiology that belongs to the infant, measured in the musicality of infant movement and the animated ability of the infant to connect with the mother through harmony, rhythm, and melody (Trevarthen, Delafield-Butt, & Schögler, 2011).

To explain such theory, an understanding of music is used. Humans are moved by music, it states, because we can hear the human intentions and emotions behind it and we can appreciate their meaning; this is part of the adaptation of the human species. Human hands, bodies, and voices are endowed with natural rhythmic and musical aptitude and human infants experience whole-body coordination to those natural elements present in the mother's interactions. Like with Beebe's research examining the face-to-face micro interactions of mother and infant, Trevarthen and colleagues have also created a microanalysis, but this time of infant movement in response to dialogue beginning from birth. The resulting theory suggests that "the infant is a highly receptive, mobile and finely tuned Self, working with dynamic neuromusculature that inter-relates all parts into one coherent, connected activity

that expresses the baby's rhythm of experience" (Trevarthen et al., 2011, p. 18) and further finds that the more a mother's pitch hovers around the note of Middle C, the more responsive the baby becomes.

Infant theory speaks to the multi-layered complexity arising from both individual and dyadic variables, including the temporal mechanisms at play, the musicality embedded in interaction, and the notions of self-contingency as well as infant narrative. This augmentation of theory and its embrace of complexity thus finds the field discussing notions of fulfilment and wholeness within the interactions. The relevance of such theory is directly tied to how mothers engage with their newborns and come to know them, as well as how infants come to know themselves. Infants are highly attuned to the emotions, feelings, and non-verbal signals of their mothers (Rosenblum et al., 2009). Because of the intense and unique exchanges of communicative and emotional energy, "moments of meeting" are co-constructed moments during which an emergent pattern is formed and the impact of which is greater than simple one-sided information transfers (Sander, 2002, p. 36). What this means, in theory, is that dyadic connection and subsequent meaning-making is not a back-and-forth between infant and mother in which the infant elicits a response from the caregiver and vice versa. It suggests, instead, that authentically dyadic connections occur in the co-created space between the two people, and in what emerges when all aspects of giving and receiving of information meet (Gaensbauer, 2016). This is important theory for understanding the workings of mother-baby pairs as well as how mothers come to understand their infants and themselves.

It is relevant to note that these infant capacities are considered innate and researchers report them occurring in fledgling ways while the baby is still in utero (Trevarthen et al., 2011). Hence, such infant abilities are not solely the realm of older infants nor of infants born at full term. According to theory, even an infant born more than 2 months before term can begin to

share in protoconversations through rhythms and movements, and by exchanging facial expressions, vocalisations, and hand gestures with a sensitive other (Trevarthen, 1993; Van Rees & De Leeuw, 1993). Indeed, neurological theory surrounding the discovery and explanation of special neurons in the brain called mirror neurons, suggests that humans are endowed, from infancy, with a mirror matching mechanism in the brain that underpins this intersubjective ability (Gallese, 2003; Rizzolatti, Fadiga, Fogassi, & Gallese, 1999).

Complementary neuroscientific theory has emerged, having originated with the neuroscientist and researcher Porges. It is called polyvagal theory. This neurobiological theory dovetails with the previously discussed theories of innate infant capacity to socially engage and derive meaning from such engagement. According to Porges and his colleagues, humans developed an additional branch of the vagal nerve as part of human evolution; this additional branch allows for the fight-flight response to come on board when required but also allows for a downregulation of such a response in order to engage in conversation and social connection (Porges, 2007; Porges & Furman, 2011). When the human infant feels safe, which is achieved through adult-led processes and linked to visual cues, the baby's heart rate and breathing will be steady and physiology will be regulated, which inhibits arousal, creating a platform for interaction, communication, and relational connection. This move toward connection and relational construction of meaning via the safety generated in this newer vagus is called neuroception (Porges, 2004). The vagal system is believed to be myelinated and available during the last trimester of pregnancy (Porges & Furman, 2011). Polyvagal theory, while relatively recent in development, is widely accepted among scientists and researchers (Wilson, 2012) and contributes a further link between inherent infant physiology and the experience of the infant in relationship.

Taken in total, these theories of infant experience help create a picture of the microsystem of the mother-baby dyad and how various contextual factors, including biological and relational factors, inform a mother's experience.

#### *IV.3.4 What does it mean to be the mother of a premature infant*

Giving birth prematurely places mothers in an even more unique ecology as it brings with it not only the expected management of the birth itself but also subsequent impacts of hospitalisation, medical uncertainty, emotional and physical separation, stalled identity formation, fears, and difficulties. Such conditions influence and direct maternal experience and are seen by researchers and mothers alike as abnormal and stressful (Aagaard & Hall, 2008; Borimnejad, Mehrnosh, Fatemi, & Haghghani, 2011; Brandon et al., 2011; T. Evans et al., 2012; Forcada-Guex, Borghini, Pierrehumbert, Ansermet, & Muller-Nix, 2011; Hurst, 2001b; Macey et al., 1987; Mendelsohn, 2005; Muller-Nix et al., 2004; Nicolaou et al., 2009; Staub et al., 2014; Taylor, 2012; Weber et al., 2012; Welch, 2016). There is a sizable body of research literature that identifies and examines these stressors and documents their occurrence and severity among the maternal population. This is addressed in the literature review chapter (Chapter III). Likewise, however, there are also some meaningful and insightful theories that speak to the thematic issues that arise for mothers and their infants in situations of premature birth. This section of the theoretical review will therefore consider some of these theories that are especially salient to my research.

While there are likely an almost-unlimited potential for topics that could be included, I am interested in those that are directly linked with articulated maternal experience, both within my own data and that of the published literature, as they are most relevant to the research questions. I am especially interested in theoretical constructs that have the ability to shed

light on the interpretation of meaning for mothers. This list includes theories of grief, loss, and posttraumatic growth; ambiguous loss; relational uncertainty; and alloparenting.

#### *IV.3.4.1 Grief, loss, and posttraumatic growth*

The field of grief theory is substantial and vast. Grief and the related terms of bereavement and mourning have been part of the human story forever, albeit with fluctuations in meaning and conceptualisation over time and across cultures (McManus, 2012). Grief as a psychological concept, however, first made its way into publication in the late 1500s, emerging in popular discourse with Freud's conceptualisations of melancholy in 1917 (Granek, 2010). Since that time, the notion of grief has moved from a designation as a non-pathological, normative experience to being typically defined in medical terms, as a phenomenon requiring both study and treatment (Granek, 2010). By the late 1980s, much of the focus in the literature was on the health consequences of grief alongside treatment of its more pathological forms (Stroebe, Stroebe, & Hansson, 1988). From there the term "grief work" arose in the Western literature, and the field of mental health became largely focussed on helping people to work through and overcome the impact of bereavement (Parkes, 2001; Stroebe, 2008; Stroebe, 2001; Stroebe et al., 1988).

The relevance of grief theory as it relates to mothers of premature infants sits within the theory postulated around parental grief. As with most topics related to prematurity, there is extensive research data looking at prevalence, impact, and sequelae of losses due to prematurity (both due to death as well as the more psychological and emotional losses) on mothers. Moreover, specific theory also exists that considers both how parents grieve and the meaning of grief in the life of a parent. The 20<sup>th</sup> century in the West is noted historically as the first century in which the death of a child is not a common occurrence (Walter, 1999); as such, the death of a child is outside of the normal order of life and carries a significant

psychological weight. Traditional theoretical perspectives regarding parental grief focussed on resolving loss and helping parents learn to let go of the relationship (Klass, Silverman, & Nickman, 2014), stemming from the same paradigms at work across general grief theory. However, theorists and clinicians working with parents began to suggest that features of grief defined as unresolved or abnormal were, in fact, normal and natural components of parental grief (Rando, 1986; Wortman & Silver, 1989). A new theory designated to understand and explicate parental grief was afoot.

The new theory of parental grief that arose in the literature has been described as one of “continuing bonds” (Davies, 2004, p. 509). Through interviews with parents and lengthy ethnographic studies, researchers discovered that the dead children were central to the meaningful internal dialogue of the parents and that parents were able to reconstruct both their internal and external worlds in a way that unbroken ties with the child—through memory, recollection, possession, devotion, ritual, and spiritual frameworks—provided a lasting, important, and meaningful part of their lives (Davies, 2004; Harper, O'Connor, Dickson, & O'Carroll, 2011). In fact, the theory submitted that not only was it unnecessary to move on and cut ties after the loss of a child, but that maintaining a connection with their dead child was a healing factor for parents (Talbot, 2002). Theorists suggest that in grasping the implications of this revisionist approach, both parents and professionals can be helped to understand the unrealistic expectations often imposed by society and practitioners to “get over” loss (Davies, 2004).

For parents facing losses that are not due to the death of their child but are, instead, a function of the context of premature birth, theoretical implications remain salient as long as they can be attuned to the particular conditions of each parent. For example, two key theoretical suppositions in “continuing bonds” parental grief theory are that of the non-pathological

normalcy of symptoms and that of the unhelpfulness of the demand to shake off the impact of loss. Both these conclusions are highly relevant in light of maternal experience for these mothers. Like their peers experiencing child death, mothers facing non-death losses are often under pressure to move past any fallout from the prematurity experience and are at risk of being assessed as mentally unwell when features of grief arise. Research examining maternal experience following premature birth has accounted for the ordinariness and prevalence of mothers undergoing emotional difficulty, suspended identity and role transition, and feelings of loss related to early birth and insufficient bonding (Flacking et al., 2013; Forcada-Guex et al., 2011; Muller-Nix et al., 2004; Whittingham et al., 2014). These losses have a likely goodness of fit within the updated theories of parental grief.

#### *IV.3.4.2 Ambiguous loss*

The term “ambiguous loss” is recent in the literature and was coined by social scientist and family therapist Pauline Boss (2004). Ambiguous loss theory was developed to address the kinds of loss arising from chronic illness, missing loved ones, autism, psychological absence, and other situations in which the loss remains unclear (Boss, 2007). In defining ambiguous loss, it is understood as loss that is unclear, traumatic, externally-caused (not individual pathology), and is confusing or incomprehensible. Further, ambiguous loss is defined as a “relational disorder” (Boss, 2010, p. 138). Ambiguous loss can occur with physical absence but psychological presence, such as a missing loved one or, more commonly, adoption and divorce. It can also occur with physical presence but psychological absence, such as Alzheimer’s disease, coma, mental illness, autism, and addiction. Ambiguous loss can affect the person with the diagnosis, as well as the caregiver or the family. According to theory, ambiguous loss creates a unique set of stressors as well as an intractable helplessness. There is no closure in ambiguous loss in that the person is both there and not there; instead, learning

to confront and hold paradox and derive meaning in non-linear ways become essential to handling ambiguous loss.

Ambiguous loss leads to a unique kind of ambivalence, a sort of ambivalence that is present because of conditions in the environment. The loss exists phenomenologically, not necessarily quantifiably (Boss, 2010). The ambiguity of the loss prevents reorganisation of family roles, rules, and rituals as everyone waits for closure or resolution (Boss & Couden, 2002). Theory relies on the presumption that there is such a thing as a psychological family and that psychological family is not necessarily the same as physical family (Boss, 2007). In applying the theory to mothers who have children with autism spectrum disorders, for example, mothers who felt more doubt about their own identity experienced higher levels of depressive symptoms, independent of the severity of diagnosis (O'Brien, 2007). Identity ambiguity is associated in the literature with feeling immobilised, helpless, and struggling with adaptation (Boss, 1999). This is a theoretical application that appears to have direct relevance to my research population of mothers of premature infants, as the struggle to create and solidify maternal identity is well documented.

A second key piece of ambiguous loss theory rests in its hypothesis that such loss is “an inherently relational phenomenon and cannot be an individual condition” (Boss, 2007, pp. 106-107). While the symptoms of ambiguous loss have overlap with complicated grief, depression, anxiety, or general ambivalence, the source is something outside of the individual and subsequently affecting how the individual exists within relationships. While there does not appear to be any published literature examining the theory of ambiguous loss as it relates to prematurity, the links seem natural and appropriate. As mothers struggle to understand themselves as mothers and get to know their infants, they encounter obstacles that originate outside of themselves that, in turn, provoke symptoms. It requires negotiation of uncertainty,

helplessness, and contradiction. Unlike diagnoses such as Alzheimer's or catastrophic events like a loved one lost at sea, prematurity offers a partial resolution of the loss that occurs when hospital discharge happens and separation concludes. Nonetheless, mothers appear to continue to work to integrate and make sense of the diagnosis and experience of early birth and what this means for their identity and relationships. As Boss's theory suggests (2010), resilience in the face of ambiguous loss requires a combination of continuity and change.

#### *IV.3.4.3 Relational uncertainty*

A related notion to the idea of ambiguity in relational loss is the idea of relational uncertainty. The theoretical concept of "relational uncertainty" first appeared in the literature in 1999 and was a refinement of interpersonal communication's uncertainty reduction theory (Knobloch & Solomon, 1999). The field of interpersonal communication has, over 30 years of research, investigated how uncertainty affects the way people formulate messages within mutual relationships (Knobloch & Solomon, 2005). Uncertainty is defined as self-doubt about how interpersonal interaction will unfold (Berger, 1979; Berger & Bradac, 1982). The term "relational uncertainty" arose as researchers sought to develop a theory that could measure how issues of emotional uncertainty develop within human dyadic relationships and where in the landscape of relational terrain they exist. Through the process of designing measurement tools, a theory was built that suggested that uncertainty in relationships arises from the way people characterise their desire, evaluation, and/or goals for the relationship. Theory advanced what was a global construct regarding communication and argued that it had particular relevance for close, dyadic relationships. Furthermore, such specific uncertainty was located within the realms of relationship norms, definitions, beliefs, and mutuality of feelings (Knobloch & Solomon, 1999).

Relational uncertainty theory essentially puts forward the notion that how one perceives one's relationship has a direct impact on one's ability to read relational and social cues and also how one processes "relationship talk" (Knobloch & Solomon, 2005, p. 354).

Relationship talk is defined as meaningful messages that convey the state of the relationship. In other words, what someone believes about the state of their relationship primes them to expect confirmation of that belief when relationship talk occurs and orients them to cues that confirm that bias. Hence, the internal experience a person brings into a relationship has a distinct influence on how social cues are read, separate from one's baseline capacity to read cues. The more uncertain a partner feels about the relationship, the more relational inferences will likely match that judgement and will therefore potentially hamper the ability to discern and perceive relational strength (Knobloch & Solomon, 2005).

As far as I can tell, no one has yet applied the concept of relational uncertainty to the mother-baby relationship and the specific context of prematurity and ensuing separation. This was confirmed by Dr Knobloch in a personal email exchange; she affirmed the application as an intriguing direction for study and reported that barring one small study with adolescents, the concept has hitherto only been utilised with adult pairs (L. Knobloch, personal communication, 6 July 2016). Despite a lack of existing theoretical data, relational uncertainty theory seems a particularly apt approach for thinking about the ways in which maternal identity is constructed, delayed, thwarted, or impaired within the population of mothers wrestling with premature birth. If a mother's intrapsychic evaluation of trust and confidence in her relationship with her baby has influence on her subsequent perceptions, this has the potential to alter the way she interacts, defines herself as a mother, and reads her infant's bids for relationship. For example, a mother who has decided that her baby does not need her will likely process a premature baby's subtle cues for connection differently than a mother who approaches the baby with a confidence in their relationship in the present and her

role as mother both now and in the future. The theory also contributes another perspective and lens on how maternal identity formation and meaning-making unfold within the context of premature birth.

#### *IV.3.4.4 Alloparenting*

Relational uncertainty and related mechanisms that impact on how mothers become mothers in the psychological sense have a focus on the internal, relational, and emotional realms of maternal experience. At the same time, there are tangible, environmental, and physical circumstances involved in mothering a premature baby that are also at play. The private and phenomenological journeys of mothers are clearly affected by these external factors and related theory incorporates acknowledgement of their repercussions. When reviewing the theoretical literature, however, I wondered if there was evidence of models that spoke directly to these environmental realities.

Other theory is founded upon aspects of mammalian physiology, anthropological data, and evolutionary requirements; this includes the aforementioned polyvagal theory, both Harlow and Bowlby's theories, and neurobiological theories surrounding regulation and the role of oxytocin in bonding. Another relevant theory is that of alloparenting, a concept exploring non-maternal parenting opportunities from cross-cultural studies, anthropological evidence from traditional societies, and research on large mammals such as chimpanzees and dolphins. Alloparents are simply non-parental caregivers functioning, at least temporarily, in the parenting role (Quinlan, 2008). Alloparents are almost always female and appear to provide support for improved maternal health, higher levels of female fertility, and increased odds of survival for the baby; the role is sometimes referred to as “aunting” as well (Quiatt, 1979, p. 310).

Allomaternal behaviour is widely found among social mammals (Hrdy, 1976) and can take both positive and negative forms, such as care, abuse, or indifference. It is theory of allomaternal care that is germane to this review. The genesis of allomothering is theorised to have derived from the evolutionary adaptation; bigger brain development required cooperative breeding, a reproductive strategy of the provision of shared care for young, setting the stage for human infants to remain in dependent phases of life for longer which, in turn, supports larger brains capable of greater plasticity, learning, and cognitive function (Hrdy, 2009). Species with slow-maturing young favour high sensitivity to the cues they admit and are significantly more likely to engage in cooperative breeding. Typically, allomothers are either less-experienced mothers who theoretically derive benefit from the valuable experience of learning to first care for another's young, or experienced grandmothers who are no longer burdened with the distraction of their own children to raise (Hrdy, 2011).

Human females are unique among apes in weaning their babies well before the infants are nutritionally independent (Crittenden & Marlowe, 2008). As such, studies across human populations observe that mothers routinely rely on the support of allomothers to help nurture their young. Allomothering appears to have direct ties to lactation, feeding of the infant, and the mother's ability to regain her fertility while her infant continues to receive high levels of care (Quinlan, 2008; Quinlan & Quinlan, 2008). However, multiple studies of various hunter-gatherer tribes, including the Hazda and the Aka, suggest that high degrees of allomother support do not correlate with a reduction of maternal investment (Crittenden & Marlowe, 2008). Perhaps due to close kinship ties or the ability of mothers to choose their helpers, mothers remain the primary caregivers within alloparenting societies and retain high levels of authority and commitment. This can be seen among chimpanzees too, as the mothers initiate

building relationships with non-mothering females who later become maternal support (Kishimoto et al., 2014).

Similar trends and arrangements are observed within both sperm whales and bottlenose dolphins. In whales, diving patterns are altered so that “babysitting” female adults remain with calves at the surface while mothers forage for food. This allows the mother greater freedom and increased calorie intake while simultaneously protecting the baby (Whitehead, 1996). Dolphin mothers also make use of allomothers to help provide infant care. In observational research with dolphins, however, it appears that mothers will not let inexperienced females near their young until the babies are slightly older. Theorists suggest that mothers wait until the babies have imprinted on the mothers and the risk of separations have therefore decreased (Mann & Smuts, 1998).

The prevalence of alloparenting care across mammalian species, including humans, and its theoretical links to improved maternal and infant outcomes suggests an imaginable congruity with any research looking at maternal experience. In the case of my research, which analyses maternal experience within the specifics of premature birth, infants are necessarily receiving care from medical personnel as well as their own mothers. Looking through the theoretical lens of alloparenting, medical staff can be viewed as allomothers. If adopting such a view, then the gleanings of the alloparenting literature become germane to the ways in which mothers and infants can be supported in such a communal context and how mothers can build and retain their maternal role without unnecessary erosion. Such historical, cooperative approaches to childcare were theorised to be essential to the development of empathy and cooperation in human society (Hrdy, 2009) and are potentially applicable to NICU situations.

## IV.4 The mother in context

Just as each theory represents part of the contextual picture for research subjects and findings, mothers themselves exist in context. Within the research, mothers exist in a dual context; they are located within a dyadic relationship with their new baby and they simultaneously reside within a larger contextual reality that spans cultural factors, environmental influences, and their own internal ecology. It is therefore important to locate the data within an interactive ecological model so that theoretical considerations of maternal experience can be understood in conversation with each other. Failure to do so replicates the disconnected silos of the theoretical and research literature.

Without ecological theory to provide a framework, interactive and interpersonal events are reduced to islands of experience and are prone to explanations that focus solely on individual factors. In order to interpret and integrate the various components of maternal experience, it is necessary to explore how these components affect each other and the mother herself; ecological theory allows for consideration of theoretical contexts as well as their overlap, interplay, and gaps.

### IV.4.1 Bronfenbrenner's bioecological theory

Bioecological theory was first developed by Urie Bronfenbrenner in 1979. Bronfenbrenner's theorising continued to evolve until his death in 2005 (Bronfenbrenner, 1979; Bronfenbrenner, 2005). In his theory, Bronfenbrenner proposed a five-layer ecological framework. The layers include the microsystem, mesosystem, exosystem, macrosystem, and chronosystem. The microsystem represents the most immediate and direct individuals, groups, and institutions impacting the developing human. The mesosystem are the interconnections between those discrete microsystems, "a system of microsystems"

(Bronfenbrenner, 1979, p. 25) that describe “interrelationships among two or more settings in which the developing person actively participates” (Bronfenbrenner, 1979, p. 25). The exosystem involves links between the individual’s immediate context and social settings that are one layer removed yet still exert influence upon the individual, even if indirectly.

The outermost layer, the macrosystem, describes the greater culture in which the individual lives and includes the context, meaning, influence, norms, values, and identities expressed in that culture. Finally, the chronosystem (a component of the system developed and emphasised in Bronfenbrenner’s later work), represents the timing of events and transitions in the individual’s life as they are mapped over the passage of time. Additionally, Bronfenbrenner also talked of “ecological transitions” which occur “whenever a person’s position in the ecological environment is altered as a result of a change in role, setting or both” (Bronfenbrenner, 1979, p. 26); he used the experience of a mother seeing her newborn infant for the first time as his first example of such a transition.

To understand application of Bronfenbrenner’s theory to the research questions, the mother can be imagined as sitting at the centre of an interactive, layered world of influence that represents the influences in her life. But instead of being just a uniform entity in interaction with others, she is also in moment-to-moment interaction with herself. Simultaneously she is in primary relationship with her infant, a foundational microsystem dialogue that sits both inside of the microsystem and within the other interactions. Understanding the mother within such an ecological framework also helps make sense of each of the theories that are relevant to her experience. Instead of separate theories attempting to explain her experience, theories become intertwined with the various layers of influence and meaning surrounding and impacting her life.

Bronfenbrenner's theory is not without criticism, however. One of these critiques suggests that Bronfenbrenner must be paired with an understanding of life stage development theory and the theories of epigenetics and neuroplasticity to form a comprehensive model (Hoare, 2009). In other words, the ecological model's layers of influence are not the only ones exerting force on maternal experience. Furthermore, there is critique from within social work that warns against using Bronfenbrenner's model to justify or purport a hierarchy of goals for development (Tudge, Mokrova, Hatfield, & Karnik, 2009). Instead, it is recommended to ensure that marginalised people and communities are positioned as self-efficacious and self-directing, capable of constructing their own path toward development.

A social work perspective in general necessitates an attempt to understand the meaning made by each individual participant and how that meaning is constructed. Social work values include advocacy and support of the most vulnerable, an emphasis on self-empowerment, and a duty to consider societal context and its impact, for example poverty or oppression, and to advocate for change (Bisman, 2004).

In light of such critical appraisals, I suggest that a working theory establishes the infant at the heart of the mother's system, sharing the centre alongside her. Omitting the baby from the centre of the maternal ecological system risks marginalising the already voiceless infant and obscures a vital way in which mothers design their development. Clinical and research literature suggests that the mother and infant must be studied together, for most experts now view both mother and infant development within the context of a mutual regulation model. In this model, it is understood that unique, specific and ongoing, momentary, intersubjective exchanges are co-created by the pair, producing energy and information that flow back to both individuals as well as forth into the dyadic field (Apter, 2015; Gaensbauer, 2016; Tronick & Beeghly, 2011). Furthermore, microanalysis of these exchanges advances the

theory that not only is each person responding to the stimulus of the other, but they are also concurrently responding to their own internal responses, producing a complex and dynamic interplay of self-other dialogue that potentiates individual and relational wholeness (Beebe et al., 2010; Beebe & Lachmann, 2015; Gaensbauer, 2016). In this way, ecological theory provides a way to not only tie diverse strands of theory together, but also the complexity of the mother and her relationship with her infant.

#### IV.5 Conclusion

Creating a comprehensive theoretical picture for mothers of premature infants mirrors the process of maternal identity formation itself. There are interacting theories with varying degrees of overlap representing different aspects of the experience. This review has examined theories of maternal identity, maternal relationships, and the facets of the premature birth experience that impact on the trajectories of those developments. This encompassed theories of bonding, relationships, intersubjectivity, maternal identity, primate research, polyvagal systems, and theories related to premature motherhood including grief, ambiguous loss, relational uncertainty, and alloparenting. Additionally, ecological theory was reviewed. Each of the theories discussed speaks to both the research questions and the data generated therein.

Discussion of theory also elucidates the very nature of the research questions themselves. Mothers are faced with tasks of meaning-making, self- and other-understanding, and interpretation of multi-layered events that reverberate internally and externally. Respectively, choosing a methodology by which to analyse the maternal interviews had to correspond and resonate with these conditions. The approach had to be one that could discern meaning in individual experience, analyse narratives for significance, and make use of the existing theory to provide elucidation and interpretation. In the next chapter, the chosen methodology, interpretative phenomenological analysis, will be discussed.



## Chapter V: Methodology

### V.1 Introduction

Before undertaking my research, I knew little about qualitative methods and even less about phenomenological ones. As I investigated methodologies and sought to understand more about the potential choices, I read comments like the following from nurse researchers specialising in phenomenological methodology: “The understandings made possible through phenomenological inquiry help to put meaning into the everyday world of practice and human interaction” (Madjar & Walton, 1999, p. 3). My career in social work and mental health has been characterised by a desire to understand the everyday experience of people and to work at the level of connecting with clients through such experience. Prior to my dissertation, however, I worked with research that was largely confined to the “gold standard” of randomised controlled trials and believed I had to extrapolate from the findings to understand the meaning behind the experience. Yet according to phenomenological researchers, I could employ a qualitative methodology to bridge the meaning of a person’s experience to a larger human experience and, in doing so, develop my “practice wisdom” (Madjar & Walton, 1999, p. 8). As I was embarking on research that focussed on a cohort largely unnoticed in the literature, the ability to shed light on lived experience and to illuminate what may have been overlooked became a compelling argument.

This chapter covers my choice of interpretative phenomenological analysis (IPA) for my research methodology, alongside the personal and professional basis of this choice, and its application to my research questions and outcomes. I discuss what the use of IPA entails, how this methodology is applied, and how it differs from other qualitative methodologies. I

explore IPA's grounding in philosophy and discuss the relevant philosophical tenets that helped clarify my methodological choice.

Next follows an examination of the particular application of IPA to my research questions. I set out my research design, including the procedures I followed for accessing participants and gathering data, focusing on the semi-structured interview process. I explain how participants were selected, and particulars of the sample and sample size. The participants are introduced in this section with brief descriptions. Finally, ethics and potential limitations are discussed.

## V.2 The purpose of the study

My research involved an inquiry into the experience of first time mothers of low-risk premature infants. The aim of the research was to try to explain how first-time mothers, without past experience or an established “mothering map”, make sense of giving birth prematurely, understand the relationship with their baby, and come to know themselves as mothers. The research had a focus on first time mothers through the specific lens of low risk premature birth.

Medical and psychological literature has provided ample and consistent evidence that infants born prematurely are at higher risk of physical, emotional, and relational problems than their full term, healthy counterparts, with higher risk of struggles within the mother-infant relationship (Boyce, Cook, Simonsmeier, & Hendershot, 2015; Brandon et al., 2011; Brisch et al., 2005; Caravale et al., 2005; L. Davis et al., 2003; Eutrope et al., 2014; Feldman & Eidelman, 2007; Forcada-Guex et al., 2011; Macey et al., 1987; McGowan, Alderdice, Holmes, & Johnston, 2011; Muller-Nix et al., 2004; Schneider, Charpak, Ruiz-Pelaez, & Tessier, 2012; Taylor, 2012; Woodward et al., 2014). Despite such plentiful study, we know little about what happens for these mothers of premature babies, how they experience the

events of giving birth prematurely and bonding with their baby, and how they make meaning of themselves as mothers. My research sought to explore just this kind of maternal meaning-making; as such, my methodology needed to match this goal.

### V.3 Choice of methodology

#### V.3.1 *My personal process*

For my research I chose to use the qualitative methodology of IPA. Choosing this methodology was a rather lengthy two-step process that involved a great deal of reading, learning, questioning, self-challenging, and reflection. First I made the decision to go with a qualitative framework. I then chose IPA.

Initially I wondered about using a quantitative approach. My background is in working with quantitative studies and much of the mother-infant literature is informed by a combination of theory and quantitative investigation. There is a paucity of good studies that focus on low risk premature infants and even fewer that focus on first time mothers. Perhaps most influential was the fact that I was very comfortable in the world of quantitative data. In truth, I held a common bias; I had come to believe that the best evidence and guidance we had took a quantitative form. I knew almost nothing about qualitative research.

In supervision I began to focus on my research questions. What did I want to know? What was missing that I wanted to investigate? What were my own goals and values? What was missing that I could contribute to? What allowed mothers and babies to be seen and heard? The process of developing research questions was surprising and illuminating for me. Whenever I talked or wrote about my research interests and goals, I sounded qualitative. My thinking reflected an interest in stories, in meaning, in voices that were missing, in how

mothers and babies embodied and understood experience. The more I read and discovered, the more I realised that despite my long-held bias, my most passionate interests could best be explored through qualitative research. In fact, it was precisely the qualitative viewpoint that was missing from much prior research, and its absence was problematic. The relative absence of qualitative data meant that the voice of the mother—and the relationship with her baby—was also missing.

Qualitative research puts its focus on meaning. It is concerned with how people experience events and how they make sense of the world (M. Q. Patton, 2005). In qualitative research, the questions aim to discover what it is like for someone to experience some particular event, condition, or occurrence and how they manage and make meaning of that experience. Qualitative researchers are primarily concerned with the essence and nature of a person's experience, not in potential cause-effect dynamics (Willig, 2013). Qualitative researchers study people in their own worlds, within their naturally occurring settings. This was what I wanted to understand and gain access to: the world of the mother and infant following a premature birth. Without subjective, personal stories, it seemed impossible for me to understand this world. Data about how babies progressed or what risks turned up in the data did not reveal the meaning of the experience, nor did information about impaired functioning in mother-baby relationships. As a clinician, I wanted to understand how we could move forward with real support for these mothers. The available quantitative data shed little light on the meaning of what was happening and how mothers of premature babies understood their world.

In formulating my research questions, I focused on the experiences of my potential participants in an effort to develop an understanding of the particular phenomenon of premature birth for first-time mothers. Both my own values and the research questions

reflected a desire to understand the interior world of the mother and her infant, alongside a hope to gain access to how meaning is made of the experience of premature birth. As I read and discussed more in supervision, I became very clear that what was required from me was a qualitative study that focused on meaning-making but also allowed for that meaning to be put into a broader context. I also considered it important to ensure that no mother's voice would be lost in the data. This combination of making meaning and giving voice turned out to be two key, complementary commitments of the IPA method (Larkin et al., 2006).

IPA was also a good fit for my own ontological and epistemological stance. IPA offers a blending of a social constructivist position with a realist, scientific one. Each participant is assumed to be engaged in authentic, unique, and valued meaning-making about her own experience and how this affects her self-concept, her relationships, and her life in general. Simultaneously, the methodology embraces the belief that there are scientific realities and that this scientific framework is also part of the context in which participants live. Employing IPA methodology thus offers a solid accord between methodological approach and my beliefs about the nature of the world/things (ontology) and how we can gain insight into that (epistemology).

### *V.3.2 Interpretative phenomenological analysis (IPA)*

IPA turned out to have a real goodness of fit with my research, my values, and my goals. IPA is an approach to qualitative analysis that has a specific interest in how people make sense of their experience. Since being first utilised as a methodology in 1996, IPA has been employed in over 293 published papers and is one of the best known and most commonly used qualitative methods in psychology, with nearly a quarter of IPA studies focusing on some aspect of illness (J. Smith & Osborne, 2008).

As stated previously, IPA has a dual commitment to both give voice to participants and to focus on how they make meaning in their lives. This focus on the exploration of experience, understandings, perceptions, and views posits that participants seek to interpret their experience into some form that is understandable to them (Brocki & Wearden, 2006). IPA further emphasises the person-in-context, with a pledge to move beyond labels, concepts, and pre-existing notions to an idiographic level of analysis (Larkin et al., 2011). In idiographic analysis, each case is individually examined in detail, thus distilling and preserving the meaning of each participant's experience and the particular context within which the participant is situated. After each case has been independently analysed, there can then be a search for patterns across cases. IPA is equally concerned with convergence and divergence within the sample, illustrating shared themes and also showing how themes play out for individuals (J. Smith & Osborne, 2008). This commitment to honouring and retaining participant meaning and voice alongside a contextual interpretation mirrored the goals of the research as well as the ethics of social work as I understood them.

### *V.3.3 Philosophical underpinnings*

IPA rests upon a strong philosophical framework drawing from both hermeneutic and phenomenological theories. The hermeneutic tenets provide the focus on interpretation; the phenomenological ones provide the emphasis on meaning-making.

A phenomenological approach requires a focus on lived experience and embodied perception; this is distinct from other qualitative approaches that may focus on language or social processes, such as discourse analysis, or those that seek to create explanatory theories, such as grounded theory (Starks & Brown Trinidad, 2007). Phenomenology is concerned with the “subjective meanings people ascribe to events rather than attempting to record or represent objective events” (Flowers, Hart, & Marriott, 1999, p. 486) and is expressly interested in

what lies hidden within participant experience (Wertz, 2011). Phenomenology arose from 20<sup>th</sup> century philosophy and originated with Husserl and his student Heidegger (Matua & Van Der Wal, 2015). Husserl sought to create a way to investigate things as they are, directly, in a person's experience. During a period in history when most science was quite reductionist and phenomena were explored independently of the people experiencing them, Husserl attempted to find ways of directly seeing and knowing about people's lives. This spawned the philosophical approach of descriptive phenomenology (Matua & Van Der Wal, 2015), a method of pure form that purports to permit the analyst to discover the lived experience of a person via direct exploration and without bias, or "transcendental subjectivity" (Wojnar & Swanson, 2007, p. 173).

Heidegger envisioned phenomenology in a different way from Husserl, thus establishing an interpretative phenomenology, which is the tradition within which IPA is located. Heidegger argued that the analyst could never be entirely bracketed or presupposition-less; in fact, according to Heidegger, all descriptions of our experience are already an interpretation, thus the researcher participates as another interpreter of meaning (McConnell-Henry, Chapman, & Francis, 2009). Heidegger (1977) developed a key notion called "dasein", or being in the world, that suggests we cannot extract ourselves from our world. We are always engaged and involved in our world, inextricably connected to our relationships and our personal world experiences. Hence we are always interpreting our experiences through our own lens. For Heidegger, the point is not to engage in a detached analysis, but to focus instead on the concept of being and how people exist in the world (Heidegger, 1977).

"Dasein" was a partial way of describing the belief that humans make meaning of their existence simply by living in the world. Humans are not spectators, but are intertwined with their lives; they are in the world, of the world, and inseparable from the world. Being in the

world occurs in the context of being with others. Making meaning and being in the world is not a special case or something that occurs only in special times. Everyday life and everyday engagement with the world is “dasein” and even unnoticed things can be rich with meaning (Horrigan-Kelly, Millar, & Dowling, 2016).

Lived experience is just ordinary life experience. There is nothing mysterious or more meaningful about it until we take up phenomenological questions, which is to say we inquire about the meaning of something (van Manen, 2016). A central notion of phenomenology is that ordinary life becomes extraordinary when held in a “phenomenological gaze” (Madjar & Walton, 1999, p. 10); by asking what an experience was like, we move beyond what we have presupposed or left unexamined into understanding the world. Heidegger believed that we understand our lives by bringing awareness to them retrospectively. IPA is a methodology derived from these philosophical ideas combined with methods that set out how we can utilise such retrospective reflection in research.

IPA’s philosophical framework rests heavily on Heidegger’s philosophical concept of “dasein”. Just as IPA is concerned with giving voice and how people make meaning, Heidegger’s philosophy sought to expose what was of most consequence to the human being, what each person cared about and how they made sense of their life (Horrigan-Kelly et al., 2016). Phenomenological inquiry is full of “reflective wondering, deep questioning, attentive reminiscing, and sensitively interpreting of the primal meanings of human experiences” (van Manen, 2017, p. 819); this is true for the IPA methodology as well.

IPA and its underpinning philosophy also find convergence with theories supporting mother-infant relationships. As “dasein”, or being in the world, is inextricably linked to being with others, relationships are a backbone of both the philosophy and the research participant experience (Sales, Piolli, de Oliveira Reticena, Wakiuchi, & Marcon). This being with others

was called “mitsein” by Heidegger and suggests that a dimension of the self is our relationship with others (Pascal, Johnson, Dore, & Trainor, 2011). Likewise, both researcher and participant are engaged in a process of analysis and self-reflection. The capacity to reflect simultaneously on one’s own experience and that of another, to seek to understand the world of another while living in one’s own, is a hallmark of healthy relational functioning known as “theory of mind” or “reflective function” (Fonagy & Target, 1997). In my research, participant mothers took this sort of reflective stance during the interviews, as did I when I conducted the analysis.

Phenomenological philosophy also speaks of “the body subject” (Murray & Holmes, 2014, p. 19) putting forward an understanding that our meaning-making is derived from embodied experience in the world (Starks & Brown Trinidad, 2007) and that the body is a way of communicating with the outside world (Sokolowski, 2000). Our minds do the interpreting of our lived experience, but “dasein” is not an intellectual endeavour. In phenomenology, the body is not just a physical body, but is an information-gathering system that informs the way in which we are aware of and understand the world. The experience of birth and caring for an infant is a maternal experience grounded in a wholly physical journey. Both infancy and motherhood are embodied experiences and connection to that source of embodied knowledge helped provide rich data.

IPA also has relevance to my research as it relates to the larger field of health psychology (J. Smith et al., 1997). As clinicians move away from a more traditional medical model, health professionals express interest in understanding how patients experience and interpret their experiences, including the meaning they assign them (Brocki & Wearden, 2006). IPA studies can supplement our existing knowledge by elucidating processes and exploring the meaning and context of experience, as opposed to measuring outcomes or developing theories

(Biggerstaff & Thompson, 2008). IPA, with its focus on meaning making, opens up the micro world—the hidden experiences that Heidegger and Husserl were interested in—beneath the observable outcomes.

It has further been argued that IPA has important relevance for the field of social work. As social work practices and organisations are often orientated around standardised policies and responses, research which elucidates and brings forward the individual experience, meaning, and voice of clients can support empowerment, understanding, and client-centred change (Houston & Mullan-Jensen, 2011).

#### *V.3.4 Philosophical underpinnings of the role of the researcher*

Based on the assertion that interpretation is inevitable and an integral part of “dasein”, the researcher is an interpreter of experience. Instead of an expectation of abandoning pre-existing knowledge and belief, assumptions are acknowledged and the researcher adopts an open, reflexive stance (Starks & Brown Trinidad, 2007). The belief that each researcher has unique life experience and bias does not conflict with the assumption of a stance of unknowing about the world of the participant.

Unlike descriptive phenomenological methodologies, Heideggerian methodologies like IPA that do not require researchers to bracket their pre-conceptions but instead ask the researcher to acknowledge any assumptions that could influence the interviews or observation. Then, the researcher reinterprets those very pre-existing assumptions in light of the new information.

This is part of the hermeneutic process that is also central to Heidegger and IPA.

Hermeneutics is essentially an understanding that to explain a phenomenon it is necessary to examine both the parts as well as the whole; to understand a particular part one must understand the whole of which it is a part, and to understand the whole, one must have an

understanding of each part (J. Smith, Flowers, & Larkin, 2009). When the researcher then approaches the transcripts and seeks to interpret them, the hermeneutic circle is created as one moves back and forth across different ways of thinking about the data, from part to whole and back again, and then from the researcher to the participant and back again (Crist & Tanner, 2003). As the researcher becomes an interpreter of the participants (who were interpreting their own experiences) in order to facilitate meaning, the hermeneutic circle becomes a “double hermeneutic” (J. Smith & Osborne, 2008). The researcher is making sense of the participant who is making sense of the phenomenon. For Heidegger, to be in the world is to seek to make sense of the world and this is true for both researcher and researched.

IPA requires the researcher to engage with complexity, including its chaotic, messy, and unpredictable forms (J. Smith et al., 2009). IPA includes the joint reflections of both the participants and the researcher to form the analytic outcome (J. Smith, 1999). It has been argued that interpretation actually makes the research more meaningful, as participant narratives can be connected to other knowledge and analyses to form a deeper understanding (Flood, 2010). The phenomenological experience does not even end once a study is finished; the methodology implies that the reader will continue to interpret the material (De Witt & Ploeg, 2006).

#### *V.3.5 IPA and research questions*

Research questions that suit an IPA analysis concentrate on what matters to the participants, things that are both experiential and relevant to their lives. These very particular meaning-making narratives can then be analysed in a way that puts these narratives in dialogue with the literature and theory surrounding the topic. IPA’s aim is to get “experience-close”, focusing on the meaning for each participant, and then considering convergence and

divergence across the data set (J. Smith et al., 2009, p. 33). For me, what this meant was a process of considering each narrative, to hear, investigate, and delve into the detail and depth of each story, its specificity and subtleties. Then I could look at how they linked with each other.

There is special meaning and relevance in using such a detailed approach with premature babies and their mothers. The world of the premature infant is small. Everything about it is smaller than the already-small world of a full-term infant. The early birth means the baby is physically smaller and typically confined for some time to the neonatal unit. The responses and communications of a premature baby are more subtle and hard to see than an infant at full term (Feldman & Eidelman, 2007). Yet everything is there if close enough attention is paid. Similarly, the world of the mother is very active yet often obscured, even sometimes hidden from view. The postnatal focus is typically medical and physical, with the mother having to share caregiving to some great degree with medical staff (Fenwick et al., 2001). Attention to what it feels like to be a brand new mother is typically missing. In spite of that, a mother's personal meaning-making and development are unfolding. They just have no external voice. It was important for me to find a methodology that did not overlook the individual particulars of each mother and each mother-baby dyad. I definitely wanted to link the experiences to the larger literature and theory, but it was equally important to give voice to each participant's story. This seemed perhaps the only way to discern what individual mothers and babies could reveal and teach.

In IPA, research questions must be open, exploratory, grounded in an appropriate epistemological position and—perhaps most importantly—be answerable and worth answering (J. Smith et al., 2009).

I ended up with three key research questions, which were:

*How do first time mothers and their premature infants make sense of the experience of premature birth?*

*What is the nature and meaning of the interpersonal processes that occur between the mother and her infant following premature birth, both in hospital and after discharge?*

*How do mothers come to understand themselves as mothers and come to know their infants?*

These questions all seek to explore, understand, and illuminate the experience and meaning of premature birth and how self-, other-, and relational-identity is created and shaped by that. The research questions enquire not just about *an* experience, but about *the* experience of becoming a mother for the first time, in the heightened context of premature birth. This is a moment of “before and after” in which a mother is born simultaneously with a baby (Stern, et al, 1998). The research questions reflect the methodology and the reality of the experience. They reflect the unknown, the openness, the depth of meaning, and the specificity and uniqueness of each journey. They are, to my mind, also very important questions to ask and answer. Consistent with IPA, the questions are not theory-driven, but are informed by the theoretical literature surrounding the issues and also identify potential gaps in that literature, in this case about the missing meaning and context of the actual experience of the mothers and babies themselves.

Like much qualitative research, IPA is absent of a hypothesis when formulating research questions. My research questions have another layer of wondering embedded within them that stems from the body of literature in which they sit. In the world of parent-infant psychology and neurobiology, there is a widely held tenet that says, “There is no such thing as a baby. If you set out to describe a baby, you will find you are describing a baby and

someone" (Winnicott, 1987, p. 88). This phrase is used to emphasise and highlight that infants develop in the context of relationships and that immediate, ongoing attachment relationships are required for human emotional and psychological growth. However, when an infant is hospitalised from the moment of birth, this believed truth is questioned. How can an infant survive and develop without this essential relationship? Is growth suspended? What happens to the mother who is meant to fulfil that role but who is not medically competent to care for her child and sometimes absent due to physical separation? The choice of IPA as methodology and the research questions developed were attempts at wondering about this, about questioning a much larger framework without any idea about what might be found.

## V.4 Research design

### V.4.1 Initial plans

When my research was first envisaged, the plan was to conduct both semi-structured interviews of the mothers as well as analysis of a clinical intervention that would be provided by trained clinicians in support of the mother-baby dyads upon discharge from hospital. I went through an initial write-up and the university ethics approval process for this plan. I met with various hospital employees and had many follow up conversations and emails in order to complete the procedures required to finalise District Health Board approval and begin the study.

As time passed and I continued to think about the research, I realised that perhaps my initial formulation was not the best way forward. With a goal of exploring the meaning-making experience of mothers, I risked obscuring the richness of the data by taking on a mixed-method project that would spread me thinly across two projects and potentially dilute my analytical focus. I discussed this at length with my supervisors over several meetings,

exploring the various options and reflecting on the most appropriate way to approach my research. We found ourselves in unanimous agreement that it would be best to narrow the scope of the project to the solely qualitative study and to embark on this with utmost care. I rewrote my research proposal and resubmitted it to the university and for ethics approval.

#### *V.4.2 The final plan*

With the help of these discussions, I designed a qualitative research plan of semi-structured interviews with mothers who had given birth to premature infants. Instead of trying to capture mothers who had just given birth, the sample included mothers who were already discharged and whose babies could be anywhere between early infancy and 5 years of age. The focus remained on first-time mothers and low-risk premature infants, though it now included mothers who may have gone on to have subsequent children. The sample was also widened to include mothers who had given birth throughout New Zealand and the rest of the world.

Developing a design, gaining ethics approval, and then having to reverse, begin again, resubmit for ethics approval, and go forward was an interesting one. While frustrating, I gained valuable insights. In the end, I believe the research design I created was better suited for the topic. It has allowed me to focus solely on the mothers and to go in depth with the interview process, providing mothers the opportunity for space, attention, listening, and reflection. It also ensured that there was no part of the research that inhabited a place of assessment or evaluation, as the clinical component was removed. Instead, I was free to fully and curiously engage in the interviews and delve into the rich detail of the participants' experiences.

#### *V.4.3 Semi structured interviews*

The research design was based on a one-off semi-structured interview with 15 participants.

IPA typically focuses on first-person accounts, usually in the form of verbal interviews.

Interviews are to be loosely structured; participants are given minimal prompts and little guidance, a process that allows them to open up to their own experience and talk about it in whatever way they wish (J. Smith & Osborne, 2008). There are only a few questions asked of participants, and they are intentionally open-ended and relatively non-directive. They are also flexible in the order in which they can be asked. In IPA, it is important to collect a richness of data that can and should be analysed on multiple levels of meaning and information (J. Smith et al., 2009). IPA can also make use of journals and other written entries, as well as observational data and focus groups, but I chose individual semi-structured interviews for the basis of the design.

In IPA, the semi-structured interview questions and the interview in which they take place have four key features (J. Smith & Osborne, 2008):

- There is an attempt to establish rapport with the respondent.
- The ordering of questions is less important.
- The interviewer is freer to probe interesting areas that arise.
- The interview can follow the respondent's interests or concerns (p. 58).

This framework gives the interview a loose structure and focus on the topic to be investigated, but still allows participants autonomy via the ability to raise issues that were not previously thought of or asked about. In this way, IPA situates participants as the experts and provides them with a full and unimpeded platform from which to tell their story (Smith & Osborne, 2008).

The semi-structured interview format also allowed my participants to be at the centre of the research design. Instead of asking others about the experience or collecting observational data, the mothers were given an opportunity not only to tell their story and describe their experiences and the sense-making that accompanied those experiences, but also to engage, sometimes for the first time, in a process of deep self-reflection. Often because of the intensified vulnerability of prematurity and the typical hospital stay after birth, mothers do not have the time, chance, or space to dwell on their reactions and thoughts about becoming a mother. The semi-structured interview provided a relaxed, open framework for them to talk, reflect, and respond to the questions and to what was emerging for them in the moment. For the women who had a child or children present, it was also an opportunity for them to be actively engaged in their role as mothers while talking about the transitional moments when they became a mother for the first time.

#### *V.4.3.1 Including children*

The presence of children at the interviews was something I had to give a lot of thought to. The children themselves were not being interviewed and any words they spoke (if they were verbal) were excluded from transcripts. However, it was also important not to act as if an infant or child was not there. From the outset, I felt it was critical to keep sight of both the mother and the baby. It was important to achieve a wide-enough focus so that there was room for the child to be acknowledged, seen, and respected, even as the mother was the main focus. If the child was old enough, I would talk directly to him or her at times, as well as letting them both know that we would pause whenever needed. It was important that the mother not feel she had to put the child's needs aside, nor that she could not take as much time as she wanted to talk about herself. In some cases it appeared that the child reacted directly to the mother's words and responses during the interview, and mothers sometimes

had to deal with these reactions. Additionally, at times mothers would direct answers to their baby instead of to the interviewer. All maternal words were recorded and it was noted to whom they were speaking.

There are few examples in the literature in which IPA methodology was used with dyads. In all cases both people were interview participants, jointly interviewed. Having the children present without being interview participants was new territory. In light of this, I contacted Jonathan Smith, the creator of IPA, back in May of 2012 when I was first devising my study design (J. Smith, personal communication). I asked him about inclusion of the babies in the research and the possibility of assessing the baby's "sense-making" of the experience. His response was that if I were to try and evaluate the baby's response I would need to include a "baby development expert" in planning, but that having the infants present would be perfectly suitable for an IPA design. As my secondary supervisor is such an expert, we discussed the possibilities in supervision. In the end, we decided that the focus on the mother was most appropriate and sufficiently broad, as it incorporated her understanding of getting to know her own infant. Furthermore, trying to somehow interview the baby raised ethical issues regarding consent, as well as the possibility that the analysis would veer toward clinical assessment, which was neither the focus nor the intent. We concluded we wanted to stay true to IPA and align with the aim of understanding the world of the mother and the mother-infant relationship, not potentially judging or rating it. Simultaneously, it remained both practically and philosophically important that the interviews were open to infants and children, that they were welcomed if present, and that the mother guided those decisions.

#### *V.4.4 The interview questions*

My interview questions were as follows. The highlighted words are thematic categories and beneath are the specific questions.

*The premature birth*

- What was it like to have a baby prematurely?
- What happened when your baby was born?
- How has the experience of early birth and NICU affected you?

*The premature mother*

- How did you feel about becoming a mother when your baby was born?
- How do you decide what sort of mother you want to be?
- How do you feel about your mothering?

*The premature baby in relationship*

- What is your baby like?
- How do you feel about your relationship with your baby?
- What has been your baby's experience of being born early and being in NICU?

*Challenges and supports*

- What have been some of the challenges that you have encountered?
- How have you been supported in your mothering experience?
- What could further support you in your mothering experience?

*Messages*

- What messages would you like to pass on from your experiences?

I do not think I ever asked all these questions in this exact way of the participants, but in every interview these topics were covered. I began every interview asking the mother to

begin wherever made sense to her and to tell me about the experience of giving birth prematurely. This often led to the participant covering much of the intended territory without further prompting. Whatever was missing was then asked in a manner appropriate to each individual.

#### *V.4.5 The interview process*

The interviews were conducted in the personal spaces of the participants, at a time of their suggestion. All participants were offered out-of-home locations if they preferred, but 14 chose to be interviewed at home and one at her work office. Most of the participants had a child or children present, making home more convenient. When children were present, interviews were conducted with the needs of the children in mind, sometimes stopping and starting so babies could be fed or attended to in other ways. It was important to make sure participants felt comfortable having their children present, as well as being flexible enough with scheduling so that they could be interviewed at a time when their child was elsewhere if that was their preference. Of the four mothers who were interviewed alone, all chose a time when their child was at kindergarten (preschool). Because the research was asking questions about their role as mother and because participants had experienced unplanned and enforced separation between themselves and their infants, I wanted to make sure that the mothers were in control of the decision about where their children would be when discussing this early experience.

All the interviews were audio recorded. Participants were given transcripts of their interviews and were invited to make any changes, alterations, or deletions before giving final approval. Most participants approved the transcripts without alteration. Some made minor corrections where I had misunderstood what they said, and one asked for minor bits of material to be omitted. Transcription of the audio recordings was done by me, providing me with a second

opportunity to hear the interview. The audio recording at the time of interview was also helpful; it allowed me to relax and listen to the participants without a focus on trying to capture any of their words. During pauses when women needed to take care of a child or another matter, I made a note of the reason for the silence on the tape and this was added to clarify the transcripts. I also made brief notes after each interview concluded, noting my immediate thoughts, feelings, and impressions.

## V.5 Participants

The participants in my study were all mothers who had been first-time mothers when they gave birth to a low-risk premature infant. For the purposes of this study, low-risk prematurity is defined as infants born between 30 and 36 weeks gestation; infants also had no chromosomal abnormalities, no significant medical problems requiring post-discharge treatment, and were all singleton births (no twins). The gestational age range was intentionally selected. In New Zealand, infants born after 30 weeks gestation do not qualify for ongoing support services after discharge from hospital unless they have a medical condition or develop mental concerns that warrant follow up. As gestational age at birth has become lower with medical advances, services have been increasingly concentrated on the earlier-born babies. As a result, this group of infants and mothers currently represent an underreported and overlooked cohort.

The participants were gathered through referral from professional networks. I distributed information sheets (see Appendix A) electronically and in person to midwives, nurses, lactation consultants, child development experts, and parenting and prematurity support organisations. They, in turn, sent the information out through their networks. I did not contact any participants directly. All potential participants contacted me directly by phone or email. If they had not already seen the information sheet, I supplied it to them and answered any

questions they had. Once they decided they wanted to be interviewed, I arranged a time at their convenience.

#### *V.5.1 Sample size and quality*

There were 15 participants. Twelve had given birth in New Zealand. Two had given birth in the United Kingdom. One had given birth in Australia. At the time of interview, four had given birth to a second child and two were pregnant. After the initial 14 interviews, I went on to conduct a 15<sup>th</sup> with a woman who fit the criteria except that her low-risk premature baby was her second-born child; she was not a first-time mother. She found out about my research and approached me due to her experience staying overnight without interruption while her baby was in the neonatal intensive care unit (NICU). She said that the hospital in her country told her she was one of only two mothers who had ever refused to go home overnight. I interviewed her in an attempt to gain insight into the pressures to go home in the evenings and leave your baby behind, something none of the other women in the sample had been able to surmount, despite wishing they could. From what all participants stated, there were no policies stopping any of the women from staying all night but none felt they were allowed. The 15<sup>th</sup> interview was analysed on its own but was not included in the comparison process that was used to generate superordinate themes. Data was extracted to illuminate topics the other participants highlighted and discussed.

In IPA, the sample is intentionally homogenous (J. Smith and Osborne, 2008). The sample is not chosen at random and the participants have shared experiences. The sample is not chosen for its diversity; it offers insights from a position of shared experiences. Hence, the narrow criteria of first-time mothers and low risk premature infants was helpful in making sure that the sample was not too diverse. Additionally, the maximum age of the first, premature, baby was capped at 5 to allow for investigation of the effect of time passing on meaning-making

but to retain a narrow-enough focus so that the child would still be young and the mother still early in her relationship with that baby. How homogenous a sample is will be a matter requiring specification for each IPA study, with some elements of that decision being out of the researcher's control. For example, in my study I did not attempt to make sure all women had partners or had attained a certain educational level. I did exclude women who had severe mental health issues, who had given birth to twins or an infant with a disability, and women who had been a part of the child protection system. Referral sources were aware of these exclusion criteria and women were further asked to declare any history in any of these areas.

Unlike in quantitative methods or even other qualitative methods, in IPA research the similarity and homogeneity of a sample is not a problem and can actually help highlight the psychological variability within the group as well as point to the specific issues of convergence and divergence (J. Smith et al., 2009).

Sample size is a matter of discussion and debate in IPA. While it is conceded that there is no right answer on the topic, it is often recommended that between three and six participants is an ideal size, especially for a first project (J. Smith et al., 2009). From an IPA point of view, there is no sample size that is too small and many studies have been done on samples of one; first projects are typically those of students and methodological advisors do not want students being overwhelmed by the intensity of the method. The main concern in IPA is generating data that is rich enough, not having ample numbers. Because analysis is multi-layered, time-consuming, and reflective, big numbers are potentially problematic. At the same time, IPA scholars acknowledge that excellent work can be done with larger samples, especially with high quality supervision (J. Smith et al., 2009).

I opted for a slightly larger sample size than is typical of IPA. My sample is not too large as to be encumbered by the method, but is large enough that I had flexibility if I ended up

changing methodology for some reason or if any of my participants decided to withdraw their participation. The number of 15 seemed to work very well.

One of the things I sometimes wrestled with in engaging IPA methodology was the level of subtle and sometimes speculative analysis that was applied to studies. In studies with samples of only one or two interviews, each word could be held up for pondering and reflection, with multiple meanings speculated upon. When I read these published papers I found myself thinking that such a level of scrutiny was somehow artificial and impeded the flow of understanding of meaning. My reaction to such detailed analysis luckily worked well with my choice of a slightly larger sample size. It meant that I could provide the multi-layered and in-depth analysis of each transcript, as well as analysis of common convergences and divergences, without getting bogged down in the analysis of each word, each pause, and each turn of phrase. As a result, my sample size is on the bigger end of the continuum for IPA. It provides a solid number of cases for analysis while still being loyal to the method.

## V.6 Analysis

The process of analysis in IPA has been described by one researcher as “drowning in a deep bowl of spaghetti” (Wagstaff et al., 2014, p. 6). I believe the reason for such a characterisation is due to the multi-strand, multi-level, multi-step analytical process that governs IPA. Overall, analysis is organised via a set of common processes alongside common principles. In terms of analysis, it moves from the particular to the shared, both within individual transcripts and between them. In terms of principles, a commitment to discerning the participant’s point of view and to focus on meaning-making are at the centre (Reid, Flowers, & Larkin, 2005) These processes and principles are applied flexibly and in response to the interview transcripts in a six-step operation. The end result is a narrative account of

how the researcher thinks the participants are thinking and includes ongoing personal reflection about how such interpretation is being constructed (J. Smith et al., 2009).

#### *V.6.1 Six steps of the process*

The six steps of IPA analysis include: “reading and re-reading” (J. Smith & Osborne, 2008, p. 82); “initial noting” (J. Smith & Osborne, 2008, p. 83); “developing emergent themes” (J. Smith & Osborne, 2008, p. 91); “searching for connections across emergent themes” (J. Smith & Osborne, 2008, p. 92); “moving to the next case” (J. Smith & Osborne, 2008, p. 100) (and repeating the previous steps); “looking for patterns across cases” (J. Smith & Osborne, 2008, p. 101), and developing superordinate themes. Essentially, IPA is initially a process of moving from the macro world of an individual interview into a position of sustained immersion into the detail and precision of its micro topics, words, communications, and meanings. After doing this with each interview transcript, the process then becomes one of emerging out of this level of precise and intricate examination into linking and connecting participant themes into organised superordinate themes that articulate a shared network of meaning-making.

#### *V.6.2 Steps one through four*

The IPA process of working through the analysis of each individual participant’s transcript is intense. While it is acknowledged that the researcher is a part of the interview and will eventually interpret the narratives, as previously discussed, in the initial stages the researcher sets aside preconceived notions and seeks to attend to participants’ words as openly as possible. The intent is to see the world as the participant does (Flowers, Smith, Sheeran, & Beail, 1998). The first steps of reading, re-reading, and then note-taking require attention to the general concepts, impressions, timing, phrasing, and descriptions, as well as the specific

choice of words, phrases, metaphors, feelings, and comments; the expectation is that the interpretation of these elements will change over time as the researcher returns time and again to the transcripts (J. Smith et al., 2009). It was this depth of analysis that gave me direct insight into the “drowning in a deep bowl of spaghetti” comment (Wagstaff et al., 2014, p. 6). I used a variety of coloured markers in the text to symbolise the various elements I was tracking and made use of what seemed like an endless pile of yellow sticky notes and generated hundreds of index cards to mark key words, passages, and individual themes for each text. The external tools of cards and notes were helpful once I reached the tying-together steps that followed; I could pick them up and move them around, arranging and re-arranging them in groups until the pieces formed a coherent picture.

#### *V.6.3 Steps five and six*

Each individual interview underwent this identical analytical process. Once one was completed, I moved to the next. Links between interviews were not embarked upon until the last interview had been analysed. Once singular analyses were finished, I used the notes and discrete themes to derive superordinate themes that emerged from all participants. At this point in the analysis, the task switches from a focus on boosting and expanding the detail present in transcripts to one in which the sheer volume of data must be managed. The data must be reduced in order to create a map of interconnected relationships and patterns, all while maintaining its essential complexity (Reid et al., 2005). Typically, analysis also moves from working directly with transcripts to working with researcher notes.

From this process, superordinate themes emerge. Analysis takes the research further from individual participants and more toward the group, as well as now including more of the researcher. It should be noted that emergent superordinate themes are categories of shared themes, not shared experience. In other words, within a theme there can be wide variance as

to how this theme is represented, expressed, and evaluated by each participant. For example, participants may be united through a superordinate theme of a “transformation of self” but some may see this transformation as positive while others see it as negative; some may include components of family and relationships while others make meaning solely through internal processes. As such, superordinate themes allow for great variance in participant experience while uniting the common pathways, themes, or motifs by which meaning is made. In this way, IPA retains a dual quality of representing the unique experiences of individual alongside higher order qualities that drive the creation of shared themes (J. Smith et al., 2009).

In the end, superordinate themes become proxies for the main findings. A hierarchy exists in which there is a superordinate theme representing a major finding, and within it sits a nested group of subthemes that explore and explain the overarching theme. The analysis of the findings locates the participant experience in the wider literature, interprets the superordinate themes accordingly, and subsequently creates a narrative that the reader can also make sense of (J. Smith et al., 2009). Ultimately, my analysis produced three superordinate themes, each one serving as a different findings chapter. The three superordinate themes were: Little things are big things, It is Hard, and How do I become a mother?

## V.7 Ethical issues and potential limitations

### V.7.1. *Ethical concerns*

I took great care throughout the process to eliminate any ethical concerns from my research. Basic ethics were upheld through the pathways of ethics approval, consent forms (see Appendix B), and adherence to social work ethical standards. Every effort was made to protect participants’ privacy and confidentiality and all participants were given pseudonyms

to disguise their identity. Additionally, because infants and young children were a secondary focus and were often included in the interview process, I paid attention to not only how I responded to mothers, but also to their children. (This was discussed in detail in the previous section on research design and process, V.3.) Avoidance of potential ethical problems centred on empowering women to direct all aspects of the interview process and to have full control over the final product of their transcript before any analysis was undertaken.

One ethical consideration that arose for me in an unexpected way was the tension between my former life as a therapist and my current incarnation as a researcher. I was relatively unprepared for how “therapeutic” the process of being interviewed would be for mothers, as well as how much previously unexplored and unprocessed content they would discuss and reflect upon. My role was clearly defined as listener and documenter, not as an agent of change. I confronted this (internally) especially in the first interviews I conducted. This was partly because I was brand new to the process and also partly due to the fact that the first interview I did was one of the most emotionally-laden. I was deeply affected by the mother’s experience and had to reflect on how to understand, manage, and make use of my own responses so they would enhance—or at minimum remain neutrally parked—the interview process. Obviously, turning into a therapist would have been both unethical and inappropriate. It was also important for me to realise that the mothers were not asking for help. In fact, one of my biggest discoveries was just how useful a process of simply listening without ulterior therapeutic motives on my part was for women. In discussion with my supervisors, I remarked that what began as an ethical consideration was, in fact, enhancing my ability to be therapeutic in ways more valuable than some of the expressly therapeutic tools I had been previously taught.

### *V.7.2 Potential limitations*

There are two general areas in which potential limitations of the research reside. The first is in the realm of the methodology itself; the second is with regard to how my particular research is presented.

In terms of IPA methodology, one probable criticism is the sample size. For some within IPA, my sample would be considered far too large and would be subject to criticism that I risk obscuring or omitting individual participants' experiences. The larger the sample, the less the tiny details can be retained and the analysis is likewise constrained by the realities of the sheer amount of data requiring analysis (Wagstaff et al., 2014). On the other side of the argument, those outside of IPA who align more closely to methodologies that use larger samples, may critique IPA for being too narrow and not sufficiently generalisable. As discussed in V.4.1 on sample size, I tried to strike an appropriate balance and think I was successful in doing so. However, both critiques suggest ways in which the sample size I have used could have been altered to make the research more robust.

One other conceivable limitation of the methodology is the role of myself as researcher. While the interpretative role of the researcher is built into the IPA framework, it is not typically addressed in detail, with IPA often being referred to as a creative process (Brocki & Wearden, 2006). The degree to which I was truly able to see the world from the point of view of the participant cannot be proven, and it is possible that my preconceived ideas could have obscured perspectives that were put forward in participant accounts. I undertook regular, reflective and extensive supervisory dialogue on this front and received ongoing feedback and insights from my supervisors on both my reflections as well as my written work with regard to these concerns. Nonetheless, it is possible that my research is limited by ways in

which I was unable to be faithful to the mandated qualities of openness and attention to the unknown.

Finally, the potential limitations germane to my particular research sample are in the ways in which my sample does not represent the natural diversity of mothers in New Zealand. My dissemination of research information was through a variety of channels that would theoretically reach any mother who had been through the experience of premature birth; participants were self-selected and self-referred. Nonetheless, my research sample included only European women and, as far as I know, only heterosexual women in marriages or partnerships with men who were also the father of the baby. As a result, my research is limited to speaking not only to the themes that arose for my specific participants, but to themes that cannot be assumed to be common to women of other ethnicities, sexual identities, or family constellations. While many of the themes likely have resonance and relevance to almost all first-time mothers of premature infants, there would certainly be variations in meaning-making that are not captured in my data.

## V.8 Conclusion

IPA is a methodology that is concerned with individual worlds and subjective understanding; it focuses on the dynamic process of meaning-making and how people make sense of their lived experiences. It is a methodology that is also strongly connected to how individual experiences map onto the experiences of others and the larger contextual frameworks—both lived and within the scientific literature—in which they take place. Overall, I believe IPA has been a good fit for answering my research questions and explaining participants' experiences.

In the next three chapters, the findings chapters, I will examine the previously noted superordinate themes that arose through the processes of IPA analysis discussed here. The

following chapter will discuss the first superordinate theme of “Little things are big things”, a theme that may have been hidden without a process like IPA; it emerged from great attention to small but important events and linking the intricate details to the shared meaning-making experience.

## Chapter VI: Finding Little Things are Big Things

### VI.1 Introduction

As mentioned in the previous chapter, my IPA analysis produced three superordinate themes, each of which serves as an umbrella category of the main findings. The superordinate themes arose from the individual narratives and their synergy with one another. Superordinate themes represent shared areas of meaning and importance, though how that meaning was constructed was unique to each participant. A nested array of subthemes sits within each broader superordinate grouping.

Superordinate themes reflected the layers of the mothers' worlds as they moved from pregnant woman to giving birth prematurely to establishing themselves as a first time mother. They comprise the external world around the mother, the internal, intrapsychic world within the mother, and the maternal world of painful feelings and emotions. I have called these themes, "Little things are big things", "Maternal distress", and "How do I become a mother?" When combined, the themes appear to represent the overall process of meaning-making that each unique mother constructed. When taken separately, each theme provides insights into what that journey looked like and how meaning-making occurred on different levels. This chapter covers the first superordinate theme, "Little things are big things".

The external world of the mother is represented in the superordinate theme of "Little things are big things". The participants in this study are first time mothers of premature infants who were classified as "low risk" due to having a gestational age of 30 weeks or greater. They represent a special subset of first time mothers as well as a unique subset of the prematurity group. They are a cohort who most often begin their motherhood journey in the medically intense setting of the neonatal intensive care unit (NICU) with a baby typically evaluated as

being medically uncomplicated.

The medical trajectory for these infants is typically well predicted whereas the experience for the mothers is without known expectation; it is all brand new. More importantly, for the mothers, the experience all centres on one special baby. The focus for the mothers is therefore on what they can glean from their surroundings about their particular baby and their particular situation.

If one were to describe treatment for premature babies in hospital, this description would likely emphasise the interventions they receive, the markers of health and improvement as well as those of deterioration and concern. It would include typical time frames for stays in hospital and corresponding milestones that must be achieved before discharge is possible. What the findings from within the superordinate theme “Little things are big things” indicate are that when analysed from a mother’s perspective, these signals of progress and diagnostic tools are translated through an entirely different frame of reference. Whilst mothers in the sample were concerned with medical feedback concerning their infant, their meaning-making about the experience focussed largely on details. It was the small gestures, the little comments, and the small events that loomed large. Typically, it was the things that others would not have noticed, may have forgotten, or would have never asked about that seemed to have the greatest impact.

This suggests that mothers are thrust into a more intuitive world where all their senses are activated and in which they cannot rely solely on cognitive learning to guide them. A more sensory and sensitive coordination of experience results, likely due to a combination of the fact that the participants have not been mothers before alongside the reality that they are forging an identity as mother to a baby, not a doctor to one.

Simultaneously, the emergence of this theme gives the impression that part of the immediate aftermath of a mother's giving birth is to activate, or attempt to activate, a babycentric way of understanding the world. Whereas the infant's hospital is measured by medical technology, a mother's way is more aligned with the way a baby is equipped to communicate: through tiny gestures, small movements, micro-moments, and subtle facial expressions and vocalisations.

This is even more pronounced in premature infants (Als, 1986; Stephens & Vohr, 2009).

Participants reflected this competence by immersing themselves in the world of little things and extracting great meaning from small interactions.

The theme "Little things are big things" reflects how mothers saw, interpreted, made sense of, and incorporated the experiences that followed the birth of their baby. The "little things" they latched onto and pondered represent larger stories and injected their experiences with a real sense of how they were able to derive meaning and understanding about themselves and their infants, as well as the implications for the mother-infant relationship that was just underway.

Within the superordinate theme are subthemes that I have labelled Moments, Words of mothers, Events, and Words of others. I will discuss these one by one.

## VI.2 Moments

Moments were the currency of participant mothers. While narratives were told with chronological accuracy, the periods of time that carried emotional significance were measured in moments. One moment that every woman in the sample discussed was the period immediately after birth. For some participants this was a stretch of only seconds and for others it was a couple of hours; but for all, it held deep significance.

For many, it was the lack of intimate contact with their baby that carried the most meaning.

Anne described the moments following a difficult, emergency caesarian section birth.

*Anne: I was lying there going, and just remember lying there yelling out. It felt like hours but it was probably only a couple of minutes. I was yelling, "Is she alright? Is she alright?" And no one would answer me because they were all obviously quite busy with her . . . She let one little cry out and then she went quiet and they had to put her on some oxygen, um on the table, but yeah, it was, it just felt like forever. Is it alright? Is it alright? And then I think finally my midwife came over and said, yep, it's alright, they've just got her on some oxygen for a little bit but she seems to be okay. And it was like. And then I said, what is it? A boy or a girl? And, um, no one answered me again . . . It was probably only a couple of minutes, but it felt like 10 minutes before I found out what baby I had and that she was okay. Which was pretty, you know, pretty scary. So yeah, I was lying there, and it was kind of like, I couldn't see, people were in my way and I was trying desperately to get people to move so I could at least see the top of her head. Um, yeah, it was a bit tricky. So, yeah, it was all a bit surreal.*

Anne outlined an oft-mentioned contrast between a medical point of view and a maternal one. For the medical staff, time is rushed and full of action. It involves an efficient and immediate response, which is competent and typical. For the mother, time is slowed down and she is unable to act or create agency. She experiences an unabated worry coupled with a need to know about her baby. Anne's words are thinly disguised anguish. Downplaying the situation as "a bit tricky" somehow heightens awareness of just how hard it was.

Like other participants, Anne was still wrestling with the implications of these early moments many years later. She struggled to tease out her own influence from that of those first distressing moments.

*Anne: Sometimes I wonder, I mean she's not a very, she's a very confident child and she's not very needy, like she doesn't like cuddles. I mean she does every now and then, which is great, I like to think how we brought her up is that she likes to do her own thing and stuff, but then I think, well, I wonder if that's got anything to do with, you know? I mean I don't know. But whether she'd be more of a cuddly, touchy child if she had that initially from when she was born. I don't know.*

Other mothers also expressed a desperation to connect with their baby after birth, but for different reasons. Ellen was able to have immediate contact with her baby, but the baby was soon moved into the NICU.

*Ellen: So then they spent like two hours stitching me up and that felt like forever . . . and you're ecstatic because you've just given birth and I was sitting there and bubbly and excited and I wanted to meet this baby, you know, properly. It was quite a weird feeling, not, yeah, not knowing where he'd gone. I felt desperate to see him again. Really, really keen to see my baby and I felt quite desperate, not seeing him . . . I was just so desperate to see this baby and it just felt, um, like I was wasting all this time and this energy on the midwife. I was chat, chat, chatting away, just wanting to, just to love this baby, but I just couldn't.*

Ellen did not experience worry but, instead, a positive excitement and a huge desire to reconnect with her baby. Despite a moment of initial connection, her need to be with her baby—to “love this baby” and to meet him “properly”—was thwarted. Like Anne, she was reflecting on this several years after the events.

Other mothers were deeply affected in a more global way. Some of this effect appeared to be linked with the birth experience; when birth was traumatic there were knock-on effects into

the postnatal moments. Jo was one example of a mother who experienced this. Like Anne, she had an emergency caesarian after a medical crisis.

*Jo: They got him to me really quickly, which is cool and I had him on me for that whole hour they were stitching me up and all and I really appreciate that. But I didn't feel connected to him at all. When he was put on my chest I was like, errr, what is this thing? It was just bizarre and horrible . . . and they said they were going to take him to the NICU from there. And so then it sort of, they took him away. And I was like, ah, yep. I sort of kind of didn't care. I honestly didn't feel any real connection to him.*

Emma expressed a similar disconnected reaction after a caesarian that required her to be under general anaesthesia.

*Emma: I worried, especially initially, but not so worried now, that it would affect the attachment and, in fact it did affect my attachment. I didn't bond with her. It took me a long time to bond with her, even though I loved her and I would have loved her even if she wasn't mine but I think because I wasn't that pregnant, I'd really only just started to show properly and really feel her . . . And I wasn't awake when she came out, so I didn't even see her for the first 14 hours. I think it was almost like it could've been anybody's baby, really. Nothing to do with me.*

For Emma, the moments after birth were intertwined with worries about the lack of bonding. In Fleur's case, it raised a more basic question of, "Is this my baby?"

*Fleur: His APGAR scores were atrocious, like I can't even remember them, but they were just, "Oh, let's take him away". And I was just freaking out. Like, half of me freaking out, half of me glad that he's out, obviously. But I was just kind of, yeah, not knowing what was happening for a while . . . What's going on, we don't know. He was*

*just taken away. And, um, I remember just sitting in the wheelchair and my ex-husband wheeling me into the intensive care unit where, I guess, you see all those babies hooked up with little monitors and little wires. And there he is. And I just kind of go, "Hmmmm. How do I know that's my child?"*

Donna also reflected upon how the initial postnatal moments were insufficient to provide her with the belief that her baby belonged to her.

*Donna: So she was born really quickly. They put her on my chest briefly, but not for long. And she was whisked away . . . I don't think I bonded with her. You know, because I was haemorrhaging and I didn't see her for that first day. It did take a while for her to feel like mine.*

None of these mothers were discussing these post-birth moments just days, weeks, or even a couple of months after birth. The babies in my research sample were anywhere between 8 months and 5 years old at the time of interview; in most cases the mothers were recounting moments that were years old. These little moments cast a long shadow. To admit to oneself and an interviewer that you felt disconnected from your baby, or that you did not care whether your baby was with you is a brave undertaking. Despite being unremarkable from a medical perspective, their reports were full of vulnerability and emotional pain.

Not all post-birth encounters with their infants were negative. For some, the contact with their infants in the moments after birth was minimal yet had lasting positive implications. Sharon is an example of a mother who had such an experience. Almost immediately after giving birth, she was whisked into emergency surgery. Before she was taken to theatre she had managed to have a short cuddle with her baby on her chest. When I asked her what it was like right after birth she said:

*Sharon: By that point my brain, I had, I mean, I had cuddled him. So I had contact with him. I'd seen him, I'd heard them sort of say he's really healthy, you know, essentially a healthy baby. And by that point where I was being wheeled off, I was, yeah, I was pretty ill.*

Sharon named the physical contact, the sighting of her baby, and the medical staff having shared information that he was healthy as the things that allowed her to let go without feeling traumatised. Interestingly, these are three of the key things that mothers who described distress often did not get.

Meg also had a positive postnatal contact experience with lasting effects.

*Meg: So I was really lucky in the fact that once I had her I got to have her, they let me hold her and stuff . . . Yeah, I'm very, very pleased that we had that time because I think it was really important. Just to get to know each other. I got to look at her and those sorts of things. Yeah. It was lovely. It was, it almost made it more normal, you know, because it wasn't a normal situation. It made it a lot more normal because, normally, you'd get to have your baby with you. So I actually do think it helped a lot.*

Meg went on to describe her relationship with her daughter, now several years old. She included the bittersweet recollection of things not being normal at birth, but felt her close and happy connection with her daughter was partly made possible by those first moments of contact.

### **VI.3 Words of mothers**

The language mothers used to describe the impactful moments makes up the second subtheme. As with “moments”, the immediate postpartum period held great significance and

this was reflected in the choice of words. Mothers did not simply tell those stories, they also selected evocative language to elicit the emotions and meanings that the stories evoked in them.

Nine of the mothers in the research used language of speed and loss to describe the moment when their baby left them after birth. The most commonly repeated phrases were: *whipped away, taken away, whisked away, they took him, they took her*, with *taken away* alone being used by six of the women and most women using multiple descriptors in this vein. Elizabeth distilled the entire experience into one conclusion “*you have to wait to be given them back again*”.

This language did not appear to be used accidentally. It is the sort of language humans use when describing trauma, loss, and feeling overwhelmed (Russell, 1978; Whissell, 2009). The speed implied in words such as “whipped” and “whisked” indicated the loss of control for the mother; she was apparently experiencing the moment of her baby leaving her as jolting. The language choices also reflect feelings of powerlessness. Participant mothers were witnesses to action being generated by others, people unknown to the mother or baby. Not all mothers used such emotive terms and this may suggest that some were perhaps better prepared.

This moment of impact and the language used to describe it also link to the other superordinate themes that will be discussed separately in the next two chapters. How mothers form a maternal identity (“How do I become a mother?”) and manage their painful feelings (“Maternal distress”) is interconnected with these moments and their portrayals by the mothers. This relatively tiny window of time following a baby’s birth had ripple effects seen in all three superordinate themes.

## VI.4 Events

Linked with the “moments” subtheme that captured tiny interactions and small-yet-pivotal developments important to the mothers is the subtheme of “events”. The events that register high in meaning and significance for the participants are the events anchored to the realities of motherhood and the normal interactions of mother-baby life, things like holding, feeding, and cuddling. Some of these, like going to visit the baby in NICU for the first time, are filled with first-time gravitas. Even so, most of these occurrences are experienced either alone or with just a partner, and are not usually remarked upon or supported by medical staff. Many of the other events are much more mundane, like nappy changes or baths. Without exception, every mother in the study described little events that had big impacts on her thinking and feeling as well as how she negotiated the role of mother.

### VI.4.1 Seeing baby in NICU

Going to see the baby in the NICU for the first time was noteworthy for mothers and many of the mothers described it in great detail. It was mentioned so often that it merits its own subcategory within the subtheme. For many mothers, the experience was full of mixed feelings. Some were so weary from medical procedures or drugs that they did not feel they could be fully aware. Others felt both fear and happiness. Several noted how such a big event for them was nonetheless a routine event in the hospital.

*Nancy: This is such a big moment and this is just, it's just a day, it's just work for them.*

*Sort of like, it's 4:00 in the morning and I'm tired and hurry up and they are just like, let me have my coffee. I mean, they don't say that, but I know it's what they're thinking. I know it's just work for them. I mean, come on, this is the first time I see my baby. Quite a big deal!*

Despite believing medical staff did not rate this event as important, Nancy went on to talk about what meeting her baby was like for her.

*Nancy: And I was allowed to hold her because she was doing so well. At this point she had all the leads and things on and, um, I got to hold her and it, this overwhelming urge of animal instinct motherness came over me and I just wanted to lick her. I just wanted to lick her. I loved her so much that I just wanted to sniff her and lick her all over. I can't explain it.*

Nancy was one of the women who did not have time with her baby after birth. This first encounter appeared to have a deep impact and aroused intuitive and maternal feelings within her; it was very important to her. Almost five years later, she recounted its impact. Perhaps the disparity between its medical ordinariness and her own heightened response is what led to her feeling it so profoundly.

Other women struggled when first meeting their infants in NICU. Again, the matter of trying to connect with and relate to their infants was common. As with Nancy, other mothers perceived hospital staff as unaware of the immensity of the occasion; they also found the medically commonplace machinery, wires, and their premature baby's appearance to be strange and frightening.

Emma, who had not seen her baby immediately after the birth and was still dealing with the effects of being medicated at the time of her first encounter, described it like this:

*Emma: So, I went to see her and I was really nervous to meet her because it was almost like meeting a stranger in a way. But I was still high off the morphine for the whole first day so I was sort of happy, but happy to see her and she was okay. She was really tiny, but I didn't really get it all.*

The next morning once her morphine wore off she “shuffles back” to see her baby again.

*Emma: She was crying, she looked so small and I had this huge urge to put her back in. It's sort of been a recurring dream since--that she's popping out and I put her back in. . . . I really wanted to put her back in my tummy and she looked so small and I felt really guilty. I felt like I hadn't done what I was supposed to do as a mum. I hadn't kept her safe in there. It hadn't been a good place for her to grow in, obviously, because she'd had to come out. I just had all this guilt. I felt terrible. I was grieving as well because it's not how I imagined it happening at all. . . . Also she was really wrinkly because the extra skin ready for all that fat but none of the fat. So she looked like a little old lady. The other weird thing is the way they sound. Her cry when she was young, I found it really eerie. It's not a normal baby cry, it's almost like a kitten. I didn't like it. It was that sound because she was so little. I didn't like that cry at all.*

This one event of meeting her daughter was the start of her journey as a new mother. Yet it was also tinged with guilt, strangeness, and grief. Instead of a joyful meeting typifying her notions of new motherhood, it was, in her own words, “the opposite of that”.

Interestingly, Emma described her daughter’s cry as that of a kitten. Another mother, Jo, used a similar description.

*Jo: Whereas in that first little while he was just like a little kitten, a little animal that I loved and I cared for, but I didn't really know or understand. And I just carried this little cat around with me all the time and gave it cuddles but didn't really know what to do with him or how to interact with him.*

Both women used the metaphor of a baby animal, one that is typically seen as cute and harmless, but simultaneously a non-human animal, a creature that is other. It would seem that

these mothers are attempting to find a bridge between the strange and unknown to comfortable maternal territory. For other mothers it was the more tangible medical interventions that created the discomfort they experienced on seeing their babies.

*Fleur: But also seeing him hooked up to all the wires. It's just, it's terrible. It kind of, it makes him, I mean I know that it helps, but it makes him feel worse than, makes him look worse than he actually is. I mean like all the wires were actually for one thing, they were monitoring the one day because something was wrong. The wires weren't starting up his heart or anything like that. But just with those wires, he looked really sick.*

More than half the women specifically mentioned the wires. Wires appeared to signify illness and danger. Wires were something medical, not of the mother's world. Confronted with the realities of this medical world, each of them talked of trying to cope, to appear competent. Again, all of this—from the initial shock to the regroup and need to carry on—is condensed in this one event.

When Anne went to see her baby in NICU for the first time, it had been 9 hours since those moments in the operating theatre when she struggled to see her baby's head.

*Anne: They wheeled me on my bed up to neonatal and I saw her in the, um, in the little box thing and she was off oxygen by that stage, but she had a tube and I, yeah, she had all these things I didn't know what they were for or, you know, why she was, why did she have to be in this box thing if she wasn't on oxygen . . . and then I asked someone if I could hold her and they were like, oh, the first lady said, "Oh it's just really good if we let them sleep at this stage". (Anne begins to cry.) I know, it still gets me a bit funny. Um, yeah, and I said, "Oh, but she's not on oxygen or anything". Then another lady*

*came through and let me hold her so that was good. She came out and I held her in bed.*

Anne's daughter was over 2 years old at the time of interview and this moment of being initially denied the ability to hold her baby still unsettled her at the time of the interview. The tidal importance of her small request to hold her baby was missed by the medical focus on sleep hygiene. Even though she soon got her wish to hold her baby, what remained painfully affectively charged was the declining of the request.

Like medical staff, family members could also unintentionally make things more difficult for mothers. Elizabeth experienced both.

*Elizabeth: When I start talking about it again I remember that feeling of helplessness. I asked one of the nurses if I could pick her up and give her a cuddle and they said, "Of course, give her cuddles, she's your baby, do what you want with her". Then later another nurse came into the room and she sort of told me off, she said, "You can't be taking her out, she's going to be cold, it's really bad for her, you have to leave her in there". I felt so bad, so bad that I was hurting my baby, that I was doing something detrimental to my baby. But I didn't know. I felt that I was just in the way. That was really, that was really the hardest part, feeling like the baby was better off just being left with the nurses and that they were humouring me by letting me, you know, I don't know help out and hold the baby occasionally and stuff. But I felt as if I was just really in the way and better off not there. Um, yeah, so I felt very insecure and that made me worry about the bond we'd have later on.*

Later in the interview she added:

*I don't think it affected my husband. I remember saying as well, it was when she was*

*first born and he got to see her the first time and he was allowed to go in the room where she was. He said, it was so amazing just that instant, he said, “Isn’t it incredible, just that bond and that instant feeling of utter love. You can’t believe that’s your baby and you just love them immediately”. And I didn’t want to tell him I didn’t feel that. I saw a baby in the incubator and thought, “Oh my God, is that ours?” I don’t think I ever really told him that. And I still didn’t, so I think he felt that instantly but I didn’t. I felt guilty for that, too. I should have had that instant sort of, yeah, you know? . . . I thought, “I didn’t have it but I won’t tell anybody because it sounds terrible”.*

This tender description of all that was contained in meeting her baby in NICU suggests the ways in which mothers are taking in all the information—verbal and non-verbal, direct and indirect—during these key events. Elizabeth felt such great shame about her own reaction that at the time of interview she had still not admitted it to anyone. The impact of the verbal information upon mothers will be discussed further in the subtheme “words of others”.

It is worth noting that some of the women had positive experiences of being reunited with their infants in NICU and, as with the more difficult events, these affirming encounters also had lasting power. Sharon provided a good example of this; by the time she emerged from surgery and recovery, her baby had been discharged from the NICU and was brought to her room. This was the first time she had seen him since the quick post-birth cuddle she managed before she was taken into emergency surgery.

*Sharon: And I mean it was nice, too, because even though I was feeling pretty lousy, having him there in his little bassinet, whatever you call them, um and I could just lie there and look at him. And he was, you know, I guess he was pretty, he slept a lot, so he didn’t need a lot of, of physical interaction in terms of him being upset crying or those sort of, those sorts of things. So I guess just being able to lie there and look at him and*

*take him in and sort of just watch him. It's quite amazing really. Yeah. I think it helped, yeah, bring it all, it just gives you that time to sort of, um, come to terms with what's happening and that there's another little life there. And I guess having, in a way, having that little bit of distance initially it probably helped with processing those things. Because I could sort of, I mean I remember watching him, just lying in my bed with him in his cot and just sort of, like, "well, you're my little boy". Yeah.*

Sharon had a difficult birth and faced the stress of her own illness. Her baby, however, had a quick discharge from NICU and was brought to her room, into her private space. This was noticeably at odds with the other mothers who found their way into the NICU space. In Sharon's room she did not have to ask permission or deal with incubators and wires. This mother-owned space appeared to make way for an inherently positive event and the subsequent conclusion, "you're my little boy".

#### ***VI.4.2 Other events***

There were a variety of other unique events that are important examples of how little incidents or occasions create big platforms for changes in thinking and feeling. Two other events arose in the narratives of nearly half of the participants. One was breastfeeding. The second was mothers discovering that things had been "done" to their babies when they were not present

All of the mothers in my sample breastfed, though some used complementary formula and the length of breastfeeding varied from a couple of months to a couple of years. In terms of breastfeeding's relevance in the superordinate theme, the start of the breastfeeding experience was another point in time that signified something big for the mothers. Management of obstacles in breastfeeding were another small event with big consequences.

For many of the mums, their first experience with breastfeeding was without a baby. It was typical for mothers on the maternity ward to be approached by staff to begin to express milk, or colostrum, to provide for their newborn in NICU. For first time mothers, this meant that their first attempt at feeding their baby was with their baby somewhere else.

Paradoxically, several of the mothers felt pressured to breastfeed despite the fact that they already intended to do so. These mothers discussed how rhetoric and staff protocols made them feel as if they had no part in the decision and, as a result, they felt pressured and diminished as mothers. In Tanya's words, "*It's all about the baby*". Nancy echoed this. "Mothers are just visitors".

*Tanya: It makes me angry about the whole breastfeeding thing. Cause they really push it in the NICU. And it's important, especially for the little babies to get it too. They push it so hard that it's like, it's almost like you don't get a choice. They didn't actually ask me if I was going to breastfeed. Ever. They give you the pump and they say you need to do this. And actually I just had her and basically a midwife came in, who I didn't know, and milked me. Like literally milked me, to try and stimulate colostrum, to try and get me to be stimulated to make some milk to give to the baby. Which, you know, I understand and I'd do anything for the kids. Even being milked.*

Tanya was able to breastfeed and desired to do so. Yet she ended up feeling used. An event that could have helped establish her sense of maternal accomplishment instead left her feeling like a dairy cow.

Sharon expressed a similar, if more tame, sentiment:

*Well it was sort of, as soon as I was kind of well enough, the next day they were like, "Right, let's see if we can get some colostrum" and stuff. And you sort of, I mean it's*

*not, I mean, I guess all you want to do is the best by your child. And because I could and my milk did come in quickly, um, that wasn't a problem . . . But then it must be awfully difficult for women who their milk doesn't come easily for.*

There was no suggestion from any mother that anything medical was amiss. Instead, it was the context, the nuance, and the framing of the moment that created the pivot from potentially positive to expressly negative.

Difficulty breastfeeding also became pivotal events imbued with meaning. Fleur missed out on early breastfeeding support and struggled emotionally.

*Fleur: At about maybe six weeks, there came a point where he was just going through some growth spurt and he just couldn't get enough milk. And the first time I gave him formula he just wasn't interested in the breast anymore. And I just always wonder if whether those first days were really crucial and if I kind of missed my boat, you know. So that's probably my biggest, like obviously he's grown up and he's a big strong boy now. And like there is absolutely no issue in his development whatsoever. And quite quickly he caught up with his peers in terms of stats, or whatever. But the only thing that remained from that period that I kind of wonder about is the breastfeeding issue. Whether with some proper care and like somebody straightaway coming to me and saying "you've got to express", whether that would have, like would those couple of days changed anything.*

Breastfeeding support was typically administered solely according to infant need. For Fleur—and likely for most mothers—mothers also have needs in this regard, and make meaning of their own experiences. Despite Fleur's certainty that her son was not

disadvantaged, she was nonetheless unable to say the word "regret". This may have signified a deep vulnerability that was not remedied via infant-only focussed attunement.

Jo had a different difficulty, one common to three other mothers. She needed a nipple shield to successfully breastfeed. Jo told a commonplace story that represented the experience of others.

*Jo: We were trying everything we could think of to get him feeding so we can get home and she just rolled her eyes and went, "Nah, we don't believe in that". But then it was only my midwife who then suggested, "Try a nipple shield". We tried it, he started feeding immediately; we went home the next day. You know? And just no one bothered to spend enough time with us to help us figure this out.*

Little oversights had big implications. For Simone, the small event of a delay in employing a nipple shield had ripple effects.

*Simone: So the reason she couldn't come home wasn't that she wasn't big enough, because she was 2.2 kilos, so she was big enough to come home, it was because she couldn't feed. But, actually, after 8 days, I had one of the midwives, you know we were attempting to feed and sometimes she'd get a latch but not usually. I think it was on day 8, must have been on day 8, must have been, and a midwife looked at me trying to feed (baby) for about 10 seconds and she said, "You should try a nipple shield, I think it would really help". Soon as we put that on, she was feeding and she was home in 2 days. And that's something that I'm quite angry about. Because all the other midwives obviously had, or NICU nurses, you know, they seem to have, they don't like nipple shields . . . so if somebody had said it to me at the start, we would have been home. And that, I really struggle with, because that was a week of being*

*away from my baby and being upset and all those sorts of things.*

Once again, sound medical practice translated to mothers through their own assessment of meaning and significance, yielding potentially unexpected conclusions. For the participants, the suggestion of a nipple shield was about noticing what they needed in order to get the breastfeeding relationship working. This little event impacted the mothers and the mother-baby relationship, as did the timing of its occurrence.

## VI.5 Words of others

All the subthemes have overlap between them, and the subtheme of “words of others” is no exception. The previous subthemes were represented through words chosen during the interviews and even included a subtheme about maternal language. This next subtheme, however, has an emphasis on words themselves, specifically those things said to participant mothers by other people. Mothers were receiving a huge amount of new information from multiple sources, yet some communications were potent and memorable, whereas others did not bear mention. Based on their own accounts, it appears they latched onto words that signalled danger, errors, or rejections: threats to their wellbeing and status as a mother.

From the outset, mothers reported a heightened need to understand what was right and how to do the right thing.

*Simone: I wanted someone to tell me how to do it and I wanted to do it right. I didn't want to get anything wrong. I really wanted to get everything right.*

*Ellen: I never spent a lot of time in hospital but it felt like a place I wanted to get out of. And I felt like I had to follow the rules. And I felt like, like at school, if I didn't do it right they weren't going to pass you. I wouldn't be let go.*

Mothers were working toward a goal of getting their babies back; they had their antennae up for potential obstacles.

Roughly half the participants discussed the significance of having to ask permission to pick up their baby. The natural inclination to hold their baby was impeded by their fears of doing something wrong. Sometimes even asking for permission was responded to as an error.

*Jenny: And I said to the nurse . . . I said this was my baby and then I looked in the thing and I said, I turned around and I said, "Can I touch her?" And she looked up and said, "Well, she's your baby isn't she?" And she looked back down. I guess I'm allowed to touch her then. I don't know, I don't want to break the rules.*

*Maria: I remember one time I tried to pick her up and one of the nurses came up to me and said, "No, actually you're really supposed to leave her in the cot because she's really quite small and you actually need to keep her warm there and not much touching". And I'm a really touchy person and I'm quite close. And then I asked another nurse and she said, "No, no, it's really fine. The more contact the baby has with the mother, the better". And that's what I thought. She was in my tummy for 9 months so it's good, that, to be close. So that's what I thought. But when this nurse told me that, it kind of throws me off you know. . . It was confused for a while. Thinking that I hurt her by picking her up. What should I do, you know? Then it was like, maybe not.*

Some mothers, however, took a more assertive stance.

*Nancy: And you know I would go in there and get her up to kangaroo care her and the people made the comment that I didn't ask permission. And I'm just like, but she's my baby. I don't need to ask permission.*

Despite describing her time on the NICU as "*a daily battle*", Nancy reaped the benefits more passive mothers did not.

*Nancy: When she was on me, the smell of her and I just knew every crease on her ear and where her hairline was and her eyebrows. Yeah, just spending all that time with her and look at her all the time. And if I fell asleep in the chair with her on my chest, she would sleep with me.*

That intimacy was something mothers reported craving; again words of others could unbalance them in this regard.

*Meg: They don't understand that we actually just want to sit there and stare at our baby. It's just like what any other mother would be doing at home . . . And they would say to me, "You can go away and do a wee job if you like". This is my job right now. Just looking at her. I'm fine thanks. "Ah, don't you need to get some sleep, love? Pop home for a while". Pop home??! Are you kidding?? Without my baby??!!*

Mothers were often looking for help to become more of a mother, not to get a break from motherhood. They were needing support in their roles, but did not want to violate rules or get told off. As a result, well-meaning suggestions that sought to give mothers time and space away from their babies often struck a sour note.

For Simone, struggling with feelings of depression in the aftermath of the birth, spending time with her baby was paramount.

*Simone: I would basically go in everyday and kind of sit there. And they were telling me, "Just go and just do something for yourself, she's got the best care where she can be. Just go to the hairdresser". And I was in such a frame of mind that I thought,*

*“What’s wrong with my hair?”*

For a vulnerable mother like Simone, the discouragement against just sitting and being a mum translated into a profound conclusion: something is wrong with me. Later Simone discussed being told off for something she wanted to do for her baby.

*Simone: And then I started crying. And she was saying to one of the other nurses, “I just don’t know what is wrong with these mums. This is the second time today that someone is crying on my shoulder”. So I thought, “Have you looked at yourself maybe?!? We are all mothers. It’s not a happy place to be in. So maybe you should be aware of these kinds of things”. I don’t know.*

The NICU was not a happy place for mothers. That was both obvious and somehow overlooked. Participant mothers operated with a kind of vigilance, seeking to carve out a role and meaning for themselves alongside a developing relationship with their new baby. This included vigilance toward what was said, the way it was said, and the message it conveyed.

## VI.6 Conclusion

Few of the moments, events, or exchanges described here by mothers would have lasted more than 5 minutes. Almost none would have made it into a medical chart or case notes. These powerful happenings and words are all little—little spans of time, little details in experience, little events within the larger medical drama. They exist in almost invisible spaces, in ways that one has to carefully look for in order to see. The superordinate theme of “Little things are big things” seems to be a strong representation of how mothers attune to the environment of their very little babies and how they come to understand what is important from a mother-baby perspective.

In the next chapter, I will discuss the second superordinate theme of "Maternal distress" and its relevant subthemes.

## Chapter VII: Finding Maternal Distress

### VII.1 Introduction

The first superordinate theme, “Little things are big things”, was detailed in the previous chapter. That theme relates to things *outside* the mother, particularly the little things that held significant meaning for her. The second superordinate theme is entitled “Maternal distress”. The theme of maternal distress relates to things *inside* the mother, specifically the difficult and painful emotions she experienced. The third superordinate theme, which will be discussed in the next chapter, is entitled “How do I become a mother?” This theme moves into the territory of things *in between*, including the relationship between the mother’s sense of self before and after giving birth, the relationship between the mother and her infant, and the relationship between the maternal lens and that of hospital-based medicine, as well as her larger contextual world.

As participants in the research were medically low risk mothers with low risk babies, and because low risk prematurity is typically medically straightforward, cases were not responded to as severe or worrisome by neonatal intensive care unit (NICU) staff. As a result, there was rarely any concern about how the mothers were coping emotionally, especially if they did not present with acute or obvious outward symptoms. Yet whereas the doctors and nurses who cared for these infants may not have experienced personal distress, the mothers of the babies did. In fact, maternal distress was predominant among all of the participants.

Emotional distress was what mothers discussed most. It appears that the low risk label for their infant—combined with the medical assessment of the babies as predictable and treatable—created a mismatch between the distress mothers experienced and the environment they found themselves in. Because the medical assumption was that the baby would be fine,

an invitation for mothers to express emotions such as fear, worry, anger, sadness, grief, guilt, or panic was largely absent. It seemed that to divulge such feelings could indicate a lack of coping or be seen as unhealthy. Yet for the mothers, it was the experience that seemed abnormal, not their responses to it. As a result, mothers used great chunks of interviewing time to talk in detail about the most upsetting, traumatising, angering, or worrisome thoughts, feelings, and events. Many mothers were still processing these experiences years later and often were raising reactions in the interview to which they had not previously admitted.

The superordinate theme of maternal distress reflects the persistence, meaning, and importance of the painful truth of these mothers' experiences. It also validates the normality of distressing reactions despite low risk medical assessments.

Within the theme are subthemes that I have labelled Separation from baby, Afraid to go home, Not my baby, No control, Get it right/got it wrong, and No whinging.

## VII.2 Separation from baby

Two of the subthemes encompass matters that point to distress stemming from an event or experience. The most predominant of these subthemes was that of "Separation from baby", which focused on the mothers' experience of being physically without their babies. Thirteen of the 14 mothers in the sample experienced separation from their baby. (One mother was unwell but her baby was not, so her infant roomed with her on the maternity ward.) Two of the remaining 13 were able to stay in hospital the entire time their baby was in hospital and only experienced separation or night time separation due to being in a different part of the hospital. Despite the comparatively minimal separation, they both discussed this separation in negative terms. For the 11 mothers who were discharged from hospital before their infant, separation was a matter they described with intensity and strong emotion.

*Elizabeth: And you feel really, like the separation is just intense. It's so intense. You can imagine what a mother might feel if her baby was to die. (crying)*

Elizabeth's experience with separation led her to imagine the feeling of her baby dying.

When Elizabeth talked about the separation during the interview she was holding her baby, then nearly a year old, close to her. She looked at her baby as she began to cry and pulled her closer.

Like Elizabeth, Tanya was also holding her baby when she talked about leaving her baby behind after her own discharge from hospital. When recounting the separation, she sometimes spoke directly to her daughter, once even asking her, "*Was I worried someone was going to take you away? Maybe*".

As with Elizabeth, Tanya also accessed a primal fear, this time that someone would take her baby. To protect a baby is a most maternal instinct. According to psychodynamic thinking, the first question the new mother must answer is "Can I keep this baby alive?" (Stern, 1995; Stern & Bruschweiler-Stern, 1998). When mothers must unwillingly leave their baby in someone else care, they cannot fully answer this question and it can be emotionally destabilising as well.

*Tanya: It was horrible leaving her there. Horrible leaving her there. I hated it. . . . I think it's really important and surely it's only beneficial for the babies to have their mums there all the time. To have that. Like with the abandonment side of it, you almost feel like, I almost feel like, I feel guilty I wasn't there all the time. So when she cried, I wasn't there. . . . I would have really liked to be there for her with those cries, even if it was just to comfort. . . . It was just that we couldn't be with her for 10 days. But is that such a big deal? To me, it's massive. But actually to everyone else, I don't know. I*

*suppose mums probably do, they understand, it would have been horrible.*

Tanya captured the sense of future worry and resulting implications from the separation.

Tanya also highlighted the mothering frame of mind that provides stark contrast to the medical one. Her wish was to be by her baby's side just to provide her baby with comfort. She did not envision her role as saviour or the one with the solutions. She simply longed to be in relationship with her baby. In continued juxtaposition between the two models, she understood that to her—and, she hypothesised, to other mums—being apart for 10 days is huge, even if within the medical model this separation was considered to be harmless.

Donna's comments further illustrated the ways mother-knowing differed from the intellectual ways of medical knowing. (Donna had given birth to a second baby by the time of the interview.)

*Donna: Yeah, because, yeah, it's just, it's against all instincts. You know, everything, your whole body is screaming, you can't leave here. Your baby is upstairs. . . .*

*Probably one of the hardest things in my life was leaving them, like going home.*

*Because it just feels so wrong, you know?*

Donna ended the above comment with a question, one that both stated her belief and sought confirmation. The wrongness of leaving her baby to go home was clear to her, yet this clarity was perceived by her as lacking within the medical environment.

Participant mothers said that doctors and nurses attempted to ease their worry by telling them that their babies would not remember the experience of NICU. This information was not necessarily helpful to the mothers. Even if a mother believed this to be true, it denied the fact

that the mother is having her own experience. Such a conclusion omits consideration of the mother's memory and her world.

*Meg: I was in for 10 days. And I had to go home. And that was the hardest thing ever. Ever. Ever. Ever. . . . I was trying to be the best mother I could for her, but I felt so out of control and so out of my depth and so scared that I thought, "What sort of a start in life is this for my daughter?" And they kept on saying, "They don't ever remember. They don't ever remember". But I will remember!! And that will affect my relationship with her. Because I will remember that I had to leave her there. I will remember all the feelings and the guilt I felt.*

Meg understood that her own experience was central and could impact the future relationship between herself and her baby. Her words convey just how intense the difficulty was for her, especially when she repeated “ever” four times. As many of the women expressed, this leaving—so commonplace and apparently medically unremarkable—went beyond anything they had had to endure before.

Regret was also a common feature of the maternal distress that arose from separation. For the mothers that spoke of regret, there was a distinct sadness that contained elements of self-reproach within. In every case, women felt as if they had had no choice but to leave their babies, but paradoxically they knew they had made a “choice” to go. It is important to note that all the NICUs had 24-hour visitation for parents. With the exception of one mother who became unwell during her baby’s hospital stay and who was therefore not allowed to visit until she was healthy again, all the other mothers had continuous access to their infants. However, NICU staff told mothers directly that they “could not” stay overnight. There were no beds available and only a few chairs. There were no provisions for mothers, such as food or blankets. Mothers remained visitors, albeit ones who could come and go at any time of

day. In order for mothers to sleep, they had to go home. Even if they were to forgo sleep, they would be directly disobeying advice of the NICU staff, something that would require extraordinary assertiveness and self-assurance from a mother. For a first time mother, it could require a level of confidence she has not yet acquired.

The confidence required of a mother was addressed in an ancillary interview I conducted with a mother called Amy who stayed overnight with her premature baby. Her baby fitted the criteria for the research except that this mother was not a first time mother; her premature birth experience was her second pregnancy. I conducted the interview because Amy was one of just a couple of mothers who had ever stayed overnight in the NICU at her local hospital. Her narrative was not included in the general analysis of data but lends important context to the issue of separation.

Just 5 hours after giving birth, Amy's baby ended up requiring emergency medical intervention. He was whisked away and Amy was left standing in the corridor watching from a distance.

*Amy: And I felt like it was this medical circus . . . And I thought, actually you're talking about my baby. My baby! That only 5 hours ago was inside me and no one was allowed to touch and now is yours. Yours to experiment with and yours to play with. And it was such, I remember standing there thinking, "He [the doctor] doesn't know I'm the mother". . . When we had [first baby] we didn't name him for a while because we wanted to wait, to find a name that suited him. Whereas with [second baby], we named him on the first day because we felt he needed a name in there.*

Amy was obviously deeply affected by the separation and the loss of control; she described her baby as belonging to the medical staff. Yet, unlike any participant mother, she

simultaneously claimed him as her own baby. “*My baby!*” she yelled. Her maternal identity and belief that her baby was hers appeared to precede his birth; she even realised that she needed to carve out his own identity within the NICU, to make him more personal and more hers. This background appeared to be fundamental in building the confidence she needed to go against NICU wishes and stay overnight for the duration of her baby’s stay in hospital. The confidence did not make it easy, as she spoke repeatedly of the overt and indirect pressures to leave; but the confidence did make it possible.

Perhaps because of this grey area where staying by your baby’s side meant disobedience, several of the mothers experienced profound regret over their leaving. Nancy’s baby was now several years old yet her distress was palpable.

*Nancy: And then on day 3 I had to go home, which I found awful, just hated leaving her and then there was this whole thing. You know, I’d drive across the causeway and it would be like on one side of the causeway I was a mother and on the other side I wasn’t. . . . And I think my biggest, biggest regret is that I didn’t stay with her all the time. And I left her.*

Nancy felt divided. She was literally divided in space and time, a mother when she was in one place, not a mother in another. She was also divided against herself, regretting the decision that she herself had made. She emphasised this by saying that not only did she not stay with her daughter all the time, but she “left her”. She used both passive and active language, highlighting how she was both powerless and the one who decided. This was a common and real contradiction for these mothers.

Like Nancy, Anne felt torn. Her regret took a self-questioning form and she was unable to quell lingering doubts and discomfort.

*Anne: And I remember her talking about having to go home and I remember thinking to myself, if that ever happened to me, I just wouldn't. I just would not go home. There was no way they could make me. . . . And it was, I don't even know if I can talk about it. It still makes me really teary-eyed. To leave my baby in the hospital. I sobbed the whole way home. "Stop the car! Turn around!" . . . The worst day of my life, having to leave her. It was just horrible (crying). Yuck. Just yuck. . . . You don't get a choice, it's like you don't get a choice. I mean, I could have said, "No, that's it, I'm not leaving", well, you wouldn't. Now I think, "Now, why didn't I say that?" Honestly, you can't. But, um, horrible, horrible, horrible.*

Another mother wondered if the emotional pain of separation was somatised into physical symptoms. Maria developed a very high fever and infection after discharge and was subsequently readmitted.

*Maria: I had to go back into hospital. I was actually happy to go back to the hospital because I was closer to her. . . . I remember thinking, "Maybe it's my body responding to this whole experience", that I actually, in my head I wanted to go back to the hospital [and] this is why it happened.*

For the 11 mothers who were discharged before their infants, the experience of leaving hospital alone was anguishing. Each woman had a unique experience, yet each described an intensity of distress that mirrored the next. Simone summarised it succinctly by saying, "I think the hardness is to leave".

This brief sentence seemed to capture what all the other mothers were saying in their more detailed and emotional descriptions. Yet the simplicity of Simone's words somehow painted the full picture. Her use of the word "hardness" was particularly evocative. There is a

generally accepted softness associated with mothers, with things maternal, with babies, with the postpartum body, with babies together with mothers. Yet there is a hardness within the medical world, a hardness of facts, data, measurements, rules, and procedures. For participant mothers, leaving one's baby was the hardest thing of all.

#### *VII.2.1 Lesser separations*

There were other sorts of lesser separations that women also mentioned as being painful. One of the most repeated was being without their babies in the maternity ward, surrounded by other new mothers who had their babies with them. Another recurring topic was the emotional strain caused by the daily comings and goings to and from their baby, including the ongoing leavings that occurred each night; many women spoke of how they longed for their babies in the night, especially when they awoke to pump breast milk.

##### *VII.2.1.1 The first night alone*

For participants who had to spend their first night as mothers without their baby, this was indelibly etched in memory. The typical maternity ward is a flurry of activity of feeding, crying, bonding, and sleeping, with mothers and babies getting to know each other. The simple physiological mechanisms of gazing into each other's eyes or smelling each other's skin are wordless yet profound (A. N. Schore, 2000, 2001a).

From a hospital perspective, a first night apart is not problematic. For mothers, the first night after giving birth appeared to be a time of extra vulnerability and openness. Mothers spoke of heightened awareness and intense emotion. To be without their newborn babies (whom they often had barely seen, if at all) was very unsettling for most.

*Nancy: She went off in the transport incubator and I just hated that. . . . You go through*

*all the motions but you haven't got a baby. You've left that baby in someone else's care.*

*Donna: It was one of the worst parts of the whole thing. I was on my own. I wasn't pregnant anymore, but I didn't have a baby. . . . I was wide awake. It was horrible. A very long night. . . . You know, they were just busy, they were there with mums who had babies. But I didn't. I was thinking about it when I knew you were coming for the interview and I thought, "That first night was pretty lonely".*

Nancy and Donna described a kind of liminal state, not pregnant but without a baby. In 2008, I attended a workshop conducted by a perinatal specialist and a member of the International Stillbirth Alliance entitled *Am I Still a Mother?* (Culling V., 2008). The workshop discussed how women who lose a child to stillbirth and miscarriage confront a basic question of “Am I a mother if I don’t have a baby?” The presenters explained that these mothers were suspended between expecting a child and having a baby physically present. They asked the questions, “What becomes of these mothers?” and “Do they have the right to be called mothers if the way we construct motherhood requires the presence of living children?”

In one very poignant part of the talk, the presenters provided transcripts from interviews with mothers who had endured infant loss. A common theme was mothers wishing they could have the bad experiences that other mothers had: the postnatal depression, the sleepless nights, the management of colic. The mothers who lost children felt these experiences were real motherhood experiences, that they grounded women in motherly ways and duties. They longed for the very things new mothers often complain about. Similar sentiments were echoed by the women in my research.

In Donna’s reflection she brought up the pain of being stuck in this in-between state. She was

no longer expecting anything, but waiting for someone, yet she had no ability to reach the baby she was waiting for. That baby was elsewhere, being cared for by someone else. Was Donna yet a mother? Could she feel like one? Could she fully inhabit that role? It seems likely the separation was an obstacle to those things occurring. The question remains just how big that obstacle is for mothers and what, if any, lasting effect it has. Clearly, as Donna pointed out, the experience can remain in the minds of mothers many years later; Donna had begun to reflect on what she wanted to say in advance of the interview and the loneliness of that night rose to the surface.

Elizabeth had a similar experience but her words expressed how the depth of the experience for mothers without their babies can be inadvertently trivialised.

*Elizabeth: It was, I just remember being in that bed and just kind of crying because there was a lady in the room in the other bed and she had her baby and she said to me, “Don’t worry, everybody cries. You’re crying for no reason”. And I was thinking, “But I have got a reason to cry! I haven’t got my baby with me”.*

Elizabeth had a strong response, but did not verbalise it. This was typical for participants when they had a reaction that did not fit the perceived expectations. They discussed how they thought things but did not say them aloud. The unspoken thoughts were maternal thoughts. In most situations, a mother’s distress over not knowing where her baby was or over her baby being taken away would be not only normalised but praised.

Other mothers told a similarly poignant story.

*Fleur: I was like in a normal maternity ward so you had all those mums with normal children, kind of there sleeping with them, cuddling them, trying to change their nappies and all that business. And, um, here with me and my baby is in another room.*

*He wasn't with me . . . it was just like, whoa! I can't even take him out of the crib.*

*Anne: Later that night I was sure I could feel my legs, then I asked if I could go back down to see my baby but she said, "No", she said, "See how you feel in the morning". So I didn't sleep much because I was thinking of my wee girl that I'd seen for like five seconds, I hadn't even unwrapped her or anything. I didn't know what she was like.*

The impact of the disparity between mothers with their babies alongside them versus the solitude of participant experience is captured by Fleur's "whoa" and was felt by many. For Anne, although she had not yet been able to connect with her infant, she still held a strong desire to see her fully, to know who she is. This desire was more painful when women felt ignored by staff.

*Emma: The night was really hard because family has to go home and there were a ton of other women in the post-op suite all with their babies. . . . Just felt awful. Wasn't pregnant anymore, but I didn't have a baby. Couldn't go and see the baby because I was so unwell. I was wide awake. It was horrible. A very long night. And I know they were very busy, but I think that if I had a baby I would have, they would have looked in on me.*

The significance of being separated during the first night was clear. Whether instinctual, physiological, or emotional, mothers forced to spend their first night of motherhood away from their infants were deeply affected; they each perceived it as an interruption in their ability to feel and behave like mothers and to relax into that role.

#### *VII.2.1.2 Daily reunions and departures*

The ongoing hellos and goodbyes were part of the NICU experience once women were

discharged from hospital and visited their babies while living at home. These daily reunions and departures became expected for mothers, but for no one was it an unemotional leave-taking.

*Maria: It was wrong, me being here and her there. And when I visited her, having to say goodbye . . . that whole routine was just horrible. It was really, really bad.*

Maria's use of the word wrong was common among the mothers and emblematic of the thematic implications. Mothers articulated a basic sense of wrongness when separated from their babies. They appeared to feel this emotionally and physically, not just intellectually and often used the terms "wrong" and "not normal" interchangeably. In doing so they built a basic paradigm: it is not normal for a mother and baby to be separated.

*Jenny: Having to leave at night, I found that really hard. Just because I knew that wasn't what you were supposed to do as a new mum. . . . I don't know that I expected anything in particular, I just felt as if I wasn't, I was, I just felt I wasn't the mother I was supposed to be. Because I couldn't do what a mother is supposed to do. . . I wasn't the one looking after her. And she didn't, it was like she didn't need me, . . . even when I wasn't there I was wondering what was going on when I wasn't there.*

When a mother was uncertain of her role, discovering her baby was fine without her could confirm a fear that she was not required. It also again confronts the first maternal question, "Can I keep this baby alive?" (Stern & Bruschweiler-Stern, 1998, p. 93). How does a mother answer this if someone else is keeping her baby alive?

In Jenny's case this questioning about whether her baby needed her next grew into a belief that her daughter did not actually need her. Jenny's concern was no longer about whether the NICU was capable of being a substitute mother; she now began to draw inferences about her

daughter's needs. This doubt about whether their babies needed them was something that several mothers struggled with. Yet in spite of the strength of her doubt, Jenny continued to hold her baby in mind, wondering about her and what was happening when she was unable to be together with her in NICU. Other mothers expressed similar inclinations. Despite worries about exclusion and maternal irrelevance, mothers engaged their minds and imaginations to stay connected, exhibiting the ability and inclination to engage in their maternal role even when their baby was absent.

Other mothers talked about how they kept control of their painful feelings while in the NICU, but were unable to feel stable after returning home.

*Nancy: Sometimes it would overwhelm me. . . . I used to just manage to get down the stairs out of the hospital and I just used to sob. . . . I was so grateful that I'd had her but I didn't want her there in the neonatal unit, I wanted her home with me.*

Arriving daily at the hospital to reunite with one's infant was also able to produce emotions too strong to be expressed within the hospital environment.

*Donna: Leaving is always really hard. And when you go back, I used to stop myself from running down the corridor to get to her.*

Why would a mother stop herself from running to her baby? It seems that Donna could not wait to see her baby, yet she squelched this impulse. Was she afraid to break a rule by running in the hospital? Or was the issue that showing such urgency to be near her baby would reveal she was filled with an intensity for which there was no place in that setting? Given the many comments mothers repeatedly made about their uncertainty regarding their importance to medical staff and even to their infants, perhaps mothers felt they must stop themselves from running in order to fit an assigned role. This was true even when that role

causes them to be smaller or more constricted than is really true to their sense of themselves.

#### *VII.2.1.3 Alone in the night*

Women often talked about the impact of being separated from their baby at night. All the participants were breastfeeding during these early days and were waking to alarms during the night in order to pump milk. They were alone in the middle of the night, in their own homes, pumping milk without their baby. For many women this was a time during which they had given themselves permission to ring the NICU and find out how their baby was doing. It seemed that finding a way to feel connected to their baby at that time was very important. Others used photos or mementos of their baby to connect and comfort themselves.

*Emma: It was quite hard to get up at two in the morning, six in the morning with an alarm and go sit in the living room on the machine and pump. I missed her at those points. We used to take a little hat or baby grow and put it in her incubator and then I'd take it home and it would smell like her.*

Emma's use of something that smelled like her daughter again corresponds to the physiological literature regarding the importance of smell, touch, gaze and other simple physical contact between mother and baby (Feldman, 2004). Many of the mothers found it psychologically painful to pump breast milk for a baby who was not there and needed ways to transcend their solitary experience, into the world of connection with their baby. In order to do this reaching out, they had to first confront the loss, the pain, and the longing in their experience. As Emma clearly explicated it, "mothers miss their babies".

### **VII.3 Afraid to go home**

The other subtheme that describes the impact of a particular experience is that of being afraid

to go home. This subtheme revolves around the fears about taking the baby home from hospital. All but one of the mothers discussed this fear.

Despite separation from their infant being terribly difficult, the mothers experienced a lack of confidence when it came time to take their newborns home. Interestingly, whether the mother had a positive or a critical view of the NICU staff and the overall experience did not change the fact that she experienced this fear. Some of the women saw NICU staff as a support they did not want to let go of. As Emma put it, “It was scary because I’d enjoyed having the nurses around in case something happened”.

The fear of not having nurses around if something were to go wrong with their baby was a basic concern expressed by many participants. Even though hospital staff saw the babies as low risk, the sense of risk was elevated for the mothers. In this regard they continued to worry, even upon discharge, that something would go wrong with their baby’s health. If it did, they did not necessarily feel competent to handle it. Bringing their infant home amplified the perceived risk.

*Maria: And then you kind of feel, with the nurses there, you feel, they’re saviours, they help you so much. Then when it’s time to go, you don’t want to go. . . . I was so scared of bringing her home and she was so tiny still. And having to face the whole thing on my own.*

Maria expressed this sense of amplified risk in her description of the nurses as saviours. The nurses had saved her baby’s life. Now the baby was hers to take home. The fear of caring for her daughter alone was big.

Sometimes mothers talked about the fear that their baby would become unwell in their care, regress somehow, or even die. Occasionally a mother would say she did not want anything to

happen to her baby while the baby was alone in her care. Clearly no mother wanted anything to go wrong, but the idea of it being the mother's fault was sometimes overwhelming. As expressed by Simone, "*Emotionally it was really hard. And then the other thing is like, the whole responsibility*". The baby, who had been predominantly cared for by the NICU, was about to become the full responsibility of the mother.

For other mothers, it was a sense of guilt that was activated. Tanya said, "*So there was almost a bit of guilt for taking her out of the NICU because I knew there she was safe. She was safe and there were people who'd help her and all those things*". The mothers had never had the responsibility of keeping their babies safe. As Meg pointed out, there were big differences in the way a mother could care for her baby and the way a NICU could.

*Meg: You need to know you're doing a good job. It's vital. Because how can you go from this environment of having the baby checked every two seconds by a nurse, constantly cared for by a nurse, having everything recorded, their bowel motions, their feeds, everything down to the last mil. You go from that one morning to one afternoon, gone. And it's like, what's the significance of all that? That must have been needed for a reason. We must have had to have all of that care for a reason, but now we don't have to have it? And how do we know she's still OK?*

A mother must care for her baby based on some combination of instinct, good judgment and her own skill. For the participants, the medical setting, however, was measured and meticulous, without any call on their mothering instinct. Professionals deemed the baby ready to go home, but the mother had no particular tools to assess the baby's readiness. She had to rely on medical staff for that information. Now, she was in charge of the baby's wellbeing and care, facing for the first time her question, "Can I keep this baby alive?" Not only did she not know the answer to that question, but what had been modelled to her by the medical

professionals was not something she could replicate.

Some women did attempt to imitate the medical model to some degree. Routines and schedules adopted by the hospital were enacted at home by about half the participants. As mothers reported increased confidence and a sense of greater relaxation they also reported that they developed their own ways of working out when to feed or change the baby. Other mothers employed technological means to achieve parity with medical staff. One worry that surfaced for several mothers was their baby's ability to breathe.

*Fleur: Maybe it's just my anxiety and stuff, who knows, whether it's me being overprotective. And maybe they knew that he was doing well and that he doesn't have any leftover medical issues. But I just felt that I didn't know much. I remember buying one of those breathing monitor things, kind of knowing, "Okay, well, breathing was an issue so if that happens again I'm going to at least, at least the monitor is going to go off". Just trying to find some comfort in that.*

Fleur's decision to buy a breathing monitor reflected not only a lack of self-confidence, but a lack of confidence that the hospital was right in discharging her baby. And the goal of the purchase was not just protection and safety; it was comfort. As for many of the mothers, the medicalised paradigm of care provided a comfort and allowed her to not be as fearful. At the same time, it was exactly the withdrawal of that medical model and the absence of a maternal model to take its place that drove the fear.

#### VII.4 Not my baby

A cardinal aspect of the distress for mothers was the pivotal tension about to whom the baby belonged. Like with the liminal state between giving birth and having a baby, the mothers were unable to fully inhabit their role as mothers. Every mother remarked on the hospital

staff's function in providing surrogate care, and all but two discussed this as difficult to experience. The fact that the NICU was able to look after babies without the help, input, or presence of the mother was a painful reality. For some mothers it created a sense of loss, for others it rankled, for some it knocked their confidence or created a sense of powerlessness.

Mothers were assigned tasks that involved the care of an infant. They pumped on schedules; they delivered their milk to the NICU; they took instruction from nurses on when and how to bath, feed, or hold their babies. These initiatives were not mother-generated nor were they spontaneous occurrences from within the relationship between mother and baby. As a result, there was little opportunity for learning one's baby, only for learning the system. With predetermined schedules and care routines, there was no obvious pathway to become more attuned to the baby's signals and needs. When combined with competent care delivered by nurses in a mother's absence, this lack of opportunity led to a lack of vibrancy in maternal caregiving. Tanya explained this restricted state.

*Tanya: I found, one thing I found quite hard was, um, sort of, it's almost like they're not your baby because they have to do things like, they have to sleep for, to put on the weight, they have to sleep for a decent stretch, like four to six hours, they need that time to grow and develop. So in that time you're not allowed to touch your baby, not that you would at home, but because you don't actually get to touch your baby or cuddle them.*

If Tanya had been able to follow her own desires she would have touched her baby more, not just when the baby needed it but when she herself needed it. Those little moments could have helped build a sense of belonging and authenticity.

Even when the mother assessed the NICU as providing excellent care, her sense of

connection with her baby was not improved. Sometimes hospital competence could even exacerbate the distress.

*Jenny: I think it made it worse for me in some ways because they were so good. And I would feel as if she was more their baby than my baby. Like, again, as if I was just kind of a spare part. And only because they were so great with her.*

For other mothers, the NICU care created frustration and a sense of powerlessness.

*Ellen: I felt like I had to follow the rules. It was very authoritarian. And I felt like, like a school, if I didn't do the right thing then they weren't going to pass you. I wouldn't be let go.*

Meg echoed similar feelings.

*It was like she wasn't ours to have and to hold and to take home. She was theirs to give away. Because we passed some sort of test that we were good enough to take her there. . . . We weren't even allowed to love them because they were premature or something. We weren't given permission to start parenting until we were given them back again.*

Mothers felt powerless and saw the NICU as powerful. Mothers did not experience a sense of control over their babies' care, nor did they feel their babies were wholly their own. Within the rubric of NICU policies, the baby was the patient and the mother was a visitor. It was only upon discharge that the mother had authority. The suspension of maternal control during the NICU time affected each mother differently, yet it affected them all. As Meg's moving description suggested, the mothers' love was also quiescent during this time.

Some of the mothers responded passively with temporary defeat, a sense of overwhelmedness, depression, or regression.

*Jo: What is going on? No wonder I don't feel like his mother, because no one is treating me like his mother. . . . It's almost like I regressed into being a teenager myself, like becoming quite self-absorbed, like it was all about me and what food I was going to get today and oh someone brought me a present and I really like presents. . . . It all sounds really heartless and bizarre but I wonder if it's all kind of linked. I was kept out of the process and not treated like his mum, so it was like, "Alright, I'm not then. I'm going to be 12 and do what I want to do". Like that.*

Jo was then able to admit something powerfully honest: "*I wasn't ready for it to be about somebody else yet*".

Like Tanya pointed out when discussing mandated schedules and her restricted access, everything revolved around the baby. The mother was a visitor and had little authority. There was also rarely time, space, or invitation given for her story to be told. Mothers were thwarted from fully entering their maternal role and were without the attention and care most new mothers are afforded. Because of the premature birth and need for immediate medical intervention, the gears shifted quickly to focus solely on the infant. It is no wonder Jo was "not ready for it to be about somebody else". So while mothers struggled to find a way to feel their baby belonged to them, they were simultaneously trying to find their way into a lived sense of maternal self and the development of a relationship with their baby.

## VII.5 No control

Feelings of powerlessness were evident in the previous subtheme, but the notion of lack of control emerged strongly enough within the narratives to merit a subtheme in its own right. Making choices was named by mothers as a key mechanism through which they came to feel like real mothers. Making choices constituted a form of action. It allowed the enactment of a

role, taking it from a label to a reality. Typically, mothers were only able to make choices about their baby's care after discharge. Prior to the infant's discharge from hospital, mothers cared for their children from a side-lined position and they often watched as decisions were made that they disagreed with, or found out about decisions impacting on aspects of their baby's care after the fact.

Mothers were able to distinguish the difference between a typical postnatal situation and the reality of a premature baby. This was summarised by Meg when she said, "*If you had a normal baby at home, you'd do whatever you want*".

Paradoxically, mothers of these low-risk premature babies often heard their babies described as "fine" by medical staff. This made the distinction they experienced between normality and their own situation both distressing and confusing, another entry point to loss of control. As Meg put it, "*These babies are just so, half-way between healthy normal term babies but not quite. And it's the not quite that doesn't get explained to you*".

Mothers were therefore left at the mercy of NICU decisions but with babies that did not seem to require intensive care.

*Tanya: I suppose that's something that I felt like a lot of things were taken away from me. Like the choices were taken away from me because she was early. Whatever's best for her is done. But it's not even what's best for her with input from me or what I think would be best. It was what they thought was best that's what's going to happen.*

Whilst hospitals likely view the care they provide as supporting the mother-baby relationship (Cockcroft, 2012; Harrison, 1993), such subsuming of maternal choice beneath hospital-driven decisions will often mean that the mother's importance is diminished. It further suggests that a truly dyadic approach is nearly impossible.

When mothers felt their importance was diminished they also felt a great deal of pressure to gain maternal relevance. How that pressure manifested itself varied from participant to participant. For many mothers, the pressure of a curtailed role inspired anger.

*Jo: I was expressing so much milk, like a dairy cow. And every 3 hours they would call me and I'd come down with my milk and they'd give it to him through his nasal gastric tube and off we'd go. And one day they didn't call me and I went down there and they were giving him formula. And I was like, "For f's sake". I mean, I'd never been so angry. Because it was the one thing I could do for him, the one connection we had, I could produce enough milk. I was so angry. There was no respect.*

It is easy to see how hard Jo was working to keep her minimal role as maximal as she could. She was not able to feed her baby from her breast, but she was connected to him through her breast milk, even though it was produced at the behest of the NICU and administered according to the NICU's schedule. Despite the fact that the giving of the formula was a one-off incident, Jo told of it with searing anger and the experience was emblazoned on her memory. She reported that she had never been so angry in her life. The meaning of this event loomed large. Her description showed a mother, already on the periphery of her baby's support system, really struggling when she was pushed further away. She was desperate to keep a connection and to find one that was uniquely her own as her baby's mother. That this contribution was so easily forgotten and replaced remained unforgettable, and perhaps unforgiveable.

For other mothers, the requirement to relinquish control of decisions to the NICU felt threatening. This was the case for Meg.

*Meg: You don't want to get offside with the people who are going to look after your*

*baby. And that, that, that is really one of the keys to it. That is it. That's it. Because you don't want to. Because, yeah, that is exactly it. That's what it comes down to. And it's almost threatening in a way, isn't it, you will do what you're told and follow our rules because you're going to have to leave me with your baby. And of course you will, you'll do anything to know that your baby is safe.*

In a way, Stern's first maternal challenge (1998), to keep your baby safe, was being leveraged against mothers. Part of keeping your baby safe when your baby is cared for by someone else is to do whatever you can to keep that other person happy (Aagaard & Hall, 2008). While the participating mothers did not present evidence that babies were poorly cared for if a mother was difficult or not liked, it was a predictable fear that such a thing could occur. A paradox therefore arose. If a mother was to fulfil her maternal duty to keep her baby safe she must abdicate part of her authority. In other words, in order to keep her baby safe a mother must let another act as mother.

## VII.6 Get it right/got it wrong

Another subtheme within the superordinate theme of maternal distress was the pressure that mothers felt to rectify a bad start. The vast majority of the mothers identified that the premature birth was the result of something(s) going wrong. They often expressed guilt about their failure to carry a baby to term and to provide what their child needed to grow and develop properly. Almost everyone put forward their theories as to what had caused the premature birth, with the majority worrying that it was maternal stress. The following were typical responses.

*Emma: I felt really bad, I felt like it was somehow my fault.*

*Nancy: Mothers blame themselves. I know I did. I felt so guilty . . . I felt like I really let*

*her down.*

*Donna: I felt embarrassed. Like I hadn't, I hadn't done it right.*

One very poignant response came from Meg.

*Meg: The guilt from the first moment has probably never ever gone away, the guilt that my body failed her, you know? And if there was going to be something wrong with her, it was going to be because my body failed and it's not her fault that she had a mummy who couldn't gestate her for as long as she needed to be. . . . And I remember thinking I need to write her a letter. Thinking where's the pen and paper? I need to write her a letter explaining that it wasn't my fault and I'm sorry. Because she's up there and she must be so lonely. And I just want to tell her how much I love her and don't be lonely baby. Mummy can't help it, she's sick, and all those things.*

For many of the mothers, this initial bad beginning created immense pressure to get things right from then on, to somehow compensate for the early failings by not making any further mistakes.

*Elizabeth: I was worrying so much about what I should and shouldn't be doing. . . . I wanted someone to tell me how to do it and I wanted to do it right. I don't want to get anything wrong. I really wanted to get everything right. . . . We already diverted from this path of, the right path, we'd already gone off on the wrong path, so my goodness, I need to get everything right from here on in.*

*Jo: Maybe it's a throwback to the NICU thing. I didn't birth him the way I wanted, so everything else had to be perfect. . . . I felt like I never got the chance to make things perfect, so I was rushing around trying to do everything and be everything.*

Many of the women consulted books and expert advice to try and to determine what the right thing to do was. For some this was instrumental in finding their way. For others, it was the reading they did prior to giving birth that affected them most deeply. For at least three of the mothers, this antenatal learning heightened their sense of failure after their baby was born prematurely.

*Jenny: Because people would say how important it is to have the initial skin on skin and all that, for creating the bond, and I just kind of wondered if I would have that with her and if, um, you know we'd have that closeness you're supposed to have. So, yeah, that was really hard actually. . . . It was playing on my mind the concern that I hadn't been able to be there for her the way I should have in the beginning. So that always played into it. Made me think things and worry about it and notice things that weren't necessarily there, or whatever.*

Jenny often became tearful while talking in the interview. During this time, as she discussed her worries about the impact of the bad start and her desire to make things right, her daughter was present. Her daughter was already several years old by then and very mobile. It appeared her daughter was aware on some level what her mother was saying and she made apparent attempts to provide reassurance and comfort. As Jenny spoke, her daughter went in and out of the medicine cabinet, each time returning with a new plaster for her mother. She would climb upon her mother's knee, gently hand her a plaster, then climb back down and go back for another. She did this until Jenny moved on to another topic, at which point she went back to her play. Her actions seemed like deliberate communication of a shared sense regarding healing.

Regret driven by awareness of the advice contained in books was present for other mothers, too. For Anne, this awareness evoked both worry and a fear of rejection.

*Anne: Because I remember thinking, "Well, how am I ever going to, you know, they talk about this bonding, chest on chest to begin with and the baby nuzzles down and finds your breast and, oh my God, it's not going to happen and she's not going to want me". And that worried me for a very long time, actually.*

Yet another mother who had also read similar information took a more critical stance.

*Fleur: All the books that you read, the biggest one was the whole skin to skin contact business. You know, first hour when they just crawl up and they, that bonding things is just, yeah, that's when the bonding starts and if you miss out on that you're basically screwed for the rest of your life. . . . And then not having that, it was a massive loss around that, and there was a worry on my part about, you know, how is that going to impact on our attachment. And, yeah, and just kind of going, well, I kind of missed my boat. They didn't say, "When you get your skin to skin contact on day three everything will fall into place" in those books either. They just say, "The first hour is really crucial". Either you have it or you don't.*

Fleur was pointing to something important here. As with the NICU, mainstream parenting advice could also impinge upon mothers. The books put forward an ideal as if it was the only healthy option. Yet as Fleur was questioning, there must be room for getting it right later, when things have not gone to plan. Mothers were focused on getting things right, but there was little talk of what was right for each unique dyad and how to discover and construct it after early obstacles.

## VII.7 No whining

The subtheme of “No whining” is underpinned by the fact that most mothers said things like “I can’t complain” or “You just have to carry on” or “I’m lucky”. All of these kinds of statements belied a certain truth about just how hard it was to be in their shoes. Yet their circumstances evoked a contradictory response, one in which mothers felt they should not give voice to their struggles but should only present things positively.

Below follow a range of typical responses from mothers who were suffering emotionally but felt they needed to soldier on.

*Jo: I felt quite strongly I didn't want people to start talking about postnatal depression or medications, so I didn't talk about it at all. I thought, ‘No, I need to just deal with this’.*

*Simone: The walls are very good. Because the thing is, like, keeping up appearances. It's like, I don't want to look like I'm not coping.*

*Maria: Yeah, they just, they look after the baby so much but they can't do anything about you. You have to get on with it.*

*Tanya: It would have been beneficial to have someone to talk to. . . . I almost feel like I shouldn't need it because it's not such a big deal. But I suppose it feels like a big deal. It's pretty hard.*

When participant mothers compared themselves to mothers of the very tiny and very ill babies living alongside their own in the NICU, they concluded that their own complaining would be inappropriate. Some focused on being lucky as an antidote to complaining.

*Tanya: And, um, you see these tiny tiny, tiny little babies, so you sort of almost feel like you've got no room to complain. . . It's not like she was really, really prem, but that's always my reaction because I sort of think, it's not actually, it almost felt like I didn't have anything to complain about.*

Tanya qualified her lack of right to complain with the word “almost”. Although she was asserting that she had no right to complain, she was simultaneously expressing her need to.

Anne talked in a similar way.

*It was kind of like, horrible, I mean. I can't complain because it was 8 nights. People do it for months. . . I've got nothing to complain about. I'm not saying a word then. But it's still, you're still going through the same emotions.*

More than half the mothers labelled their experiences lucky, sometimes because they did not have long hospital stays, sometimes because their baby was not seriously ill, and sometimes just because their child survived. The luck described was similar to a kind of survivor's guilt (Baumeister, Stillwell, & Heatherton, 1994) where celebration of their experience would be ungrateful and complaining about it would be unfair. Yet their need to talk about the painful aspects of the journey was clear.

*Meg: I couldn't believe it when I found out you were doing this particular paper on that particular age bracket, because I thought I was just imagining it. I thought I was just imagining the fact that we'd been overlooked.*

Mothers did not claim the right to complain, yet faced real distress worthy of complaint. Once again, the low-risk label appeared to confer its own kind of risk, making a valid complaint difficult and intensifying an already trying situation. Even mothers who recognised

this dilemma and used the interview process as an opportunity finally to air grievances still carried the partial belief that complaining was unjustified.

*Anne: I don't mean to be awful to them because they were lovely up there and they took good care of her. But it's just little things like that, I don't think they thought about.*

*Jo: I feel bad being so negative about NICU because they do such good work and they work hard and I'm sure all the doctors and nurses go home at the end of the day going, "Job done, ka pai [Māori expression meaning good], kept babies alive today". But there's a gap and it needs to be addressed. Someone needs to address it. . . . You know, um, I do feel bad being so negative, but it was my experience.*

The mothers thus sum up the superordinate theme of maternal distress. The experience belonged to the mothers and it included distress at the centre. As Elizabeth concluded, “*When I think back to that time, it's still a very, the intensity of the emotions you experience, that never really goes away*”.

## VII.8 Conclusion

Maternal distress was a predominant feature of the experience for participants. While not their sole response, distress manifested itself across the many important events and interactions mothers engaged in, both with their babies and with others in the NICU milieu. The somewhat hidden and unexpected nature of this distress served to make the distress that much more difficult to process.

In the next chapter I will discuss the last superordinate theme to emerge, namely “How do I become a mother?”

## Chapter VIII: Finding How Do I Become a Mother?

### VIII.1 Introduction

The last superordinate theme is entitled “How do I become a mother?” In the first findings chapter I outlined the first superordinate theme of “Little things are big things”, describing how participants repeatedly found meaning, depth, and significance in the small and unremarkable details of their experiences. In the second findings chapter, the superordinate theme of “maternal distress” was discussed, bringing to life the realm of painful emotions experienced by the participants. As mentioned before, “Little things are big things” describes the importance of things *outside* the mother, while “Maternal distress” describes things *within* or *inside* of the mother. In this last findings chapter, the superordinate theme of “How do I become a mother?” focuses on transactions *between* the mother and another, including what occurs between mother and infant, the interactions between mother and hospital culture, and the interplay between different aspects of the mother’s sense of self.

In a sense, a mother is born psychologically much as her baby is born physically. What a woman gives birth to in her mind is not a new human being, but a new identity: the sense of being a mother. . . Becoming a mother is accomplished by the labour each woman performs on the landscape of her mind, labour resulting in a motherhood mindset, a deep and private realm of experience (Stern, 1998, p. 3).

It is often said that a mother is born when the baby is born (Stern & Bruschweiler-Stern, 1998). Until there is a baby, there is no mother. Once there is a baby, the mother then embarks upon a journey of determining how she feels as a mother, who she is as a mother, and what motherhood means to her. This is a multifaceted process, involving the physiological, the mental, the emotional, and the psychological realms. Much of the literature

on mother-infant interaction immediately following birth suggests that both mothers and infants are participants in the process of getting to know the other and discovering the self (Beebe et al., 2010; Tronick et al., 1998). The mother-infant relationship appears bolstered by continuous warm contact and maternal support (Feldman, 2004; J. R. Schore & Schore, 2008).

For the participants in the research, there had been a disruption to the expected trajectory that occurs for healthy, full term mother-baby pairs. Instead of continuous contact there was enforced separation; instead of the mother learning to care for her infant incrementally and on her own terms and time, the baby was cared for by hospital staff for anywhere between several hours to many weeks. Much of the usual maternal role was overseen by medical staff while mothers either observed or were absent. In the face of this difference, how did participants find their way to feeling like the mother of their infants?

In the interview process I asked mothers to talk about the process of becoming a mother. Their answers took many different forms. Just as mothers expressed worry and uncertainty about their babies, they wrestled with worry and uncertainty about their own identities as mothers. For some of the mothers the creation of identity was a painful struggle fraught with confusion, anxiety, and sadness. For other mothers, it was a suspension of role, waiting to find a way to get connected to their children. For some it took days or weeks; for others it took years.

Each participant expressed great love for their child and happiness that they had chosen to become a mother. Simultaneously, every participant discussed difficulties in learning to feel like a mother; they faced many obstacles to feeling confident in their role.

In many ways, this final superordinate theme spotlights the meaning of the word “dyadic”. A

dyadic framework is commonly understood as an intervention, policy, or support aimed at two people in relationship with each other (a dyad), most typically a mother and a baby. What participant narratives appeared to be highlighting was the fact that even when two people are present together, the focus can still be individual; when health professionals see two people instead of one relationship, one of the pair can be forgotten. The mothers provided a distinction between something that is truly relational and something that is merely happening in the midst of a dyad. This subtle discrimination is, as far as I am aware, unexamined in the literature where dyadic interventions are typically assumed to be equally aimed at both parties.

The superordinate theme of “How do I become a mother?” reflects an unexamined reality for mothers of low risk premature babies. Despite the medical assessment of “low risk”, the path to step into the role of mother is not straightforward. In the medical context in which there can only be one patient, importance of relationship may be eclipsed.

The provision of neonatal intensive care unit (NICU) care is individual: the baby is the sole patient. At the same time, newborn infant survival and development depend on both a relationship and relationship quality (Cozolino, 2014; Rosenblum et al., 2009; Siegel, 2001). As Winnicott famously said, “There is no such thing as a baby . . . if you set out to describe a baby, you will find *you are describing a baby and someone* [emphasis added]” (Winnicott, 1987, p. 88). A mirror statement could be made for a mother. To describe a mother, you will also find you are describing a mother and someone: her baby. The experience of participants suggests that when there is an absence of normally unfolding physiological, practical, and emotional circumstances that allow mothers and babies to connect in the hours, days, and weeks after birth, becoming a mother can become something suspended, diminished, or altered.

The superordinate theme is made up of component subthemes that I have labelled “Not a real mum”, “Sadness and depression”, “Powerlessness”, “Not a real prem”, “Looking, touching and being”, “Second baby”, and “Time”. I will examine each subtheme individually.

### VIII.2 Not a real mum

When it came to the personal challenge of creating a maternal identity, each mother experienced significant difficulty. The difficulties took many forms, one of the most salient and prevalent being the belief that “I am not a real mother”. There were many factors that led participants to feel as if their role as mother was not real.

*Jenny: It was just so unlike what you expected . . . I didn't know that I'd expected anything in particular but I just felt as if I wasn't, I was, I just felt I wasn't the mother I was supposed to be. Because I couldn't do what a mother is supposed to do.*

Jenny painted a summary picture of the situation. Despite having vague expectations, she appeared to intuitively know that her path toward motherhood was not as is should be. She later added, “*I think in some ways when it's the first time you don't know what you're missing*”.

Jenny was simultaneously missing something and aware of its absence. If first time motherhood simply conferred ignorance, then mothers would not likely feel distress but would simply accept things as they are. Yet all the mothers, in different ways, fought against what was unfolding. They were certain something was missing in their new mothering experience, but lack of past experience meant they were not entirely sure what the missing element was.

*Jo: You end up feeling disempowered and frustrated and not a mum really. Which is a*

*bit rubbish, really.*

Jo and other mothers reported feeling on the outside, not really a mother. When mothers did not feel like real mothers—mothers fully able to claim the title of mother—they struggled to lay claim to their baby.

Other mothers discussed this disconnection as feeling both powerless outside the situation and at the same time lost within it.

*Maria: The whole situation was horrible for me. It's not like I didn't want to be a mother. But I knew that, I kind of feel like, you feel like it's your job and you've got to get through it and it's hard but you've got to do it.*

*Tanya: It didn't really feel like it was them trying to be encouraging or whatever.*

*Sometimes I felt like I was going through the motions because that's what she needed. She needed me to do those things for her.*

Both Maria and Tanya clearly depicted the struggle to infuse the actions of motherhood with the emotions of the maternal role.

Mothers were endeavouring to establish a sense of maternal identity while enduring separation, confusion, and emotional pain. They were simultaneously reliant upon medical professionals to ensure the health and survival of their child. This was complicated for several mums. They experienced the NICU as both a barrier to the relationship they wanted with their baby, and also as a primary source of their baby's care.

*Jo: I felt really disconnected to him but really angry at the same time. I don't know that I was the easiest parent to work with in the NICU. I just felt like, frustrated, and I know they do amazing work and keep some really unwell babies alive and I know I should*

*respect them.*

Even positive feelings about the NICU staff could elicit distress and the conclusion that a mother did not feel like a real mum.

*Donna: The neonatal staff were great . . . I felt embarrassed. Like I hadn't, I hadn't done it right. Yeah, right, I didn't want people to see me and see I wasn't pregnant and wonder where the baby was because she was in hospital.*

Donna is pointing out a complexity of separation and having a baby in NICU. It is not just the pain of separation that she is facing; competent NICU care provided to her baby during her absence evokes shame.

Participants also perceived a lack of capacity as a mother at times when they attempted to do something for their baby and their actions were either thwarted or failed in achieving their intended goal.

*Anne: I was expressing a lot in my room and then I'd walk the milk down to her and they'd put it into a tube feedy thing. And I remember asking if I could do that, because, I mean, I kind of wanted (trails off) . . . and they said, "Oh no", well I didn't get to do it.*

Most babies were initially tube fed and mothers were expressing milk for them. As feeding a baby is a central part of motherhood, Anne's desire to pour her own milk into her baby's feeding tube was a natural inclination. It was perhaps the closest she could come to being a mother in such a moment. She later described tube feeding as something that looked simple to do. Being denied the opportunity to do this was vexing, pushing her further back from her baby than her intuition told her she should be. It seems highly possible that her inability to

finish her thought and explicitly say what she wanted was connected to her distress.

Maria also experienced a sense of failure as a real mother after making an effort on her baby's behalf. Her first rooming in attempt ended with her daughter doing poorly and with staff sending her back home.

*It was really heartbreaking because they told me, you know, "she's gone backwards. You can't". She wasn't drinking enough milk and she was kind of going backwards. So they actually had to put her back in the incubator. . . . They told me, "You have to go back home and wait". It was horrible.*

When it was time for Maria to take over care of her baby, her baby's health faltered. In contrast to the NICU's care, Maria's care could not keep her baby healthy. Maria summed this up only as being told "you can't", and as "horrible" in its impact on her. After being sent home, she must wait again for another chance to fully mother, a chance the timing of which she cannot influence.

Sometimes the inability to assert oneself as a mother and succeed meant that mothers gave up the effort as, for example, Jo had temporarily done when she decided: "*I'm not then, I'm going to be 12 and I'm going to do what I want to do*" (see also VII.4).

In Jo's own reflection she found her behaviour strange, yet she linked it to her inability to find a way to act as her son's mother. The regression occurred after the attempt to mother failed. Jo also experienced a setback when attempting to room in before taking her baby home.

*Jo: I was so desperate to prove I was a good mum and I could take care of him and I was fine and of course it all turned to pot. . . . And I spent the rest of the night crying*

*because I felt like a failure because I couldn't even have my baby with me for one night.*

Jo's need to "prove" herself created an overwhelming pressure and she ended up becoming so dysregulated that she asked the nurses to take her baby back to the NICU.

Mothers tried to prove themselves in other ways, too. It was common for participants to try and do what they believed "normal" mothers would do. Meg awoke on the maternity ward, fresh from surgery, and felt the immediate desire to try and act like a normal mother.

*Meg: And I thought, right, ready for the day, and I was taking out all my IV lines. And they were like, "What are you doing?!?" and I said I have a baby in the neonatal unit and I need to start look after her like a normal mother.*

While mothers feared they were not normal, their moves toward more engagement with the maternal role—even when not feasible—indicated the opposite. They were in fact thinking just like "normal" mothers.

NICU realities of separation and typically regimented, measured, and precise ways of working presented unfamiliar and trying obstacles to the new mothers. Unable to relax into a moment-to-moment unfolding and mutual learning, mothers felt under pressure to perform and measure up. Similar to what was expressed by Jo above, feelings of being overwhelmed were common to many.

*Donna: And a lot of times I remember thinking 'What have I done? I didn't think it would be like this'.*

*Elizabeth: I remember sitting there crying thinking, "What have I done? What is this whole motherhood thing?"*

### VIII.3 Sadness and depression

Sometimes the struggles of trying to carve out a maternal identity created sadness and depression. This was true for many. Two of the mothers were diagnosed with postnatal depression, with five others saying they had experienced something close to this.

*Simone: So I ended up with postnatal depression kind of stuff and, yeah, I was going through this whole kind of thing and just not coping.*

*Sharon: Whether it was depression or postnatal depression, um, where I felt like I would, I'd lost control of the situation, where I couldn't literally couldn't sort of cope . . . you can only go so long before you start to crack.*

Other mothers spoke of the emotional endurance required and how this taxed their mental health.

*Maria: The focus is not on you anymore. . . . It's hard to talk about because it hurts so much. I think it's one thing to deal with the physical problems you encounter. But another thing is to deal with the psychological part. And that can be worse. Because you can get depression and stuff like that . . . I had to be really brave.*

Like Jenny, Maria found it painful to discuss even years after the fact.

Depression and the limited maternal role in NICU were also linked to the physical environment and confines of the NICU's organisation.

*Jenny: You're sitting in a chair that you can't sort of, I don't know, it's a very sterile environment and it's, um, it's a very strange situation. I had, you know, some, I got really, really down. I wasn't depressed at any point, but I got really, really down.*

*Really sort of insecure about my role. I'm going to start crying.*

Jenny spoke of the strangeness of the situation, even including a chair that she could not quite describe. She was left feeling insecure about her role. More than 2 years later, the experience still evoked strong emotion.

#### VIII.4 Powerlessness

Feelings of being overwhelmed, and of sadness and strangeness were also associated with another subtheme, that of “Powerlessness”. Mothers described experiences of perceived powerlessness and the emotional difficulties that accompanied these feelings. Without opportunities to feel acknowledged, involved, and capable they struggled to move forward into a maternal role.

*Meg: There is no correlation between what is happening to the mothers and what she has been through and the situation with the baby in the neonatal unit . . . the baby was the patient and the mother was the visitor. . . . We were never ever seen, we were never viewed as a team. I just can't stress enough the fact that they need to acknowledge the mother as part of the unit with their baby. They're not two separate things. One is nurturing the other. The baby is nurturing the mother just as much as the mother [is nurturing] the baby.*

Meg’s idea of mutual need and mutual connection strikes at the heart of the disparity between the maternal and medical cultures. Without their babies—and some agency with regard to what happened with them—the mothers struggled to feel like mothers. As Tanya put it, “*All they want and all you want is to have them close. But you know you can't*”.

Mothers’ experience of powerlessness regularly surfaced in their inability to make choices or

influence the course of decisions.

*Jo: There was no decision making in the NICU, I felt like a babysitter. I didn't have any real role or responsibility or anything. I was just doing what they told me.*

*Meg: It was just really difficult not being able to do what you imagined you would do. You're just told, "That's what you do", and you're so scared of doing something wrong and being told off that you do it. And it's like where's your autonomy as a mother? And everything's been completely taken away from you.*

Powerlessness often arose for mothers when things went differently than they had planned, or turned out in ways they regretted due to an inability to act or have influence.

*Ellen: There was one, one night where I was really, really tired and they basically took him and gave him a formula feed during the night. I had been really resistant to the formula. And in hindsight I think, "What was that about? There was no way I would have allowed that now". Still, I can't believe that happened.*

*Tanya: I would have done different things. Yes, okay, she did need that block of sleep, but actually she'd be getting those at night when I wasn't there. And I wasn't holding her all the time, but if I wanted to hold her because I was feeling like I wanted to have a cuddle, um, you know, I should get to have a cuddle, . . . I would have preferred more cuddles.*

In retrospect, mothers saw their disconnection and lack of agency as largely unnecessary. Despite the fact that their maternal identity was still under construction, choices, and moments that conflicted with what they believed was needed devalued their sense of themselves as mothers and the experience itself.

Sometimes routine hospital policy provoked a powerlessness that was injurious to maternal wellbeing. This was the case when Jo watched a safety DVD that was required viewing before mothers could room with their babies.

*Jo: He wasn't allowed in the room with me until I'd watched this DVD on how to give a baby CPR. And how to stop a baby choking. Which I watched and thought, "I don't want him in with me". Like, "I no longer want this baby in my life because what if he does?" And no other mums have to watch a DVD on CPR before they're allowed to go home with their babies.*

Not only was Jo required to watch a mandatory DVD—something that immediately highlighted her powerlessness as compared with mothers who had a full-term birth—but the material itself evoked a further level of powerlessness, a feeling that she would not be able to save her baby if required. The ability to save her baby was something she saw as being in the purview of medical staff. This led her to a temporary abdication of her maternal involvement, something she felt very upset by at the time of interview.

Other mothers felt the medical staff was more deliberate in their wielding of power, using it to control mothers via their instincts to protect their babies. Meg explained that this fear of staff power was the reason she acted powerless and obeyed policies she did not like.

*Meg: It's almost threatening in a way, isn't it? You will do what you're told and follow our rules because you're going to have to leave me with your baby. And of course you will, you'll do anything to know that your baby is safe.*

This again suggests that strong maternal instincts and thinking were actually in play when mothers stepped back from their mothering role. The threat Meg talked about was a theoretical one, yet the possibility of her baby not being properly cared for in her absence

meant that she treated the threat as real.

Sometimes it was not a threat but a feeling of being watched and evaluated that drove mothers to feel powerless.

*Elizabeth: And I think, oh, another thing, they obviously write down about all your visits and the coming in and stuff . . . you felt quite watched to start with.*

*Nancy: How do you ever build a relationship when you're being watched so much and someone is telling you what you should and shouldn't do all the time? . . . I felt like I was really doing the best by her but I felt like I was criticised for how I did that.*

Even getting to go home with your baby could seem like an outgrowth of a watchful NICU evaluative process.

*Meg: Like she wasn't ours to have and to hold and to take home. She was theirs to give away. Because we passed some sort of test that we were good enough to take her there.*

With such structural impingements on mothers' sense of self, identity, and efficacy, it is not surprising that almost no mother reported feeling like a mother until after her baby was discharged.

### VIII.5 Not a real prem

Another subtheme within "How do I become a mother?" relates to the specific designation of low risk prematurity. As new mothers seek to understand their infants and their roles as mothers, making sense of their infant's condition is critical. For mothers of low risk prems, grasping the implications of prematurity was often contradictory and confusing. Low risk prematurity is typically applied to babies born after 30 weeks of age and includes babies who

are higher birth weight and with low levels of medical concerns. Low risk premature babies have a relatively predictable and manageable trajectory of medical care.

A low-risk label does not mean babies are cared for within a designated low-risk unit in hospital, however. While most neonatal units are divided into sections based on current severity of medical need, there is in fact only one NICU in each hospital and each unit is by definition providing “neonatal intensive care”. As a result, low risk babies are cared for by the same staff and under the same procedures as high risk babies.

This gap between the low risk designation and the intensive care model was critical to the mothers for many reasons and formed an obstacle for many in the creation of their own mothering map. Many of the mothers felt forgotten or less important because their babies were not medically needy or fragile. They spoke of feeling diminished, and being without justification for their complaints and worries. Some mothers felt angry that they were unable to care for their own child when it appeared to them that the level of care needed was within their capacity to deliver. Some mothers even felt that they were being hampered by red tape, creating situations in which their infant was confined to hospital when they could have been at home. Each mother spoke of the confusion that arose for her as she tried to grasp exactly what was wrong, what was fine, and when her baby would be ready to go home.

Participants described their babies in similar ways, as if they were caught in a strange liminal state.

*Meg: Half way between being healthy normal term babies but not quite. And it's the not quite that doesn't get explained to you.*

*Sharon: I guess, too, being that weird, sort of not extreme prem, just kind of a little bit prem. A little bit prem.*

*Ellen: I always felt like a pseudo-prem. Even doing this interview now.*

Not quite prem, not really prem, not extreme prem, pseudo prem. These were terms repeated by mothers. It is noteworthy, too, that Ellen's use of "I" when she is referring to her baby was a common occurrence when the mothers spoke. Mothers often spoke as if they and their babies were one thing, sharing one point of view. It was as if the babies' experiences and their experiences were so interwoven that their language reflected this. Meg used the language of "we" when describing how low-risk babies do not fit NICU criteria.

*Meg: Almost like we're just a bit of a pain in the arse.*

Often the confusion that the "not a real prem" status created meant that mothers felt sidelined and confused.

*I couldn't get my head around the fact that the babies are there, so there must be a reason for it, otherwise they wouldn't be there. So why not acknowledge the fact that they do need to be there and show us some respect and say why. Because if they didn't, they'd just let us have our babies and go home. But we're clearly not allowed to have our babies, because you've made it quite clear that we're not good enough at looking after them ourselves. We're not capable, but nothing's wrong. So where does one tiny little baby sit in all of this? And what can I do to help her? What can I do, as a mother?*

Meg appears to resolve her confusion by concluding that the hospital believes it is the mothers—not the babies—who are not functioning well. Other mothers regarded the hospital staff positively but nonetheless were not protected from feeling slighted.

*Donna: I mean the staff in the neonatal unit were great but she was low risk . . . "Ah, she's fantastic, she's not really an unwell baby". And I guess she wasn't, but to us it*

*felt like this was completely outside our experience. We'd never known anyone to have anything like this. To us, she's very unwell.*

It was an unknown experience not only for Donna but for all the mothers. The “not-quite-prem” status held many back from being able to talk openly and receive support at the time.

Donna continues:

*Donna: It's great you're doing the research. Cause when you're in there you feel like you can't really complain because my baby's not a 28 weeker or a 23 weeker or one of these really sick babies, you know?*

The lack of validation caused other mothers to doubt and dismiss their experiences.

*Tanya: I do think that the very early babies need to have more support and things. But I think surely that they can have somebody there to support the other ones, too. Because it is a very bizarre sort of situation. But then I suppose, I sit there and think, “Well she wasn't sick, so actually she was fine. She just need a little bit more, um”, I suppose I feel like she was fine, so actually, like I think it would have been beneficial to have somebody there to talk to about those sorts of things, because she was I fine I almost feel like I shouldn't need it. Do you know what I mean? You shouldn't actually need it because it's not such a big deal. But I suppose to you it feels like a big deal.*

Tanya expressed an internal conflict the mothers faced. She could not name what it was that her baby needed more of, but she tried to put the pieces together. She knew her baby was not sick, yet she was in hospital. She knew her baby was fine, yet her baby's condition was not as it should be because she was also in the NICU. These paradoxes impacted the participants' abilities to claim their own motherhood status. For mothers, the situation with their babies was a big deal, but it was not acknowledged as such.

Anger was also a common reaction to the “not quite prem” framework.

*Ellen: I felt a bit ripped off, . . . unsupported, and actually felt like we had to battle a lot just to kind of have normal experiences with what was clearly quite a normal baby in the end, or what seemed like a low risk kind of baby.*

Ellen’s point of view is representative of the mothers who saw their babies as receiving unnecessary medical interventions and experienced them as normal but trapped. These mothers discussed their babies’ care as being part of a system that was too risk averse for their situations. Being born early sometimes meant babies spent time in NICU as a precautionary measure, which in turn hampered maternal efforts to become mothers.

*Jo: I felt there were set up to support really, really unwell babies. Their policies and procedures and protocols are about unwell and very prem babies, yet some of who they look after are not as prem or not as unwell, yet you are still funnelled into this pattern . . . They treat everyone like it's important and urgent and no choice, no time for talking. When actually there is plenty of time for talking. . . . What's going on? No wonder I don't feel like his mother, because no one is treating me like his mother.*

Jo’s anger is explicitly about being denied the treatment she felt she deserved as a mother, which situation seemed to have arisen due to a “not-a-real-prem” baby being cared for as a “real” one.

The mothers’ sense that their babies were not “real” premature infants matched the research about how neonatal nurses perceive their work. In my email correspondence with one of the lead NICU nurse researchers, Roberta Cricco-Lizza (7 June 2014), she wrote:

*The NICU nurses in my high-acuity, research-intensive unit usually preferred to care*

*for the "sickest of the sick." They were attracted to the most complex levels of technology and liked to learn about the latest treatments and the newest research about care. Many of the nurses really identified with being a "super nurse" who picked up subtle changes that made a big difference in rescuing a critical infant. As much as there was high emotional labor when an infant died, there was also much reward in "saving" babies.*

The nurses are oriented toward their work and their duty of care to the NICU babies.

Unwittingly, it appears the culture may subsequently fail to support low risk mothers' psychological and emotional needs.

### VIII.6 Looking, touching, and being

There were three subthemes that pertained to factors that exerted a positive influence over the participants' ability to answer, "How do I become a mother?" The subtheme, "Looking, touching, and being" pertains to a specific avenue mothers employed to help answer the superordinate question.

When asked what enabled them to come to know themselves as mothers and understand their relationship with their infants, participants regularly named moments when they had uninterrupted alone time with their baby. It was special time when they felt able to really sink into being with their babies and observing them.

Sensory contact was always identified; it included cuddling, breastfeeding, gazing, smelling, and skin-to-skin contact. The ability to look at one's infant was also a persistent feature of maternal interaction. This was not normal looking without purpose, but was described as long leisurely periods of taking in their babies with their eyes. Even though opportunities for sensory contact were often delayed and rare, mothers took them when they could and found

them very meaningful.

*Meg: I think the best thing was when I took her home and we spent a lot of time sleeping together and feeding in bed and after that, that was that. I just knew that we were a little team. . . . I needed her. I needed her stuck to me.*

*Jo: The first night was amazing because he was where he belonged. He was with mum. We got here and we sat on the couch and I just gave him cuddles for hours and hours. That's all we did the first day was just cuddle and be together.*

*Elizabeth: We roomed in and obviously she stayed in that first night so I'd be coming in to feed you (looking at her baby) and um, then the next day I was able to just wheel her into my room. And it was just, it was just like a dream together. It was amazing.*

Whether during rooming in or after discharge, these shared moments of unimpeded being together, looking, and physical contact were touchstones for the mothers. When participants shared these stories their tone of voice typically lifted and brightened, mirroring the palpable shift that had occurred in the experience.

*Donna: The rooming in . . . It was wonderful, really, and it was like having that time that we would have had if she had been born full term. So I could just spend that time just looking at her and, like I'm sure, it was like she was my baby.*

Something very powerful occurred when the mother was given—and took—the chance to look at her baby.

*Emma: A lot of my fears just dissipated just watching her.*

Anne told a moving story of taking a chance at connection via looking.

*Anne: I think that last night in hospital she was allowed in my room. And then it was, I felt a little bit more like she's mine, because I actually undressed her just to look at her. I didn't undress her to change her nappy or anything. Whereas I didn't feel like I could do that in there because, I don't know like they'd be looking or like, "why is she doing that?" But I hadn't actually had a really good look at her so I kind of, I remember lying her on the bed, um, because yeah, you're in your own little, lying her on the bed and just unwrapping her and studying her.*

This was juxtaposed with the daily reality of NICU life that had come before.

*Anne: There's only so many of those little curtains you can have, those wee dividers, I mean there's not very many, there's not one for every cubicle. And it was like trying to grab one of them so you could actually have a moment by yourself with her . . . It's kind of very impersonal.*

Anne also mentioned how she had used videotape to retroactively allow her to take in her baby at birth. (Anne was the mother who had lain on the operating table, unable to see her baby and growing upset about it.) Her midwife had taped the birth.

*Anne: It actually has helped because I get to see her.*

Even postpartum and on videotape, the impact of looking, touching, and being together was consistently profound for mothers.

### VIII.7 Second baby

Another subtheme presented itself as an avenue for positive growth and influence. The subtheme of “second baby” emerged from the stories of women who had given birth to a second child by the time of interview. Five of the participants had become mothers for a

second time. Three of the five had another premature birth. For all five, the birth of their second child and the experience of mothering again was very influential in reviewing and understanding the experience with their first baby.

For one woman, having been through a premature birth once was very helpful in knowing what to expect and in realising that the hard times would not last forever. For another woman, the second birth allowed her to rectify some of her regrets and assume more authority and maternal control. For the other three, the second birth provided emotional healing and reassurance that being a mother was something they could achieve in a competent and happy way. While second births did not occur for the majority of my sample, inclusion of the insights of mothers who did birth again is relevant in relation to answering the question raised in the superordinate theme, as many first time mothers of premature babies will eventually go on to birth again.

*Tanya: With [second baby], I knew what I wanted and I knew what I was going to do.*

*And if somebody didn't like that, well that's my baby and it's tough. Whereas with (first baby), I didn't feel like I could do that, . . . I suppose [ second baby] felt like my baby a lot quicker than [first baby] did.*

For mums like Tanya, having the experience of a first birth under her belt gave her an already-established sense of motherhood to work with once she had another child. This was in spite of the fact that Tanya's second baby was also premature. For other mothers, it was the second birth, by way of contrast, that finally provided that maternal strength.

*Maria: The whole experience of becoming a mother was not good. And I was thinking, "Why do people say that having a baby is the best thing in the world? It's not". But then I understood everything when I had [second baby]. It was easy. It was*

*straightforward . . . And I realised, looking back, how much easier it is to have a normal baby. I understand what people were saying about having a baby, it's actually quite nice.*

Jenny told a similar story.

*Jenny: [Second baby] was totally different. I kind of felt like she loved me. I remember saying to a friend, “It’s funny, I feel like I can tell she loves me which is so weird, already, because I didn’t feel that with [first baby]” . . . It just came naturally with (second baby). I think because things happened naturally and as they could. The bond and everything and I could breastfeed. I feel as if I’m needed.*

Other mothers in the study voiced their worry about getting pregnant again, for fear of having another traumatic birth or premature delivery. However, for all the mothers who had given birth again, it was an experience that both strengthened and highlighted their ability to feel like a real mother.

As mentioned in the previous findings chapter (Maternal Distress), Amy was a 15<sup>th</sup> participant in the sample, interviewed as a second-time mother who had stayed in the NICU during her premature baby’s stint in hospital. Amy’s status as an experienced mother not only allowed her to reject advice to spend her nights at home, but also meant she had a similar pre-existing maternal identity to draw upon, much like the other mothers in the research who had had a second baby. Amy’s established sense of herself as a mother also appeared to free up room in her mind to observe and reflect on what was happening in NICU, as opposed to feeling that she must simply endure or obey. This mental and emotional freedom meant that Amy had insights into the world of the nurses and how to navigate the NICU as a mother.

*Amy: And you can usually tell as soon as they walk into the room whether they’re*

*nice or not, whether they look at the monitor when the alarm goes off. And the ones that are not so nice, it's really noticeable, you know, they always have alarms going off, there's so much noise all the time. The ones I had trouble with, would go to the monitor, look at it and then look at the baby. And the really caring ones would look at the baby, open it, and touch it, and then look at the monitor.*

Amy's ability to watch and observe led to information about NICU nursing culture and its effects on mothering that I have not seen documented elsewhere. She delineated a difference between staff who had a primary orientation toward the baby and those who had a primary orientation toward machines. She further correlated the infant orientation to a style of nursing that was both sympathetic toward mothering and mirrored her own mothering instincts.

While the participant mothers who had subsequent births were looking back at their first birth with fresh eyes and gaining positive effects from that, Amy was able to use her first birth to give her second, premature-birth experience a different perspective. In both cases, it appeared that being able to reference another birth helped heal the emotional sequelae of low risk prematurity.

### VIII.8 Time

The last subtheme, "Time", is also the third subtheme that offered a mechanism to positively contribute to answering the question of "How do I become a mother?" Over and over, mothers reported that time was required to create a surety about their role as mothers, to make sense of their experience, and to move forward in relationship with their babies. As with the opportunities for looking at their babies, the kind of time mothers required was specific. A slow, mother-paced, and infant-attuned time was required.

The more mothers were able to care for their infants and succeed at it, the more they grew into their role and the more they enjoyed it. Time also allowed women to get past fears that they would lose their babies or that their babies would become ill again. Similarly, time was necessary for mothers to feel they knew their babies uniquely, not as a premature baby who needed a certain kind of care, but as *their* baby with specific expressions, moods, needs, and desires that could only be known by a mother.

The effect of time was both cumulative and incremental. Mothers did not tend to describe lightning-bolt moments; instead they discussed the changes that unfolded gradually over the passing of time.

*Elizabeth: I don't think it was immediately love in a way actually . . . for those few days I think it was just like shock in a way. This is just a creature. How did I make the transition? I think it just was very slow, something that came really gradually.*

*Tanya: I definitely think having that time, just by ourselves, to be able to do those normal things that people would do with their baby was really good. . . . It was more, I suppose, learning what she needed and all those sorts of things. Learning her cries, different cries, and things. How did I do that? I suppose it was just time and getting used to it.*

*Jo: It was a bit of an organic process over time. . . . And it's only been very recent, in the last two months or so, I would say, that I've really gone, actually I do know what you're about. I know your moods. You're a little person and we are moving forward.*

Jo's description of her baby as a little person who she truly knows is vividly opposed to the image she used of him when he was first born, as a "little kitten".

Time also served as a marker for what mothers had achieved in their maternal thinking.

*Jo: On his due date, I was so happy that I'd had that extra month with him. And I remember thinking that must mean I was bonded to him.*

This retrospective affirmation was achieved by noting the passage of time and how her own perspective had changed.

Meaningful time together also occurred in hospital. Mothers were able to carve out that time in small amounts while still in the NICU. Sometimes the effect of time spent with one's baby even surprised them.

*Nancy: Just, spending time with her. Having her, I mean, she was, it was almost like she was still such a part of me because I had her down my top all of the time, you know, and I wouldn't have a pee for 8 hours because I didn't want to move her. And I, and she was such a part of me. I don't know if it makes sense, but, yeah, she was just such a part of me and it was spending that time with her.*

It is interesting that Nancy wondered if her explanation made sense. It was as if there was no logical answer for why time together was so effective, yet it was. For others, time together did not make a difference until mother and baby were at home.

*Meg: It was like they'd just given me this thing to care for. Like a robot. And it wasn't until I got to spend a lot of time with her by myself in the night-time feeds and things that I started to realise that actually, that she is my baby. Nobody is going to come and take her away. Yeah! I get to keep her.*

For Meg, time passing not only transformed her from feeling like a robot to feeling like a mother, it also dissipated her fears of losing her baby. The result was an affirmation both of

herself and her relationship with her baby. Other mothers reached similar hopeful conclusions.

*Emma: She's a normal baby and that has become evident over time. I think I just gradually accepted that what happened to us was just our story. It wasn't what I wanted, but it's our story and again it makes it special.*

In this instance, time afforded Emma a way to integrate the past unwanted events into an encouraging narrative that she could claim as her own, a shared story with her baby.

For some mothers, time was important in pushing back against the unwanted events that had occurred during their time in the NICU. After Jo had her failed attempt at rooming in, hospital staff began to worry about her mental health. When staff suggested she may be experiencing postnatal depression, she took matters into her own hands.

*Jo: I basically just discharged myself. . . I thought, "You guys are jokers. Now you care? Now you're worried about my mental health? Nobody even asked me how I'm doing for a week and now you care?" It just seemed so patently ridiculous.*

The fact that staff intervened with concerns for Jo only at this late stage caused Jo to re-evaluate her assessment of their input. The moment of rejecting their advice and taking her baby home was a turning point for her in her sense maternal identity and her belief in her connection with her baby. It did not allow instantaneous adoption of a full maternal identity, but was the start of that process for her.

Time was also needed for other mothers to reject what they perceived to be a negative medical model assessment.

*Fleur: You know, it's okay to not like that period. It doesn't mean that I'm a bad mum.*

*It doesn't mean that I'm a failure as a mum.*

Fleur discussed these insights when her baby was almost school aged. She used time to sustain a long and reflective process in order to set things right in her mind and hold onto a healthy sense of maternal identity. Other mothers also relied on time to reorient their sense of self. For Simone, the passage of time was essential in deactivating a long-held fear about her capacity as a mother and for awakening her to new possibilities.

*Simone: I remember before, seeing these new mums just sitting there and staring and their babies and I was like, get a life! (laughter) Then, oh my word, I was sitting there in NICU holding her, my neck got so sore, you'd just sit there and stare . . . It's kind of the motherhood stuff. I never thought I was like that. You oooh and aaah over babies, then you hand them back. Then a friend of mine had a baby and she's very tomboy-ish and then she said, "There's a switch that goes on". And I used to say, "I'm just so afraid that there will be a power cut and my switch wouldn't work". But I think it did work. So, yeah. Yeah, I think it flows.*

Simone's metaphor of a switch and a power cut was poignant. Over time, she not only felt the activation of her maternal switch but witnessed a burgeoning mothering identity that she had doubted was possible.

### VIII.9 Conclusion

The internal process of becoming a mother is unique for every mother, no matter the birth experience. For participant mothers, the transformation was also particular for each woman, yet they also shared collective mechanisms of knowing and learning, as well as comparable obstacles. Much of what participants identified as difficulties answering the “how do I become a mother?” question centred upon the lack of congruence between their role as

mother and the space for that role within NICU, as well as their absence of pre-existing mothering experience. As Elizabeth summed it up:

*Elizabeth: Caveated by the fact that I don't have another experience to compare it to, I would say that, um, I felt, um, in some ways it hindered the inner mother thing because obviously in NICU they have to work on schedules, they have to monitor all the babies very carefully and they have to, um, keep things ordered and monitored. And so you, they're not mothering babies in there.*

In order to become a mother, mothers have to be able to mother. This is different to being able to nurse. However, even as avenues were blocked and inclinations thwarted, mothers found ways to move toward establishment of identity, even as they often waited for aspects of this process to occur.

In the next, discussion chapter, I will bring together the three superordinate themes of the three findings chapters and address the ways in which the maternal narratives and meanings were interrelated as well as how they evoke new learnings and insights. I will discuss the way the superordinate themes fit into an ecological framework and use existing ecological models to create a new model of context specifically for mothers and infants. I will also examine the ways in which aspects of maternal meaning-making that are not visible in existing academic and medical concepts influence the experiences of participant mothers.

## Chapter IX: Discussion

### IX.1 Introduction

My research focused on 15 first-time mothers and how they made sense of the experience of premature birth, how they came to understand themselves as mothers, and how they came to know their prematurely born children. I interviewed the participants in a semi-structured format, asking just a few general, open-ended questions. Mothers chose how to tell their story and what to talk about, going back in time to whatever point they felt appropriate and continuing to the present moment.

In the interviews, I listened as mothers made meaning of their own experiences. Once analysis began, I sought to understand how they made sense of their maternal world and identity, as well as how they incorporated the emotions and relationships this new identity brought with it. I began to place that understanding into a larger interpretative framework grounded in the extant literature.

The relevant bodies of academic literature surrounding the research included biological/physiological/neurological data regarding bonding, maternal behaviour, and infant development; psychological literature regarding stress; separation; attachment; first-time motherhood; maternal mental health and infant mental health; sociomedical findings regarding medical culture, neonatal intensive care unit (NICU) experiences, prematurity, and negotiating illness; and social work literature relevant to working within hospital settings and with issues of prematurity. I also considered theoretical literature about how women develop maternal identity; how relationships develop between mothers and infants and are experienced by each, as well as the meanings of such dyadic relationships; and theory related to some of the unique aspects of the premature birth

experience, such as grief, loss, and medical culture. After completing the review of both the literature and the theory, I became aware of the need to consider and include a review of ecological frameworks in order to encompass and relate the themes that emerged from the research data; thus the review of literature on ecological perspectives was also included.

## IX.2 The participants in context

Participants in my study represented a unique and relatively unstudied group of mothers. In keeping with the focus of the research, they were all first time mothers without significant medical or psychological risk factors when they gave birth to a premature baby. They were also distinct in terms of to whom they were mothers; they were mothers of premature infants classified as low risk due to their later gestational age and absence of ongoing medical issues or chromosomal defects. This combination of low-risk first time mothers with low-risk premature babies meant that much of what could be discerned from existing literature—which is largely about higher-risk prematurity—had to be knitted together from information garnered from various studies. Discussion about the “low-risk” subset of mother-baby pairs I interviewed and about the research findings that emerged from those interviews first requires some context.

Currently in New Zealand, as in most of the Western world, the medical expertise and technology exist to care for babies being born as early as 24 weeks gestation and very occasionally 23 weeks. More and more, these very early born, low birth weight babies are regularly admitted to the NICU as patients (Kaempf et al., 2006). However, according to an interview with Liggins Institute Distinguished Professor Jane Harding, a researcher in perinatal health, a mere 50 years ago, babies born as late as 34, 35, or even 36 weeks gestation often died (Gibson, 2017). Since approximately 1990, babies born at 28 weeks

gestation and beyond have experienced a better than 90% survival rate, a rate that improves as the baby's birthweight and gestational age increase (Gibson, 2017).

The focus of medical research has tracked these changes in mortality and morbidity while advancing medical care so that the majority of major problems currently faced by premature babies occur almost exclusively in the earliest born, lowest birthweight groups. Babies like the ones who fitted the criteria for my research typically present with few significant medical problems and very rarely face threat to life. The health concerns they do commonly present with are most often easily addressed and resolved during their NICU stays. However, despite the relative ease for medical professionals managing such low risk cases, mothers perceive the situation of their own infants quite differently. This was true for the mothers in my study as well as reflected in research literature inquiring into maternal perceptions of prematurity (Ahn & Kim, 2007; Brooks et al., 2012).

Simultaneously, mothers who do not evidence symptoms severe enough to necessitate medical or mental health intervention also tend to be benignly excluded from attention. Again, both the analysis of the participant mothers' commentaries and my review of the literature suggest that mothers themselves see their needs differently (Hurst, 2001a; Sargent, 2009).

From the outset, participant mothers talked about their experiences in terms that intertwined them with their babies. The superordinate themes that emerged and the stories each mother told were narratives about relationships. Mothers were not just processing how things were for them; they were processing how things were for their babies and how that affected them both. This togetherness was even represented during the interview process. Of the 15 participants, 11 chose to have their children present while being interviewed. All of the four participants who did not have a child with them had children

who were old enough to be at kindergarten (preschool) during the day. One of these four was being interviewed via Skype and another was at her place of work. The other two women who were in their own homes dedicated a portion of the interview to showing me photos of their babies.

### IX.3 Emergent superordinate themes

I did not know what to expect when I began conducting interviews, but after meeting the first participant I began to see how important their narratives were. The double low-risk label—one for mother, one for baby—actually created a unique risk profile. Low risk equated with a silencing or a forgetting, and mothers often felt invisible and without a voice. Mothers had something to say, but no one seemed to have realised it, or even have asked. The more I listened, the more I grasped that their stories represented something important and mostly missing from the greater conversation about premature birth and motherhood.

The semi-structured interviews allowed participants to choose what they wished to emphasise in their narratives, where to delve into detail, and how to assign importance and meaning. The interviews supported the power of self-definition and self-determination, fundamental social work practice values (Tower, 1994), through a structure that encouraged participants to make sense of their experiences on their own terms and in their own way. The interviews also appeared to allow for the possibility of personal transformation to emerge through being heard without judgment and by a listener bearing witness to personal truth (Gubrium & Holstein, 1998). Many participants shared feelings, details, and responses not previously disclosed to anyone in their lives and then utilised these disclosures to reflect, integrate, and create coherent personal narratives.

Through analysis, findings began to emerge. Some of what was highlighted by the maternal narratives was also identified in the existing literature; other emergent ideas appeared absent from the literature, or offered an alternative or somewhat contradictory point of view. The three previous findings chapters discussed each of the three superordinate themes. These themes were named: Little things are big things, Maternal distress, and How do I become a mother?

#### *IX.3.1 A framework for the superordinate themes*

Before discussing the superordinate themes separately, I will consider them together. After discussing them in this way, I will then lay out each theme separately and consider it in terms of the literature.

Throughout the analysis and write-up process I wrestled with how these themes fit together. Finally, in reflecting upon what the mothers were describing as missing from the conversation, I found an answer that lay in the meaning of what was absent.

Each of the superordinate themes in my research represents something unseen yet potent. The first theme (Little things are big things) is about things the mothers saw and experienced that were unseen by others, such as tiny moments that occurred while they were just touching their babies. The second theme (Maternal distress) is about things the mothers felt deeply but could not say or express to others, such as intense sadness experienced when they had to say goodbye to their baby for the night. The third theme (How do I become a mother?) is about things mothers wanted and needed to do or be, but were blocked from acting on by others. This formed a triad of themes representing the hidden, the unsaid, and the inhibited. The three most salient topics mothers brought forward all existed in the shadows of what was actively noticed, discussed, and allowed.

The evidence that they inhabited a sort of “back stage” position does not diminish their importance; what was happening on the medical centre stage was not what was happening for the mothers.

There is a Sufi story about a “wise fool” that goes like this (Mijares, 2014, p. 149):

Once upon a time...

It is late at night. The legendary wise fool, Mulla Nasruddin, is crawling on his hands and knees under a corner street light. A close friend discovers him and thinking that Mulla may be a little drunk, tries to help.

“Mulla, let me help you up! Do you need help to find your way home?”

Mulla replies, “No, my friend. I’ve lost the key to my house. Here, get down on your hands and knees and help me look.” Groaning, Mulla’s friend lowers himself onto the hard pavement and begins to crawl around. He makes a thorough search, peering into all crevices in the cobblestones, gradually and laboriously widening his search. After what seems like hours, his knees are aching. No luck.

“Mulla, I’ve looked everywhere within thirty feet. Are you sure you lost your keys here?

“No, actually, I think I lost them about a block away, over there.”

“Mulla, Mulla, you idiot! Why are we wasting time here then.”

“The light was better here.”

Sufi stories reside within a tradition that employs paradox in order to illuminate self-

realisation and help people unlearn who they think they are so they can see a fuller expression of self (Douglas-Klotz, 2003). In this case, the story also points to a fundamental mistake we can make as humans; we sometimes seek answers only in places already visible. Yet things can also be hidden in plain sight. In other words, events and emotions can unfold before our eyes, but if we are trained to not notice, we typically do not see. Even relational theory has come to understand this. Interventions that look to repair parent-infant bonding recognise that one member of the dyad leaves clues that are hidden in plain sight (Powell, Cooper, Hoffman, & Marvin, 2013).

To understand the participants' journeys and meaning-making it is therefore necessary to understand that their memories and narratives suggested a process that was unfolding largely without notice. The "little things" they held dear were mostly happening when others were present. The distress they experienced might be repressed but was nonetheless visible through both their actions and inactions. Their process of becoming a mother was being constructed under the guidance of professionals and the witnessing of family and friends. It could be argued that their experiences remained concealed because no one ever thought to ask them about these.

There was another, deeper layer to the veil of invisibility over the mothers' journeys. Babies in NICUs are under regular observation. The infant in NICU is in fact monitored more scrupulously than would be possible outside of a medical setting. While mothers are not NICU patients, presence or absence is noted and their mental health must be accounted for, with any concerns raised in relation to their mental health receiving referral. Participants themselves spoke of feeling watched and observed. Furthermore, health professionals were regularly teaching mothers how to do things like bath a baby, handle wires, manage an incubator, or make use of a nipple shield. It could not be argued

that either mother or baby was actually invisible or forgotten.

Yet what was important to mothers remained invisible. This perplexed me for a very long time. Was it possible that the medical settings were uncaring or disinterested in maternal experience? Was it as nursing research has suggested, that low risk babies are less interesting to staff and their mothers less a part of NICU culture (Cricco-Lizza, 2014)? Or was it the medical belief that emotions interfere with the objective analysis required to do good work, as suggested by research on compassion fatigue (Huggard, 2003)? It seems likely that each of these things played a partial role in why participant mothers revealed and emphasised the things they did. However, none of these theories appears sufficient to explain the phenomenon of all three superordinate themes occurring outside of other-awareness.

In contemplating this question, I realised something important about what mothers said. Mothers repeatedly felt that their needs were ignored, even in the presence of their infant. In other words, even when mother and baby were together, medical staff (and sometimes family) were unable to identify and support the maternal needs. While it would be relatively easy to forget about the mother's needs when she was not present, it would be much harder to forget about her when she was right there. What became clear to me over time was that mothers were able to discern when people had a dyadic perspective and when they did not. Specifically, mothers were interacting with people who could not see the needs of the relationship between the mother and baby; instead, they could only see the baby's needs and then look to the mother when they felt she could assist with what the baby required.

Academics specialising in dyadic research have pointed out that people often “err by ignoring the connectedness or nonindependence of dyad members’ responses to each

other" (Wittenborn, DolbinMacNab, & Keiley, 2013, p. 6), treating dyads as two independent individuals. This misunderstanding leads to an "incorrect plan of analysis and a loss in the accuracy and complexity" of the experience (Wittenborn et al., 2013, p. 7). When we seek to understand a dyad by treating each member's information as discrete, we therefore miss the deeper truth.

As I analysed the narratives, I named this "the tennis match phenomenon". The stories mothers told about how they were included, referred to, and defined by professionals, affirmed that the linking of their experience to that of their infant was neglected. Those interacting with each mother and baby seemed to alternate their focus, turning from the baby to the mother, back to baby, back to mother. The baby was the patient and the mother an adjunct to the baby's experience. This phenomenon has been reflected in observational research in neonatal units in which 94% of nursing time was focussed on tasks, even when the mother was present (Fenwick, Barclay, & Schmied, 1999). A medical orientation such as this helps to explain why participant mothers regularly noted that nursing staff never learned their names and usually knew nothing of their birth experience, much less their life before the NICU.

When the dyadic perspective is overlooked, both the research literature and participants' experiences suggest that only individual responses and reactions can be absorbed; the relationship itself is not regarded as a valid entity. This, for example, might explain a common participant story. A nurse, who potentially felt she was making a compassionate suggestion when she told a mother to go home and get some rest, ended up offending the mother who received this suggestion. The explanation for this miscommunication might be understood as follows. The nurse was looking at an exhausted mother next to the cot of a sleeping baby who did not need anything at the moment. She saw them as separate, even

while likely operating under a false belief that she saw them as a unit. Underpinning her suggestion was therefore not “what does the relationship need?” (a question that would oblige thinking about both members of the dyad and how their feelings interact with each other), but “what does the baby need?” then followed by “what does the mother need?” If the baby was appraised as needing something the mother could offer, the nurse would likely suggest she do it. If the baby was assessed as needing nothing, the nurse would likely turn her sights to what the mother needed as an individual. Individual evaluations like this are conceivably why nurses never encouraged the participant mothers to just sit and watch their babies, yet why each participant raised this as something she felt the need and desire to do. In the same way a person can feel lonely in a room crowded with people, a mother can feel invisible even when she is observed with her baby. Without the relationship, she is untethered.

In attachment-oriented strands of couples therapy, “the client is the relationship between the two partners” (S. M. Johnson & Greenberg, 1989, p. 99). In a NICU, however, the baby is the sole patient. The mother is a visitor. Yet the dyadic perspective remains necessary to understand the maternal experience. As writer and psychotherapist Stadlen (2011) pointed out, the word mother refers to a relationship. Clinicians and researchers in the fields of affective neuroscience and intersubjectivity have said the same, namely that you must look at the interplay between the mother and child (Fosha, 2001).

Intersubjectivity, then, becomes the “royal road” to relational experience and contains the vital ingredients of sympathy, empathy, sensitivity, caring, and loving (Stern, 2008, p. 181).

Babies develop within relationships. Their understanding of themselves and the world emerges from within an intersubjective reality (Fonagy & Target, 1997; J. R. Schore &

Schore, 2008; Siegel, 2001; Stern, 2008). They inhabit a dyadic existence and their mothers' meaning-making is entwined with their own. This suggests that while the maternal experience is hidden from the main stage of the medical environment, it is clearly visible to the infant. In fact, research into how infants understand relational communication has proposed that infants detect intention, noticing the unseen meaning behind the action (Meltzoff, 1995; Ruby & Decety, 2001). This discernment on the part of babies stresses the importance of understanding the mother's dyadic perspective. It is not only vital to her, but it is vital to the baby, too.

When I embraced a dyadic perspective for my analysis of the narratives and their superordinate themes, the links between themes and the underlying sense-making fabric revealed itself. Through adopting a mother's lens to look through, the research was able to uncover what was hidden in plain sight: the dyad.

#### *IX.3.1.1 The dyad in context*

Just as the understanding of low risk prematurity and low risk mothers must be put into context, so, too, does the emergent dyadic perspective require contextualisation. As noted in the literature and theory review chapters, an ecological framework is an integral aspect to understanding, processing, and interpreting my research. The use of Bronfenbrenner's ecological model (Bronfenbrenner, 1994; Bronfenbrenner, 2005) assisted in integrating theoretical literature into a contextual picture and also helped to place participant mothers within their lived environment. Such context overrode the tendency of the literature to examine issues in disconnected silos.

The realisation that what was missing (and what tied the superordinate themes together) was a dyadic point of view suggested that there is something missing in traditional

ecological theory as well. In Bronfenbrenner's model, individual human development is placed within the layers that surround and influence the person at the centre. The model allows for nuanced and specific construction of the contextual elements to reflect the unique experience of each human being. However, Bronfenbrenner's model (Bronfenbrenner, 1992), and ecological models in general (Friedman & Allen, 2011), situate an individual at the centre. They are models of *individual* human development and experience, even as they are well aware that humans are in continual interaction and influence with other people. In light of what mothers in my research are pointing to and the subsequent awareness that the maternal experience is a dyadic one, the conventional ecological model requires some revision. Participant mothers are much more closely aligned to Māori ecological frameworks and the location of the individual within the whānau (Durie, 1985), though even that is not an exact fit.

A more appropriate and attuned ecological model for my research would be one that considers the dyad-in-context instead of the person-in-context. Such a shift in focus does not diminish the importance of maternal experience nor purport that the mother is no longer the centre of the research query. What it offers is an inclusion of the maternal meaning-making experience within the ecological model. In other words, because mothers create meaning through interaction with their infants, their ecological framework is built upon dyadic experience, not an individual one. Family systems researchers have begun to look at the research on adult couples in this way (Lyons & Sayer, 2005). For example, in the case of chronic illness, questions will be asked that pertain to the unwell individual, but there will also be questions that seek to ascertain the impact on the relationship itself as well as on cross-partner effects. In the case of a first time mother and her newborn infant, development of the mother's maternal identity and creation of her maternal map is at the centre of the ecological system, a development process that is

relational and dyadic at every turn.

The dyad-in-context model is a revision of ecological theory that parallels ecological theory put forward by Māori scholars. According to Durie (1985), there are four cornerstones to health from a Māori perspective; one of those cornerstones is te taha whānau (the family dimension). Health is an inter-related phenomenon and the kinship system is one of the key dimensions; identity derives much from family (Durie, 1985). The notion of whakapapa, (genealogical links), is a central feature of what it means to be Māori and one definition of whakapapa is to “place in layers, lay one upon another” (Rameka, 2011, p. 247). Māori scholars note that traditional Western definitions of health and mental health tend to focus on the individual; this is a definition of health that is at odds with Māori thinking. Such Western notions privilege individual wellbeing over interdependence and collective wellbeing (Panelli & Tipa, 2007). In contrast, from a Māori perspective, an insistence on independence falls short of health and is considered a kind of immaturity (Durie, 1985).

While Māori health philosophy is not focussed on the dyad, it parallels a dyad-in-context model in so far as it extends the notion of wellbeing beyond the boundaries of individual functioning and looks to define health in synergistic, holistic ways. Durie further noted that another aspect of health is the importance of words and feelings to be considered as shared vehicles of expression and communication, with emotional awareness being closely linked to cognition (Durie, 1985). Wellness must include this emotional awareness; when health is dominated by analytical thinking only, self-expression is diminished, wellness is reduced and children are disadvantaged (Durie, 1985). The relevance to the dyadic model is clear; within the dyad emotion and feelings are heavily utilised modes of being and communicating for both mothers and babies. When

overlooked or omitted, the cost to the mothers and the effect on the dyad has been discussed (see VI.5, VII.2, VII.5, VIII.2, and VII.4).

#### *IX.3.1.2 The three superordinate themes*

While bearing in mind the overarching dyad-in-context framework that connects the three superordinate themes, I will now return to each on its own. The discussion of each theme is related to findings from across the relevant literature. Some studies that did not seem particularly germane to the research prior to analysis, attained newfound significance as the analysis progressed. Gaps and discrepancies that emerged between data and literature will also be noted.

#### *IX.4 Superordinate theme one: Little things are big things*

“Little things are big things” was discussed in the first findings chapter which considered the impact of micro-experiences on maternal meaning and the mother-baby relationship. Mothers named a litany of tiny events, little moments, and brief snapshot occurrences as some of the biggest influences in their development as mother. As discussed in the findings chapter, this theme inhabits the territory of things that are not typically noticed or recorded, except by the mother and baby. The sub-themes of Moments, Words of mothers, Events, and Words of others all detail the small words, interactions or occurrences that held huge meaning for mothers.

As maternal theorists have suggested, the process of becoming a mother is about knowing, moving from the unknown to the known, and doing so through experience (Mercer, 2004; Roller, 2005). The knowing that evolves between a mother and her baby is a mutual knowing and takes place through things like smell, touch, and close-proximity

sight. A baby's world is not one of language, or big, readily-deciphered communications and movements. Cognitive and intellectual learning can be helpful but guidance comes from an intuitive, full-body response based in large part in physiology (Hofer, 2006; Porges & Furman, 2011; A. N. Schore, 2000; Tronick, 2005). While hospitals can measure outputs and inputs, vital signs, and levels, mothers are measuring tiny gestures, small micro-movements, subtle shifts in facial expression, or quiet vocalisations. Mothers and their babies are co-creating a shared connection in which knowing is transmitted in both directions. This co-creation of mutual communication is affirmed by our knowledge of neurological patterning, psychological functioning, and physiological bonding processes; the mother and her infant are in fact neurobiologically connected from early foetal life, and this underpins the development of a dyadic relationship (Feldman et al., 2014; Feldman et al., 1999; J. R. Schore & Schore, 2008; Trevarthen & Aitken, 2001).

The participants were engaged in a semi-structured interview process with the prompts of only a few open-ended questions to guide them. They therefore had authority over what to mention and what to emphasise. The things mothers chose to describe were not things that would usually be noted in a medical chart. What was therefore significant to the maternal meaning-making experience was absent in the medical framework. Yet, it was within that medical framework that mothers were forging their identities and relationships with their babies. Even language could represent a barrier between the maternal and medical perspectives. For the nurse, a baby was "transferred to NICU" after birth; for the mother, the baby was "taken away". Whether it was a discrepancy in word choice or a tiny event unnoticed by everyone except the mother, these little things had knock on effects in terms of how mothers understood themselves and their experiences as mothers.

Researchers and theorists in the field of psychotherapy have investigated these micro-

moments and their importance in the change process. According to the Boston Change Process Study Group (2005), in the midst of the predictable course of everyday relationships come unpredictable, affectively-charged moments that change the course, tenor, and meaning of these relationships. These moments inhabit a kind of time that is outside linear time and contain elements of the unknown and the untraveled embedded within them. They are moments that can change one's identity. Such moments open a door to a way of meeting and connecting with another person so that both people are changed, (Gaensbauer, 2016), thus creating a new intersubjective understanding and reality.

When mothers (and others) are in the territory of these little yet powerful moments, they have entered the new domain of “nanopsychology” (Stern, 2008, p. 181). The term nanopsychology derives from nanotechnology and the understanding of nanoparticles. Nanoparticles are microscopic particles that have different physical and chemical properties than the same particles do when their size is larger (Tinkle et al., 2006). In other words, nanopsychology suggests that when relational interactions are experienced in extremely tiny moments, those moments have properties and power that are not present when examining these moments strung together to make a larger picture. This alteration in the big picture because of a focus on micromoments was reflected within the participants’ narratives. Recall the mother who talked breathlessly about the time she unwrapped her baby to just look at her, to take her all in for no reason other than to really see her. This happened over a week after birth and lasted less than 5 minutes, yet it was a turning point in her experience. She moved from feeling like a stranger to feeling like a mother in this special moment of time.

How did participant mothers know to look for and notice the little things of which they all

spoke? No one told them to do so. In fact, if they were to have solely followed medical instructions, they would never have done so. However, not only did mothers engage in such discoveries, they fought for the right to do so. When participant mothers found this desire thwarted, they protested, even if only internally. As attachment theorists have suggested, relationships are co-constructed not just by two minds but also by two bodies; both babies and mothers demonstrate a desire and a capacity to come to know each other immediately and through the sensory experiences of each body (J. R. Schore & Schore, 2008). Participants seemed in possession of this sensory intuition and knew it to be trustworthy.

Touch is one such sensory system of knowing (Maitre et al., 2017). It provides mothers and babies with an implicitly dyadic form of connection and communication. Participants regularly noted the heightened significance of touch moments: when they could touch their baby and when they could not, as well as moments in which they had to first seek permission to do so. As Stadlen (2011) pointed out, touch is a simultaneous communication, not an alternating one like talking. Mother and baby are affecting each other immediately and on multiple levels. Participants talked about the many ways in which they felt connected, alive, emotionally charged, and surer in their motherhood when they were in physical contact with their babies. Related research would suggest that babies were equally affected (Feldman, 2011; I. Gordon et al., 2010).

According to the existing literature, babies and mothers seem to know each other through sound as well. The baby begins to know the mother in utero, through her voice and her movements, and this continues through the birth process and into the baby's emergence into the external world (Madaule, 2015). The mother's voice, along with her touch, body, and warmth, provides the transition from internal womb life to the new outside

environment. DeCasper & Fifer (1980) found that babies differentiate between female voices and prefer that of their mother just hours after birth. When this oft-quoted research is mentioned, it is usually not noted that the infants studied were in a group nursery environment, handled by a number of female nursery staff, and had received a maximum of 12 hours postnatal contact with their mothers, something described by the researchers as “limited maternal exposure” (DeCasper & Fifer, 1980, p. 1176). The preference for maternal voice withstands separation and the reduced opportunities for interaction, as well as the newness of the relationship. It therefore seems logical to deduce that when mothers and babies are separated due to prematurity and NICU placement, babies will retain a preference for both their mother’s voice and for their mother.

Mothers in my research often disclosed early fears that their babies did not prefer them and did not really know them. This was a source of great sadness for them. Perhaps knowing about infants’ general preference for their own mother and her voice may have enabled NICUs to provide more opportunity for those small moments of meaningful connection. In contrast to their time in hospital, the majority of the mothers remarked that their babies “woke up” and became less sleepy and more vocal once they were together at home. Outside the medical environment, mothers experienced more interaction with their babies and more opportunities for ordinary day-to-day connection. Instead of following NICU protocols and schedules, the data suggested that participant mothers often muddled through by igniting their own instincts and responses to infant cues. As several mother-infant researchers have concluded, the mother’s intuitive behaviour supports the infant’s innate communication (Beebe et al., 2010; Malloch, 2000; Papousek & Bornstein, 1992). This could be one reason why mothers commented that their babies began to communicate more once they were discharged home with their mothers.

The participant mothers were all “inexperienced” first time mothers, yet somehow they knew what they were meant to do. Even when they could not enact their desires or follow their instincts, they knew something was stifled or thwarted. They sensed when things were off course, though they did not always know why. Mothers spoke of feeling a need to run to their babies, physical pain when they had to leave, calming sensations when they were close by, and fear when they could not be close. Even though they were mothering premature babies who were generally smaller than term babies and thus sending even more fragile signals (Feldman & Eidelman, 2007), the mothers still moved to inhabit their babies’ world through sensory coordination. One of the fundamental processes they utilised to connect with their babies so fully and mutually was to notice, focus on, and emphasise the little things, the meaningful micro-moments, the tiny yet powerful interactions and events that only they appeared wired to see.

The findings in this first superordinate theme suggest that the very things mothers focus on and find meaning in are not available for examination and discussion in the world outside the mother. Because so little qualitative research has been done with mothers of premature infants and almost none with low risk premature babies and their mothers, it is impossible to say if these micro-moments are the currency of all first time mothers of premature babies, or even of all first time mothers. Theories of psychotherapy and intersubjectivity (Gallese, 2003; Trevarthen & Aitken, 2001; Tronick, 2003) seem to indicate, however, that this way of coming to understand another and oneself is an essential element of being. What is striking, then, is the apparent absence of dyadic meaning-making and knowledge about the importance of dyadic interactions within the professional networks that the participant mothers found themselves in.

It appeared that the necessary medical focus on the infant’s health created both an

impairment in the mother's ability to assert herself fully into her role and a suspension of her full transition into her new identity. Perhaps that thwarting of the natural processes was exactly what created the hypersensitivity to and awareness of the little things when they presented themselves.

I was unable to uncover any literature that discussed the significance or occurrence of micro-events in the trajectory of maternal meaning-making. Some attachment research, however, has outlined the physiological moment-to-moment unfolding of mother-infant interactions when there are no obstacles, such as those that are posed by prematurity and NICU hospitalisation (Beebe et al., 2010). It seems likely that the temporary obstacles posed by hospitalisation and premature birth result in only temporary impingement of the relationship. The initial relationship disconnect necessitates the vigilance and focus on the critical importance of the little things that the mothers in my research repeatedly dwelled upon. The mothers had not actually disconnected; they were still actively working to gain full entry into the mother-infant relationship and full embodiment of their maternal identity. As a result, they noticed and clung to the little things; they committed them to memory and they became a lasting part of their meaning-making journey.

It seems obvious that the “little things” participant mothers fixed upon are ports of entry into the dyadic world. Information generated by body-based sensory systems also appears to provide a mutuality with infants who share in this body-centred way of connection (Porges, 2007; Trevarthen, 1993). Again, this points to another reality hidden in plain sight. Medicine, in this context, is also all about the body. When the body is absent from larger meaning and dyadic consciousness, however, it functions only to provide individual information about individual symptoms and experiences. When the body is a portal to the relationship, new insights are born. For mothers, new meaning is also

discoverable.

## **IX.5 Superordinate theme two: *Maternal distress***

The second superordinate theme was maternal distress. All mothers described painful feelings and found meaning in these troublesome emotional experiences. While every mother expressed gratitude and desire for her baby, the most animated and repeated disclosures were surrounding the difficult aspects of maternal experiences. The distress enveloped the sub-themes of Separation from baby, Afraid to go home, Not my baby, No control, Get it right/got it wrong, and No whining.

### ***IX.5.1 The distress of separation***

When mothers discussed what distressed them, the universal and most emphasised source of distress was about having to separate from their babies. The separation stressors included not being able to see, hold, or stay with the baby right after birth, being on a different floor of the hospital than the NICU (being alone in the maternity unit without a baby), and having to go back home at night while the baby was still hospitalised in the NICU. Within the literature, there are qualitative studies confirming the issue of separation as a major stressor, and there is also a body of scientific literature documenting the negative impact of separation on mothers and babies (Aagaard & Hall, 2008; Brandon et al., 2011; L. Davis et al., 2003; Erlandsson & Fagerberg, 2005; T. Evans et al., 2012; Flacking et al., 2013; Heydarpour, Keshavarz, & Bakhtiari, 2017; Holditch-Davis & Shandor Miles, 2000; Mehler et al., 2011; Nyström & Axelsson, 2002). The quantitative medical literature is focused on prematurity, however, and has not paid the experience of separation for mothers much attention. This evidence gap raises an interesting question: how many of the negative outcomes associated with prematurity, especially later term

prematurity, are underpinned by the adverse consequences of mother-baby separation?

With the adoption of a dyadic perspective, the influence of separation upon outcomes becomes a central, even if at present an unanswerable, question. Nonetheless, a look at the literature can begin to reveal its relevance.

In the decades following World War II and the development of attachment theory, theorists and clinicians argued that post-birth separation was harmful to both mother and baby as well as to their relationship (Barnett et al., 1970; Bowlby, 1958; Bowlby, Robertson, & Rosenbluth, 1952; Klaus et al., 1972; Robertson, 1953). Because it was unethical to randomise mothers into groups involving involuntary separation from infants, belief in the theory largely remained with people who shared a philosophy of understanding, such as the attachment scholars and their research predecessors like Spitz (Spitz, 1945; Spitz & Wolf, 1946).

At the same time, there was a natural experiment being conducted as the result of World War II. With mass evacuations of children due to bombing in major suburban areas, babies and young children were routinely separated from their parents and billeted in orphanages and safe houses (Rusby & Tasker, 2009). The Hampstead War Nurseries were founded by Anna Freud (daughter of Sigmund Freud) to help shelter and care for evacuated children (Midgley, 2007). Evacuee children often arrived as babies and toddlers, and typically endured the death of at least one parent due to war, most often their father. Lengthy separation from their mothers was also common, even if reunited after the war's conclusion. Freud's staff observed children extensively and documented their observations for analysis. Freud's conclusion about the children's wellbeing was this: "billeted children were saved from *physical* harm, but not from the emotional consequences of separation from home and family, which were only gradually

appreciated later" (Midgley, 2007, p. 948)

As time passed, the potential side effects of mother-infant separation began to permeate mainstream culture, and medical facilities moved toward keeping mothers and babies together in hospitals. When birth was uncomplicated and mothers desired it, babies were housed with mothers. However, hospital NICUs remained places where mothers and infants were routinely separated, something that persists in the present day.

In 2009, researchers in Russia took advantage of existing hospital policy and were able to conduct a randomised controlled trial to submit the separation hypothesis to rigorous research: does post-birth separation have an independent influence on mothers and infants? (Bystrova et al., 2009). In a maternity hospital in St Petersburg, policy called for routine separation and swaddling of all babies after birth. Consequently, randomising babies into groups that included unrequested mother-infant separation did not pose an ethical dilemma. A total of 124 mother-baby pairs participated in the study. Dyads were assessed when the baby was one year old with no other intervention other than the hospital experiment. Data collected 12 months after birth pertained to maternal sensitivity, infant regulation, and dyadic mutuality.

Results indicate that skin-to-skin contact during the first hours after birth is of particular importance and has enduring effects on the infant and the dyad. Even mothers and infants who were reunited after an initial two-hour separation could not compensate for the impact of early disconnection and showed lower levels of mutuality and sensitivity as well as higher levels of dysregulation one year after delivery; this was a similar finding to those dyads who remained separated during the entirety of the initial postnatal hours. Researchers labelled this two-hour postnatal window a sensitive period (Bystrova et al., 2009). This is distinguished from what neuroscientists call a critical period. Critical

periods are requirements of development and if unmet the impact cannot be reversed.

Sensitive periods are important for development but there is potential for revision or remediation reversal of the effects later in life (Knudsen, 2004).

The potential existence of a sensitive period in early development that is facilitated solely by mother-infant contact was reminiscent of an earlier piece of research investigating the outcome of a simple intervention with soft baby carriers that allowed babies to be carried, or worn, on the mother's body. Findings from this earlier study concluded that regular use of a soft baby carrier worn by the mother, as opposed to keeping one's baby nearby in a separate carrier such as a portable car seat, enhanced maternal bonding, increased rates of attachment security, and was sufficient on its own to produce these effects (Anisfeld, Casper, Nozyce, & Cunningham, 1990). In other words, no other intervention was necessary. Unlike the Bystrova study, no sensitive period was examined here; instead the focus was on how effective simple shared body contact could be in enhancing the trajectory of relational health.

Both the 1990 and 2009 studies demonstrated that holding a baby close to one's skin improves a mother's experience, a baby's functioning, and the strength of the relationship. Thus, it is possible that continual non-separation could be a remedy for the impact of initial separation. Participant mother experiences underscore this possibility; once discharged from NICU, keeping their babies close was a feature of almost every maternal narrative. Mothers would just sit on the couch and hold their baby or keep the baby close in other ways, such as carrying or sharing a bed. They were making up for lost time and intuitively seeking to repair the earlier insult. Their apparent ability to surmount the adverse effects of separation suggests that the notion of a sensitive period, not a critical period, is accurate. It also highlights the emotional and psychological effort that

goes into repairing the process.

#### *IX.5.1.1 The historical context of separation*

Within the history of neonatology there is a contextual narrative that is almost entirely overlooked in the literature and apparently absent from the research on maternal wellbeing and parenting after premature birth. Before the invention of the incubator in 1880 and the corollary medical knowledge surrounding premature infancy, care of all newborns was regarded as the province of mothers (Baker, 2000). Doctors initially had a more difficult time gaining mothers' confidence and cooperation in premature infant care than they did in applying new technologies for treatment (Budin, 1907). The first premature infant nurseries were disastrous and had mortality rates of over 75%; doctors quickly realised that without taking into account the motivations, needs, and involvement of mothers, babies would continue to die (Baker, 2000). In 1900, French obstetrician Pierre Budin was one of the leaders of the world's brand new neonatology movement. Budin believed that mothers must be hospitalised alongside their infants in order to protect the baby and keep the relationship from disintegrating. He found that mothers provided excellent observational care and could often tell something was wrong with their babies long before staff could; similarly, he saw that when the bond between the two was kept intact, both parties thrived (Baker, 2000).

However, in the early 1900s as more of the medical community became concerned with the welfare of these very young babies, advocacy for infant care rose to greater prominence. Alongside advocacy came the specialisation of care and the transfer of care provision from obstetrician to paediatrician. Eventually, by the 1940s, the incubator also became a widely used and well-accepted part of treatment for premature babies. This combination of specialty medical care and use of high-end technology gave rise to

another profession: the neonatal nurse. As historical researcher and paediatrician Jeffrey Baker (2000) reported,

The neonatal nurse, in fact, inherited a position somewhat analogous to that held by the mother in the French obstetrical tradition . . . The nurse was the critical mediator in the transfer of responsibility for the premature infant from mothers to doctors . . . The working out of boundaries between physicians, nurses and parents has thus continued to be a major theme of the expansion of neonatology to the present day (p. 326).

Such historical context is more than just interesting background. With the dyad-in-context framework as a lens, we can see that prior to the establishment of professional neonatology, mothers and infants were chiefly viewed as a unit, with infant wellbeing entwined with that of the mother and presumption of care and expertise being solely maternal. While every participant mother expressed gratitude for available expert medical care, her distress at separation also pointed to problematic elements in the construction of the medical system and the biases therein.

Winnicott's previously mentioned maxim again comes to mind. In Winnicott's words, "There is no such thing as a baby. . . if you set out to describe a baby, you will find you are describing a baby and someone" (1987, p. 88). Winnicott was positing a notion that babies do not exist outside of a relationship. At its most basic level, this is literally true, for a baby will not survive without the help of an older, more competent human. Winnicott's statement was also meant to extend beyond the physical into the emotional and psychological: babies derive an understanding of the world through relational contexts. They come to know themselves by being known. The same can be argued about mothers. A mother comes to know herself as a mother through her relationship with a

someone, her baby. When mother and baby are separated they are still in relationship with each other but they are experiencing this relationship alone. The knowing and learning that are meant to take place cannot be fully activated outside the particular relational context. While babies alone in a NICU always have a “someone” who is looking after their physical needs, they are without the “someone” that Winnicott spoke of, without the emotional care the wartime orphanages also could not provide.

#### *IX.5.2 The distress of imperfection*

Mothers also experienced distress over worry that they would get things wrong and that they were not as competent as medical staff. These worries evoked a medical culture of expert and patient, doer, and receiver. In this unidirectional relationship, mothers felt they must display medical expertise in order to warrant designation as good caregivers. Yet the medical model is not the maternal model and it does not embrace a dyadic viewpoint. Relational research indicates that inexact communications and “interactive sloppiness” are healthy components of relationships (Boston Change Process Study, 2005, p. 694). In other words, a mother relating to her baby with love and intersubjectivity will involve moments of imperfection. This interaction involves a different sort of presence, and one that underpins warm mutuality. When mothers model themselves on medical culture, however, this perfect imperfection is unnecessarily diminished. As a result, the importance of mothers is also diminished, the end result being maternal distress.

It is important to recognise that interactive sloppiness is not an apology for lack of competence. This imperfect relational style is actually understood as a kind of best practice (Tronick, 2003). A typical experience shared by participant mothers concerned their lack of knowledge about how to hold their vulnerable babies, how to remove them from the incubator, and pick them up. They would watch nurses do this seemingly

without effort and the baby would not fuss; then they would try, feel nervous or unsure, and end up asking for help. The process would take longer when the mother was at the helm and the baby would often become temporarily unsettled. Mothers often felt like failures and hesitated to pick their babies up the next time an opportunity presented itself. However, from an intersubjective, dyadic viewpoint, mothers and babies were getting to know each other, whereas the nurse and the baby gained no further connection.

When mothers attempt to pick up their baby they enter into a feedback loop in which the baby gives a signal, the mother reorients, the baby gives another signal, the mother course corrects again, and eventually they come together, finally getting it just right (Beebe et al., 2010; Beebe & Lachmann, 2015; A. N. Schore, 2000). While imperfection and “sloppiness” are visible in the back-and-forth adjustments, that baby is learning that the mother cares, responds, and eventually understands; the mother is learning how to read her baby and deepen her maternal abilities (Siegel, 2001). In extension of this theory into a NICU setting, a baby in the arms of the already-competent nurse may not experience transitory discomfort but that baby also misses out on the opportunity to communicate, be heard, and be known. Similarly, in the expert medical model, if a baby does begin to fuss, it is assumed the problem is with the baby, not the nurse or the relationship; the mother, however, reflexively blames herself. Once a dyadic framework becomes the landscape for context, the mother-baby interaction is reframed.

Slowly, the neonatology profession is beginning to notice that something is amiss for mothers. In 2013, Professor Terrie Inder was interviewed on Radio New Zealand’s *Nine to Noon* programme. Professor Inder is a paediatric neonatologist from New Zealand and a specialist in prematurity. She is an expert in her field and known throughout the world. In the interview she said the following:

We've studied the difference between parents being present and the amount of presence and holding in the neonatal intensive care unit and shown it improves the baby's neurobehaviour. And we've also found that infants do need to have experience of human voice and of human touch, particularly during the sensitive time if they're born prematurely. So the things that we thought when we started this research, like the machines and the drugs and the other sorts of things would be very important and have turned out, actually, to not be as important as the experiences that the baby has. . . . I think that (support of parents) is critical and we often don't talk about it enough. Half of our parents leave the neonatal experience with an anxiety disorder and a quarter leave with depression. . . . It is very important that we as medical professionals now set in place ways to evaluate our families prior to discharge, to provide them with counselling support to process the experiences and the difficulties they've felt and then have programmes in place to empower our parents in partnering with the providers, the physicians and the nurses to take care of their babies. In Sweden, I have to say, at the other extreme, mothers are admitted into the neonatal intensive care unit with their infants for the entire length of stay (Inder, 2013).

Inder's words linked all the previously discussed distress factors together: the separation, the negative impact, the sadness of mothers, and the need for better support. She then said something revealing by referencing how Sweden manages all these variables. She did not endorse the Swedish system, nor did she condemn it. It is nonetheless something she said that she thought she must mention.

In March of 2015 I happened to have the opportunity to meet one of Inder's Swedish counterparts, Professor Uwe Ewald. Ewald runs a NICU in Uppsala, Sweden. In an earlier

interview (Ewald, 2013), when asked about what he does, here is how he described the work (note that English is not his first language so some of the wording may appear a little uncommon):

I do something which makes a difference for parents. Actually that is what I like about my job. So in the unit, I have very small, very sick babies and I have all these parents who are also in a very particular situation. They have a lot of sorrow, they have a lot of crisis, they have very little happiness and they are working very hard. So for me, they are as important as their own child. And I see them as the guidance of the child. They are the parent, I am not the parent. They are the parent.

Much of the distress the mothers in my research spoke of is to be expected. Not only the distress of separation, but the worries, fears, unknowns, health scares, and loss of control would naturally be upsetting to most people. To be without any distress when one's baby is in NICU would be an abnormal response. In the Swedish system that Inder referred to, the starting point is one of understanding suffering as legitimate. This allows a potential solution to emerge. Participant mothers were aware that something was amiss in their relationships with their infants and that an understanding of this lack was missing; they suffered but did not feel legitimised.

The potential consequences of such maternal suffering include impact on the communication between the mothers and their infants. Mother-infant communication is unique and has recently been deeply analysed for its component parts and features, including pulse, quality, tone, narrative, speed, timing, and pitch, with the conclusion that a "musical narrative" is created between the two (Malloch, 2000, p. 47). Babies tell stories and even make musical jokes while mothers share in the story telling, respond with precise changes in voice timbre and pitch. Professor Malloch (2000) of the Macarthur

Auditory Research Centre Sydney has concluded that

When our ability to share emotions is impaired, it appears that the elements of communicative musicality change in ways that make them less musical . . . systemic movement occurs between mother and infant, movement that allows mother and infant to express themselves in ways that are sympathetic with the other (p. 48).

Thinking about the music that mothers and infants are primed to make together and the negative impact on them when that ability is impaired raises a chicken-and-egg type question. Is it that mothers who are stressed, anxious, or depressed bring with them the impairments that interfere with joyful music making? Is the stress of being born early sufficient to put dyads at risk? Or does the tipping point only happen when these factors are *combined* with the environment of the typical NICU with its unknowns, medical intensity, inbuilt stress, and policies of separation?

Such questions provoke inquiry into aspects of NICUs that may create unnecessary suffering. Research from the field of paediatric oncology has examined the experiences of parents and offers the concept of “surplus suffering” as a category of suffering that is outside of the unavoidable painful experiences that emerge directly from the cancer experience (Clarke & Fletcher, 2005, p. 121). Surplus suffering refers to unnecessary suffering that results from health care systems: how parents are treated, the rules in place, errors in care or poor treatment, as well as any contradictions and confusion the systems create. Interviews with parents whose children were being treated for cancer found that parents claimed ultimate responsibility for their children, yet often felt powerless. They believed they cared more for their child than the medical team, so therefore had to be assertive and watchful; however, these attempts were typically met with apparent displeasure from the health care providers. Other researchers have found that medical

staff are accustomed to relationships described as asymmetrical, thus when parents attempt to wield greater levels of power, conflict often ensues (Lozowski, Chesler, & Chesney, 1994). Ironically, in Clarke and Fletcher's (2005) research it was clear that both parents and the medical care team shared the same desire: the goal of giving the child back his or her health while minimising any suffering. They noted, "The means to attain this goal, however, is understood differently by parents than by medical professionals" (Clarke & Fletcher, 2005, p. 124).

The narratives of the participants in my research confirmed that surplus suffering was a factor for all the women. Like the parents in the oncology research, the mothers spoke about painful experiences of being disregarded, confusing and contradictory messages from medical staff, and feeling like their baby needed more than was being given.

When looking at this superordinate theme from a dyadic perspective, an interesting gap in the extant research and literature emerged. The body of literature documenting how a baby needs the mother (or mother figure) is vast. It spans across neuroscience and physiology into psychology, infant mental health, and infant development. However, when I searched the literature to see what evidence there is that a mother needs a baby, I could find very little. Almost all of the minimal consideration regarding a mother's need for her baby is confined to the psychodynamic literature. I found a mention in a review of the regulation literature that considered how babies regulate mothers as part of the process of mutual regulation (Winberg, 2005). However, the mutual regulation discussed indicated that the baby's effect on the mother was to upregulate the mother's responsiveness to the infant's needs. In other words, both sides of the dyadic regulatory system were geared toward meeting infant need. I also found other research suggesting that when mothers of stillborn babies do not get the opportunity to hold their infants, they

are at increased long-term risk for depressive symptoms as well as physical effects such as poor sleep and headaches (Rådestad et al., 2009). Researchers have framed this as an unmet maternal need.

Psychiatrist Stern (1995a) in his explication of how mothers become mothers said, “While the mother is behaviourally organising the baby’s world—his cycles of sleep and hunger—the baby is helping her reorganise her own representational world. He is turning her into a mother” (p. 24). This psychodynamic theory suggests that mothers need their babies in order to become mothers and that such need represents a positive mechanism of evolution. Unfortunately, it is far easier to locate literature that links a mother’s need for her baby with pathology, largely because the notion of need is often conflated with the notion of pathological emotional neediness. As a result, most of the writing is concerned with maternal need that suggests an intrusion of the mother’s state of mind into her mothering and her relationship with her baby (Fonagy & Target, 1997; A. N. Schore, 2009; Stern, 1995b; Winnicott, 1960). Other than Stern’s theoretical framework, I could find no investigation of the realities of such healthy transformational need in the literature. In terms of research gaps, there thus appears to be untapped opportunity to explore the topic of healthy maternal need for one’s baby.

The absence of the idea that mothers needs their babies as much as babies need their mothers again places maternal distress within the blind spot of medical culture, a position that becomes visible when adopting a dyadic viewpoint. Repeatedly participants reported that interaction with their infants occurred at the behest of professionals. Mothers felt they were told what to do for their baby, including everything from breastfeeding to getting proper rest. These behaviours were not in conflict with the mother’s desires; mothers simply wanted to make the decisions for themselves. Thus, mothers experienced ongoing

distress at being dismissed or directed. Their primary need was consistently simple: their baby. When viewed within a dyadic context, this is obvious. The rare inclusion of this need once again highlights the lack of authentic dyadic work.

#### **IX.6 Theme three: *How do I become a mother?***

The last superordinate theme was “How do I become a mother?” The sub-themes suggested ways in which this process was difficult and demanding. The main message from this final theme was that becoming a mother for the first time in the midst of low risk prematurity was hard. Hofer and Sullivan (2001) in a study of maternal behaviour, concluded that the way in which women choose to mother is highly sensitive to the ways in which they evaluate and feel about their environment. Contextual maternal perception is thus linked directly to how mothers make meaning of their experiences. In terms of the first time mother participants in my research, becoming a mother in the context of a NICU meant that specific medical culture wielded influence and impact.

There is again a broader background context that helps to illuminate the discussion of this theme, a context that is addressed in one joint paper written by a group of neonatal medical professionals. In 2016, a team of 26 health care providers with experience working in NICUs around the world co-wrote an article entitled *Stronger and more vulnerable: a balanced view of the impacts of the NICU experience on parents* (Janvier et al., 2016). Each of the 26 writers was a health professional, with 20 neonatologists among them. All had infants who had been in NICU and thus were familiar with the NICU experience. Of the 26, 14 had NICU experiences as parents that were due to prematurity. And of these 14, five had babies who fit the criteria for my research. Authors outlined the

lessons they learned and made suggestions for practice but it is in their emotional reactions and psychological responses to entering the NICU as parents—not professionals—that they offered important context.

As with the previously reviewed historical research on the advent of technology and the replacement of the mother's role with that of the nurse, the perspectives of these doctors-turned-NICU-parents suggested there is something implicit in the NICU experience that forms an obstacle to becoming a mother, regardless of who you are. The authors (Janvier et al., 2016) wrote:

As health care providers familiar with the NICU, we thought that we understood the impact of the NICU on patients. But we were not prepared to see the children in our own families as NICU patients. We were not ready for the ways in which the medical jargon could be alienating to us when used to describe “our” infants. We were not ready for the lack of control that accompanies a typical NICU stay. . . .

The experience of having an infant in the NICU altered both our professional and our personal lives in profound and permanent ways (p. 2).

Embedded within the writing of these health professional is the contrast between treating a vulnerable baby and being part of a vulnerable dyad. Once they found themselves in the world of my participants—a dyadic world—their previous map no longer made sense. Each participant confronted the question “how can I become a mother?” The context provided by the article suggests that how well mothers navigate this challenge is not solely a reflection of them as individuals. Bearing that in mind, I will examine the third superordinate theme.

There is small but significant body of evidence that suggests that mothers of premature

babies have very different perceptions of things than medical staff do. Mothers are found to perceive their newborns as sicker than medical staff evaluate them (Nyström & Axelsson, 2002) and to sometimes treat their babies as normal even though medical staff advise against that perception (Lupton & Fenwick, 2001). Research from Auckland, New Zealand in 2012 (Brooks et al., 2012) found that mothers of NICU babies rated them as sicker and facing a more serious condition than clinicians did, and concluded that mothers' ratings were not correlated with actual illness severity. The mothers also rated their infants' illness as not likely to have as much of a long-term impact as the clinicians believed it would (Brooks et al., 2012). So, by comparison with medical staff, mothers were simultaneously more worried in the present but more hopeful for the future. The researchers concluded that mothers' ratings are unrelated to objective clinician ratings and therefore require interventions into "faulty perceptions" so as to reduce their levels of stress and correct inaccurate understandings (Brooks et al., 2012, p. 638).

The language used is consistent with other studies that characterise maternal perception (Ahn & Kim, 2007; Moon & Koo, 1999). The mother's judgment is most often labelled as faulty, especially if it differs from that of medical staff. Yet it is clear that mothers have a different set of criteria than the strictly medical ones used by clinicians, even when the mothers are also clinicians, as Janvier et al. (2016) made clear. It is also reasonable to conclude that if the maternal lens is perceived as less important, less valid, or less interesting than the medical lens, mothers will have a difficult time establishing themselves in that identity. Mothers are attempting to become mothers to their babies, after all, not doctors to them.

Perceptions of mothers by medical staff are also a potential hindrance to becoming a mother. Participants discussed pressure to stay on good terms with nurses given that they

must leave their infants alone in nursing care. According to the literature, most nurses have firm opinions on what makes a good mother. Mothers who do not fit the criteria for being good are typically seen as difficult and are often avoided (Lupton & Fenwick, 2001). Such lack of interaction and relationship with staff has a potential influence. The culture of the NICU is partially defined by its provision of intensive care. As earlier noted, according to NICU nurse researcher Cricco-Lizza (personal communication, 2014), for mothers of low risk babies, the realities of shorter NICU stays often mean less engagement with staff, as well as less time to become part of the NICU culture. Cricco-Lizza's research (2014) also found that most NICU nurses are primarily focused on the most vulnerable babies and derive the most satisfaction from treating those infants. Mothers of low risk babies are less likely to be of interest and possibly more likely to be seen as unnecessarily worried. This appeared to be the case for many participant mothers in my research and led to great confusion. Their babies did not adhere to the picture of prematurity that appeared to activate medical staff care and concern, yet they were nonetheless residents of that world.

Participant mothers in my research confirmed the tremendous influence of staff on their experiences. Many looked to the nurses for expert advice and guidance. Others felt watched and hampered by their ways of interacting. For all mothers, establishing a smooth relationship with medical staff was critical to be able to maintain their presence in the NICU and get to know their babies, and therefore themselves as mothers. More often than not, the only individualised attention participant mothers felt they received from medical staff was when staff worried about excessive maternal emotionality. Otherwise, mothers reported, the staff often did not even learn their names. As was noted by Luthar (2015), when the medical culture prevails as the role model for learning motherhood, maternal behaviour, instinct, and wishes will often end up pathologised.

Mothers described their responses as more emotional than the medical staff. This makes sense. Mothers are emotionally invested in their babies and tied to them in a completely different way. However, sometimes expression of such emotion was perceived to be received poorly by medical staff in my research. Nurses appeared to see it as helpful to tell mothers to go home to rest or have their hair done. Doctors told mothers their babies were fine and there was nothing to worry about, leaving mothers worrying about why their babies were in NICU. However, worry, in fact, seemed to be an important way that mothers learned to become mothers. Worry made mothers more vigilant. It linked them to the micro moments and events described in the first superordinate theme (little things are big things) as it helped to create conscious awareness of every little thing that was occurring. Worry should not be pathologised just because it occurs. In fact, mothers who do not worry at all are probably of more concern than mothers who worry “too much”. Every mother in the sample reported worry decreasing once their baby was at home and time had passed. Worry appeared to link with the second superordinate theme of distress mostly because it was invalidated.

Worrying thus seems useful and a tool in becoming a mother. As Stadlen (2007) explained, new mothers will often use worry to examine a situation and work out what is wrong, trying on different scenarios to see what may be happening for her baby. “The word worry is normally used to suggest a pointless and repetitive way of thinking. A much more appreciative word is needed to honour intelligent motherly concern” (pp. 19-20). Once again we see a maternal response—this time in an effort to become a mother—is a dyadic one.

The quest for better words to represent an appreciation for maternal efforts and to reflect a dyadic perspective is not trivial. Language emerges in culture and co-evolves with

meaning, hence vocabulary becomes an important repository of information about how people and ideas are understood (N. Evans, 2003). Linguistic literature reveals that there are a few languages with dyadic kinship expressions; these expressions occur most frequently within the native Aboriginal Australian dialects. These terms are referred to as “kintax” and encode kinship relations into the grammar and speech of everyday life. The kinship terms are ones in which two people and their relationship are subsumed into one word. One salient example of this is the use of a single word to mean mother-and-child. Within such a language, it is impossible to separate the two. This is language animating the dyad. Within New Zealand, Māori language also includes kinship terms, with whānaungatanga being the most well-known. Whānaungatanga is a key part of the philosophical system that regulates human behaviour and is understood as the kinship bonds that determine actions, rights, and status, something that cannot be generated by a disconnected individual (Henare, 2001); it also represents a dyadic relationship within each person, connecting the physical and the spiritual worlds (McNatty & Roa, 2002). Locating the individual within an inextricable network of family and interrelationship is part of Māori ecological philosophy (Durie, 1985).

When first time mothers struggle with a sense of identity, expression of dyadic legitimacy can support that process. Language to communicate such authentic appreciation of the dyad is, however, largely missing. For the mothers in my study, role establishment had not yet occurred. So while they experienced the same impulses and maternal instincts, they acted on them less than literature has suggested was possible for parents on paediatric oncology wards (Clarke & Fletcher, 2005). First-time motherhood also appeared to add a layer of surplus suffering that my participant mothers were only peripherally aware of in the immediate aftermath of their first baby’s birth. For participants who had gone on to have a subsequent child by the time of interview, the

awareness of that previous suffering emerged after the second birth and was discussed often. Mothers noted how the second birth helped to clarify and heal some of the first-time birth distress. They also discussed how they felt they were immediately and organically able to be mothers the second time around, inhabiting the role already, not having to work for it.

Multiparous mothers—mothers who have had two or more children—have developed a schema for motherhood. Schemas are organising mental structures based on past experiences that allow a person to understand experiences through an established lens (Wachtel, 1980). First time mothers may draw on experiences they have had with other mothers, as well as being mothered themselves, but they have not yet developed their own schema for mothering. This puts them at risk for adopting beliefs that may not fit with their own needs or that of the dyad (Luthar, 2015).

As Ewald (2015) pointed out, mothers who learn to mother on the NICU are often taking their cues from medical staff. My participants revealed that this was an uneasy situation for them. The lack of a dyadic perspective meant that establishing an authentic sense of themselves as mothers was painful and daunting, and they felt a need to defer to the wishes and mandates of staff. Repeatedly, mothers confessed a lack of entitlement to complain; in interviews, however, they expressed much they wished to complain about. Mothers had great discomfort with their own grievances because their babies were low risk. Their babies were not as badly off as many others in NICU and they were also aware of the health-promoting expertise being administered by medical staff. Yet they simultaneously confronted obstacles posed by medical culture and felt disgruntled about that. This created a sort of double bind for the mothers, in part due to the fact that they had never mothered before. A more a dyadic framework offers a bridge between the

worlds. Once it is acknowledged that mothers need to be in dyadic relationship with their infants in order to become mothers, then the tension between simultaneous gratitude and criticism might largely evaporate. Mothers become free to express both; they can be seen and heard.

Being listened to seems to be a potentially critical aspect of becoming a mother.

Attachment theory posits the necessity of constructing a coherent narrative of one's past in order to achieve security (Siegel, 1999). The need to construct a story and tell it is what is important; it is not the events themselves that are significant, but the meaningful manner in which the story is composed (Main et al., 1985). For some participants, the interview was the first time they had told their story and had it received. Being listened to allowed the story to be integrated into reality and also afforded mothers a chance to process their previously unprocessed experiences in order to create meaning (Laub, 1992). Previous research has identified that telling one's story also facilitates autobiographical memory and the ability to create a shared narrative to tell one's child later in life (Fivush, Haden, & Adam, 1995).

Listening to someone's story is not as easy as it first appears. Listening, according to poet Mark Nepo (2013), involves holding our opinions and identity lightly and loosening our grip on how we see the world so that the views of another can "expand us, deepen us and rearrange us" (p. 10). Listening is an intentional act, in contrast with hearing, which is behavioural and physiological (Fredriksson, 1999). This distinction between listening and hearing is relevant to how mothers come to know their infants. By being with her infant in close physical proximity a mother is able to take in all aspects of her baby and come to know who the baby is. It is also relevant to how mothers come to know themselves. Being listened to provides a foundation for the process of becoming.

Listening is also certainly part of what medical professionals could be engaged in to support mothers, but is something that the participant mothers rarely reported receiving. Nursing research suggests that listening, along with caring presence and touch, facilitates connection that allows for intersubjectivity and an attentive patient-nurse communication (Fredriksson, 1999). Research from the field of paediatrics describes how medical humanities education is now teaching the importance of narrative stories (DasGupta, 2007). Listening to patients' stories is understood to be possible even when patients are nonverbal; this skill is predicated upon the capacity for the medical practitioner to be still and receptive, managing his or her own reactions and making room for the patient's story. If cultivated and utilised, such a skill goes a long way to being able to perceive the communications of the baby, and of the dyad. But as DasGupta (2007) pointed out, this sort of passivity is antithetical to medical culture. "If anything, medicine acts; it examines, interprets, investigates, scans, incises, debrides, and sutures. In grammatical terms, almost all of medical practice occurs in the active voice" (p. 1386). What the medical culture tends to perceive as passivity, a mother experiences as active work and a dyad defines as receptive.

Unlike passivity, receptivity suggests mutuality and vibrancy; it is a relationship that is alive and actively creating an interpersonal reality. In this way, being a mother is intensely creative. When the dyadic process is interfered with, mothers instead inhabit a liminal existence that they must overcome in order to become mothers in a meaningful way. Participant mothers inhabited a dyadic identity, despite the obstacles they encountered in doing so. Their distress, their tight grip on micro-moments and micro-events, and their difficult journey into motherhood all suggested that if the medical system and support networks surrounding mothers were to also step toward dyadic seeing, things might be significantly improved. As Stadlen (2007) cautioned, if we do not notice

what a mother is actually doing then only the baby experiences her work, yet the baby cannot easily communicate this to anyone.

## IX.7 A bridge across the superordinate themes

Moving from the either-or position of medical versus maternal, individual versus dyadic, will require its own relational context. Just as mothers are in relationship with their babies, they too are in relationship with the medical culture. The pitfalls of obscuring the mother-child dyad are clear. It is likely that obscuring the maternal-medical dyad is also detrimental to both mother and clinician. That is to say, there must be possibilities for focussing on both the mother and the medical professional. Like with the mother and baby, this is more likely to happen if there is a focus on their interplay. When researchers sought to look at the effects of teaching counselling skills to neonatal clinicians, they found a continual mismatch between what the physician perceived and what the parents did (Stokes, Watson, & Boss, 2014). This rift was not improved by improving physician communication or making sure adherence to protocols or verbal clarity was up to scratch. Instead, only through the inclusion of emotion in decision making and the acknowledgement of its important place in the process could the gap between professional and parent could be narrowed.

The critical role of emotion points to the reality that human beings process not just with their brains but also with their hearts; while this is obviously more so for mothers, it is also true of medical professionals. Researchers who examined how neonatologists communicated with parents of dying babies also spoke about the wisdom of emotions, suggesting that emotions represent a powerful contribution that does not conflict with knowledge; in fact they may be the highest manifestation of human response to stress (Janvier, Barrington, & Farlow, 2014). The same researchers concluded that even when a

child is dying and cannot be cured, there is always “something we can do” (Janvier et al., 2014, p. 45). The kind of doing proposed also offers a bridge and a moving into the relational realm, for it is a doing largely of an emotional and social nature.

## IX.8 Conclusion

The discussion of my research has placed participants and findings within a contextual understanding. Participants created meaning through a dyadic framework of seeing and experiencing the events surrounding premature birth. Similarly, findings generated meaning through the context of superordinate themes that joined participant experience and linked it to an existing body of literature and thought. The three superordinate themes signify the most meaningful and persistent topics to arise from participant interviews; simultaneously, they also inhabit a hidden relational world accessible to mothers. Yet once a revised dyad-in-context model is employed, the invisible maternal world becomes visible.

Movement into the dyadic, relational realm ties the themes, the larger contextual factors, and the medical world together to the mothers and their babies. Acknowledgement of the centrality of dyadic ways of being also generates a set of important questions. Is there room for an open-ended dialogue in which mothers can be truly seen and validated without having to put medical expertise to the side? Simultaneously, is there the possibility of a medical system that considers not just the infant patient, but also the kinship system and the mother-child bond that is building and being influenced by every choice? How can professionals—medical practitioners, nurses, and social workers alike—be better supported to connect their own work to the maternal world? These are some of the questions that will be taken up in the next and final conclusion chapter.

In the next chapter, I will review the superordinate themes and discuss the meanings and implications of the participants' stories and what the themes give rise to. I will examine the ramifications of the dyad-in-context model and explore how it frames greater understanding of maternal wellbeing and health. As Durie (1985) stated when writing about Māori health perspectives, thus far attempts to define and measure wellness have been much less successful than our attempts to delineate and grade illness. The dyad-in-context model is one of relationship, wholeness, and wellness and it can thus help guide responsive practice. In advancing such an aspiration, the next chapter will consider the significance of the research and make recommendations based on my findings. This will include exploration of how psychological, medical, ecological, and social work theory and practice are touched by the research and how responding to such influences can shift policy and practice toward enhanced efficacy.

## Chapter X: Conclusion

### X.1 Introduction

By way of an introduction to my conclusions, I believe it is best to return to where I started the research. I began with the stories of mothers. One mother at a time, I sat and listened. The mothers talked. But they did not only talk. They also mothered. Some of their mothering was explicit. During the interviews I witnessed mothers change nappies, breastfeed, bottle feed, make play dough, repair toys, find DVD's, peel bananas, pour juice, rock infants to sleep, cuddle babies, make dinners, soothe teething pains, and bounce toddlers on their knees. They shared their stories as they simultaneously shared their lives. When children were not present during the interview, mothers dug out photo albums and opened laptops to share photos; they pointed to family portraits on their walls and showed me items of clothing. Despite their vast differences in personalities and parenting styles, participants were mothering even when ostensibly doing something else. They never commented that this was abnormal, nor even especially difficult. I suspect that if anyone had asked what they had been doing earlier that same day, their answers would have uniformly referred to being interviewed. I doubt a single one would have mentioned that they were also mothering.

Prior to this research, I would have answered similarly. What I have since come to understand is what the mothers taught me. I learned—not then and there, but over the course of the entire thesis project—that mothering is not just something a person does. Mothering—at least for my research participants—is a way of being, seeing, and making sense of the world.

My research was not concerned with just any mothering, however. My research subjects were first time mothers without known risk factors. Their babies were all single low risk

premature infants, born late enough and weighing enough so that there were no serious, persistent medical concerns, and without known significant chromosomal abnormalities. The participants represented a relatively under-researched group, largely due to the lack of identified risk in both mother and infant. I selected this subset of mothers and babies through the counsel and support of colleagues working in the field of mother-infant support, most especially my supervisor Dr Patricia Champion. The default invisibility of my participant population was due to the justifiable concentration of research and resources on the highest risk, most vulnerable, and most needy premature infants and mothers. Outside of this most pronounced and intensive risk group nonetheless reside the majority of mothers and babies. The bulk of premature babies are in the lower risk categories and, obviously, all mothers will be first time mothers at one time. There is scant data on first time mothers with low risk premature infants, and there is a mostly unquestioned assumption that neither mother nor baby is adversely affected by the experience in any persistent or harmful ways (see Chapter III Literature Review for further information). This presumption defies evidence—minimal but mounting—which points to unique risk factors and risk profiles and recommends the need for awareness, investigation, and response.

In this chapter I will present a review of the research questions and project. I will describe the major themes and findings, focussing on their main messages and implications regarding the way we understand maternal experience, premature birth, and the creation of professional models of support. I will evaluate the ways in which the research is significant across psychological, medical, ecological, and social work domains. Drawing from those areas of significance, I will make recommendations for improvement in the way we respond to mothers. Finally, I will identify and discuss the limitations of the study and offer suggestions for future research.

## X.2 Research questions and findings

The research I undertook was interested in how the mothers understood their internal, relational, and life-world experiences, especially as they had never mothered before. Specifically, my research questions asked mothers how they came to understand themselves as mothers, as well as how they came to know their babies and understand the relationship between the two of them, whilst initially mothering within a medical context. To recap, my research questions were as follows:

*How do first time mothers and their premature infants make sense of the experience of premature birth?*

*What is the nature and meaning of the interpersonal processes that occur between the mother and her infant following premature birth, both in hospital and after discharge?*

*How do mothers come to understand themselves as mothers and come to know their infants?*

In answer to my questions, 15 mothers took part in semi-structured interviews lasting approximately two hours. Interviews were audio recorded, transcribed by me, and then analysed according to interpretative phenomenological analysis (IPA) methodology, hence giving attention to meaning generated from both depth and breadth of topics. Individual transcript analysis called for scrutiny of the unique, subtle, and important messages from each mother; areas of meaning and consequence common to all participants were derived from analytical frameworks that called for the identification and structuring of emergent themes across narratives as well as the interpretation of narratives within the larger bodies of relevant literature and real-life contexts.

Three shared motifs formed the superordinate themes that then created the structure of the three main findings. These three superordinate themes were “Little things are big things”, “Maternal distress”, and “How do I become a mother?” Despite differences in content and composition, each theme was about relationships. Each theme also represented something currently obscured or invisible to anyone other than the mothers, things “hidden in plain sight”. Dyadic thinking suggests that perhaps these things of maternal meaning are also visible to and alive for the baby in some way, but that is not entirely possible to know. What was true about all the superordinate themes was the persistent fact that what the mothers found most essential and full of meaning was outside of the realm of the day-to-day notice of neonatal intensive care unit (NICU) medical systems and the professionals working within them. I do not mean to imply that such lack of awareness equates to a lack of care, concern, or skill. Instead, I propose that there is an absence of shared vision between the maternal and medical worlds when it comes to first time motherhood and low risk prematurity. This is accompanied by a misunderstanding about what it means to work with a dyad, which is typically conceptualised as working with two related individuals together.

#### *X.2.1 Finding 1: Little things are big things*

The implications of the first superordinate theme of “Little things are big things” revolve around the ways in which tiny, uncharted events and interactions established the greatest sense of meaning and importance for participants. Through this superordinate finding, the research suggests that the maternal world parallels that of the premature baby. Premature infants, by virtue of their immaturity, communicate in tinier, subtler, and less obvious ways than full term babies do. Their signals are easy to overlook and adults in companionship with them must be highly attuned so as not to miss opportunities for mutual understanding and connection. Yet, of course, the babies themselves cannot tell us this. Participant mothers were

functioning in similar ways. They inhabited a maternal world in which apparently insignificant words, actions, and happenings carried great importance, often far greater than the things that were evaluated by others as worthy of attention. Like their babies, they could not communicate this directly; they simply knew that what was most meaningful to them was not being noticed by the medical world.

Furthermore, the knowledge mothers possessed about how to orient toward their infants and find meaning in the little things was not taught, nor was it based on previous experience. Mothers found their way through some internal, intuitive path. Once again, findings point out the way in which a dyadic perspective alters the frame and makes the invisible visible. Mothers appeared to find their way to their infants and their maternal identities through the dyad, through inhabiting dyadic space and dyadic awareness. When a dyadic frame is lacking, the maternal window also closes.

#### *X.2.2 Finding 2: Maternal distress*

Implications of the second superordinate theme, “Maternal distress”, surround the way in which distress is a persistent and lasting feature of first time mothers who have given birth to low risk premature infants. This replaces the mostly unchallenged notion that the combination of mothers labelled low risk alongside babies labelled low risk equates with an experience that carries a low risk for emotional pain and anguish.

The universally discussed and most repeated aspect of distress that the mothers reported was that of unwanted separation from their babies. In an era in which the value of non-separation between parents and children in situations of stress is well noted and rights of children in hospital situations are defined according to their need for parental presence and support, the NICU remains an outlier. There are clear medical, financial, and practical rationales for why

babies reside in NICU after mothers are discharged from hospital but that does not alter the distress that mothers experience. Notably, the participants' struggle with separation links with updated psychobiological findings regarding the existence of a sensitive antenatal period for physiological mechanisms of bonding to take place between mothers and newborns. Despite reassurances from staff and family that babies will be alright and despite their own intellects attempting to convince them that they were overreacting, participant mothers nonetheless all reported the ways in which they fought against both separation and its effects on them—emotionally, psychologically, strategically, inwardly, and outwardly.

Maternal distress due to separation again highlights the way in which medical culture is at odds with maternal ways of knowing and being, and the way in which an absence of dyadic frameworks creates disconnection between the mother and maternal needs. This particular issue also expresses the shift from dyad to triad within the NICU; the NICU nurse—placed within a historical context of acting as a medical mother-substitute—now becomes an unintended obstacle to mothers achieving full access to their babies.

Nurses and the medical culture are implicated in another unforeseen reason for maternal distress: the distress of imperfection. Participants spoke of the self-assessment they employed to evaluate their role and performance as competent and “real” mothers. Much of this judgement stemmed from comparisons between their knowledge and abilities with those of the nursing staff. Some mothers felt diminished by staff who would not allow them to participate, gave them rules to follow regarding cuddling times or feeding schedules, and who told them what to do; others felt indebted to staff who explained how to complete care routines and modelled the ways in which babies should be handled or responded to. On both sides of the coin were mothers who gauged themselves in relation to nurses. Perhaps unsurprisingly, no matter how mothers evaluated nurses, they self-evaluated as lacking. Once

more, a dyadic framework shifts this evaluation from one that finds distress in imperfection of the individual to one that finds value in the messy, interactive, mutuality of a mother and baby coming to know each other. The mother-infant architecture may have less initial, apparent adult competence, but it allows for the baby to communicate and be heard, to protest and be responded to; the mother's very uncertainty and vulnerability is what gives rise to the baby's efficacy. As such, new knowledge and experience in both becomes possible.

Outside of a dyadic context, however, mothers cannot be validated in this way. This gives rise to the notion of surplus suffering and the way in which maternal distress is categorised as problematic. Instead of being understood as positive—which is to be distinguished from desired or enjoyable—distress is seen by both mothers and medical culture as something arising from mothers' own failings or as an unnecessary emotion. Yet who would think a mother normal or healthy if she were unbothered by premature birth and the subsequent hospitalisation of her child? Participant experience advances the notion that maternal distress could make an important contribution to understanding maternal experience and how to support mothers of premature babies. Through normalisation and validation, maternal distress could be used as a compass for finding where maternal need requires acknowledgement and where dyadic meaning emerges.

#### *X.2.3. Finding 3: Becoming a mother*

The significance of the third superordinate theme, “How do I become a mother?”, resides in the discernment and knowledge about what it takes for first time mothers to craft a maternal map and identity when they are parenting premature babies. Because mothers develop in ways that are highly sensitive to context, the medical realities and circumstances of NICU and hospital life become a potent factor in how mothers make meaning of motherhood.

In research documenting the experiences of NICU doctors who became NICU parents, Janvier et al. (2016) highlighted the gulf between the professional identity of a caregiver in the NICU and the personal identity of a NICU caregiver (see also IX.6). Throughout that article, the doctors-now-parents repeated the phrase “not ready” to describe how they felt when they became parents of NICU-hospitalised infants, further remarking that they were permanently changed by what happened. If medical professionals who have spent their careers as experts within NICUs could feel unready and irrevocably altered by having a baby in NICU, it cannot be a surprise that participants felt overwhelmed and struggled to feel like mothers.

At the same time, precisely because those NICU doctors and nurses had been unprepared, it also suggests that prior to their personal experience, they lacked the awareness of just how hard it could be for parents. When this awareness is coupled with nurse research identifying that NICU nurses prefer work with the sickest and most medically complicated babies, implications for how lower risk mothers navigate mothering emerge. A failure to realise the difficulties mothers may face in trying to become mothers within a NICU, combined with a focus on mothers who have high-risk babies, inadvertently generates obstacles for mothers of low-risk babies trying to forge and claim their own maternal identities. Without intention, mothers of the lowest risk babies become the most neglected population within the NICU culture: first they are excluded through the ignorance of how unprepared parents are in general; then they are excluded by not belonging to the subset of risk that is deemed most interesting. Although it is highly unlikely that any of this occurs consciously or with any desire to diminish maternal experience, low risk mothers such as the participants are thus made exquisitely vulnerable.

This nested array of medical norms and lack of perception mean that attempting to become a mother becomes a process of wanting to mother yet feeling excluded, of having maternal instincts but finding them thwarted, of worrying yet being told not to, and of ending up with a double layer of risk through the mere fact of presenting with very low risk. I now begin to understand the reality for participant mothers and I think back on the words of Meg, the first woman I interviewed. When I first met her she said she thought she might have “*imagined the fact that we’d been overlooked*”, something that many subsequent participants echoed. Now at the conclusion of the thesis it has become evident how, without embracing the maternal lens that participants were looking through, their realities can end up seeming like something they had imagined, something that only existed in their own heads.

### X.3 Significance

Through the willingness of participants who shared their stories—taking these out of their own heads and trusting me with them—the meaning and significance of their individual experiences can be broadened and applied. The research can be used to shed light on the implications of their messages and the ramifications for supporting mothers in similar situations. The research findings are important in relation to four main and interrelated areas: psychological understanding, medical practice, ecological theory, and social work support.

#### X.3.1 *Psychological significance*

As I have mentioned several times throughout the thesis, a central tenet of infant mental health and perinatal psychology is the notion, derived from Winnicott, that there is no such thing as a baby (1987). A baby lives in relationship to a “someone”, a caregiver in loving relationship with the infant. When you look for a baby, you find a baby-and-someone. This is at the centre of our understanding of what a dyad is; it is not merely two people physically

near each other, but two people whose identities and experiences are intertwined and mutually enhancing. This research adds complexity to Winnicott's concept in a couple of ways. Firstly it offers an additional understanding that reverses the statement, and secondly it argues that the statement is paradoxically both true and untrue.

In the first instance, findings indicate that not only is there no such thing as a baby, there is no such thing as a mother. If you look for a mother, you will find a mother-and-someone. Just as the original phrase implies a baby's psychological dependence on an adult someone (mother) for the lived experience of identity and the world, so too does the alteration imply that a mother requires the same. Without a baby, there is no mother. Participants' stories highlight that the mother's need for her baby goes beyond mechanistic or physiological priming that supports a mother enacting mothering behaviours. Instead we see that mothers create meaning, mapping, and identity in relationship with their infants. It was the inability of medical systems and practitioners to hold this bidirectional, dyadic perspective that saw all three superordinate themes land in the shadow of mainstream views. Once embraced, maternal experience comes to life.

Secondly, findings advance Winnicott's notion to a paradoxical place. Whilst the original meaning of the idea that "there is no such thing as a baby" (Winnicott, 1987, p. 88) remains true, participant mothers and their babies also showed that there is—in the NICU—such a thing as a baby without a someone. Despite the fact that babies clearly receive excellent medical care that supports their physical survival and health, babies are without the sort of someone that Winnicott intended. It is not clear exactly what unfolds for babies during this time and if they, like their mothers, inhabit some kind of liminal waiting space. Whilst speculative, if understood through the lens of sensitive psychobiological windows of development, it appears that babies work with mothers to overcome the strains endured and

may well have the capacity to repair any sustained damage. Nonetheless, they are a baby without a someone in that initial antenatal period in NICU. Here another tier of the paradox surfaces. Through analysis of participants' stories it now seems evident that even when the connection between baby and mother—between baby and someone—is stretched, the absence of connection still offers a place in which a mother is part of the dyad. In other words, the mothers' sadness, anguish, protests, difficulties, and concerns all represented ways in which they were trying to mother, ways in which they may have been thwarted but still were acting from a position of dyadic connection. If the mothers had been entirely disengaged or without dyadic perception, their distress and discomfort would not have been possible. They could have operated more like medical staff, caring but with an objective, largely unemotional stance. The fact that they often felt they failed to be allowed to mother, or failed to be a real mother, belied the fact that they were already acting from a position of mother.

These revisions and augmentations of Winnicott's original thinking are significant beyond the theoretical realm. Once a dyadic perspective is adopted—and once that is combined with comprehension about how lived dyadic experience constructs maternal identity and shapes the way mothers make meaning of themselves and their infants—the reactions, responses, needs, and desires of mothers within NICU culture must be re-evaluated.

### *X.3.2 Medical significance*

Throughout the interviews, mothers found themselves at odds with how they perceived medical culture. The NICU by definition is a medically intensive hospital ward designed for providing high quality medical care; the NICU is not in the business of mothering. The problem does not appear to be the fact that medical culture does not mother better; the problem appears to be the existence of a void between the medical world and the maternal

one and a current lack of a way to bridge this gap. Mothers are compelled to value the contributions of the medical world; without the involvement of the people in this world their babies may not survive. However, maternal contributions are not usually understood as mandatory components of infant success in NICU. In many ways, participants' narratives highlighted the sequential thinking of NICU: mothers felt sidelined until just before discharge when they were then called upon to exercise authority and responsibility for their babies. When mothers tried to fit themselves into the medical way of being they suffered. The fit was not comfortable, nor was it appropriate. But in the absence of other options, fitting into the medical world was the best mothers could do.

Medical culture is characterised by action and evaluated by the efficacy of those actions. Assessment is an important part of medical strategy, but to go no further than simply to watch is not commonly part of medical intervention. It appears that maternal ways of being are much less about action and more about reception and shared response. Just as Campbell-Enns and Woodgate's (2013) research with mothers who were also cancer patients showed that all decisions were made through the filter of the relationship with children, participant mothers could not easily disentangle what they were feeling from what they were perceiving about their baby. When a mother sat by her baby's incubator doing "nothing", it could appear to staff as if she was not needed. These were often moments when mothers would hear suggestions about self-care or taking breaks. This was a recommendation made possible by looking through a medical lens. When examined through a maternal lens, passivity and expendability transforms into receptivity. There is a vibrant and alive quality to reception. Receiving, decoding, and enacting unspoken messages is a creative process, a kind of alchemy in which something invisible to medical staff is transformed into essential maternal knowledge. Receptivity thus underpins maternal meaning making. Yet this receptivity is

fundamentally at odds with medical evaluations of contribution; usually it may not even be apprehended.

The value of the maternal way of being provides a convincing argument that first time mothers of premature babies cannot be properly supported until we abandon the either-or position of the medical versus the maternal and we create a way in which both are included, valued, and upheld. This appears to require professional and medical reframing of maternal behaviours and responses so that mothers can be positioned within a dyad even if only the infant is a patient.

There are implications for improvements for both practice and satisfaction of nurses, too. Whilst the relationship between the mother and the baby is primary, mothers are also in relationship with nurses. Nurses are the closest thing to a mother infants have when their mothers are absent; mothers entrust their babies to the care of nurses and research is clear that both mothers and nurses have strong feelings about those dynamics and their personal influence. Here again is an opportunity to reject the maternal-medical split and focus, instead, on a kind of mutuality in which the value of each can be confirmed and defended without requiring the mother to be like the nurse, nor the nurse to be like the mother.

### *X.3.3 Ecological significance*

There is also larger meaning in reworking ecological theory to include the possibility of a dyad at the centre of experience instead of an individual. I think the pitfalls of mistaking the back-and-forth between mother and baby for true dyadic work have been well demonstrated. Adherence to a traditional ecological model can be problematic in this regard. Ecological theory and biopsychosocial ways of understanding people within the realities that influence them are critical aspects to social work thinking and advocacy. However, when it comes to

application of ecological frameworks to mothers and infants—in this case, to first time mothers and their premature infants—traditional theories may actually inhibit best practice and cause social workers to misunderstand maternal responses.

Shifting to a dyad-in-context model as an additional way of thinking about mothers enhances practice and could improve our understanding of mothers and thus our support of them. As before, this is not simply about intellectual theory. At the heart of good social work practice is an authentic commitment to empower people according to their own goals and values. Just as obscuration of the dyadic reality is detrimental to mothers within the medical world, it is likely similarly unhelpful within the world of social work practice. I think this is especially true within a New Zealand context. The position of individual identity as inextricably bound to and deriving from connection with whānau is the platform of Māori ecological thinking. Including a slightly more precise structure for maternal identity creation and meaning-making is consistent with such a non-individual philosophy and possibly steps the thinking somewhat closer to the reality expressed by participant mothers.

The dyad-in-context model also returns to the question of maternal needs and reframes them. If there is an individual at the centre of the experience, that necessitates understanding maternal distress or maternal need for her baby as something internal to the mother, though under influence from a multitude of forces. However, when need is understood through a dyadic contextual lens, it becomes an element of the relationship, something mutually enhancing. The baby needs the mother; the mother needs the baby. Instead of dependence or weakness, need—dyadically evaluated—is contribution and an ingredient of growth. The same applies to discomfort, distress, or difficulty. They are part of the relationship, not just unnecessary and bothersome experiences belonging to the mother.

It is important to note that the situation of a dyad at the centre of any proposed ecological framework does not diminish or discount the contextual factors that directly and indirectly influence mothers and mother-infant dyads. The established thinking about the role and importance of context, environment, and circumstance remains on solid ground. In a traditional ecological model, a mother's links to social, institutional, and family networks; local environments; societal norms, policies, and frameworks; and cultural values and structures all have an impact on her particular lived experience. So too are these same multitude of factors at work for the dyad-in-context.

#### *X.3.4 Social work significance*

The meaning for social workers and the subset of perinatal social work resides in how social workers construct and make sense of their role. At present in New Zealand, social workers employed within NICUs work within a health model that mirrors the structure of medical staff. Social workers carry high caseloads with workload triaged according to acuity and assessed need. This is a parallel systemic structure to that of the nursing system, albeit with a different set of professional goals. As with the nurses, the primary attention to the highest risk infants and their families makes sense, especially in a setting in which infant death is not unusual. Unfortunately, such a focus typically necessitates overlooking infants and mothers who do not present with obvious cause for concern.

Whilst medical professionals have aims of treating and resolving medical problems, social work has goals that are different. Advocacy, support of human rights, emotional and psychological support, empowerment, providing access to knowledge, and liaising between medical staff and parents are all part and parcel of the social work role. Social workers hone their skills to accurately identify people's vulnerabilities and strengths and to ensure that their needs are not overlooked. As previously discussed, the very nature of participant mothers'

low risk status confers upon them heightened vulnerability as well as a greater likelihood of neglect by NICU support services, including by social work support services.

Social work theory and philosophy are already consistent with what the mothers need, but currently evidence suggests that the high-risk, individually oriented focus creates a blind spot. In that blind spot are participant mothers and their babies. The significance of the research for social workers suggests that in order to truly fulfil the goals and roles of the profession, there may be a need for further education about the importance of valuing dyadic relationships for parenting in early childhood.

Acknowledgement of and advocacy for the dyad—not just the medically fragile baby, the acutely distressed mother, or the family with socioemotional risk factors—provides social workers with another way to see, evaluate, and respond to maternal need. It also provides an equalising force that opens the door to a fuller and more inclusive NICU culture.

## X.4 Recommendations, future research, and limitations

### X.4.1 Recommendations

When I first began writing up my analysis, I would frequently think about what I would like to recommend, especially all the ways I believed policy and training should change. By the end, however, I had finally understood the dyadic picture the mothers had drawn. As a result, my recommendations are based upon that understanding and are primarily concerned with how professionals can also learn to see and be with the dyad.

Many researchers and clinicians are concerned with premature infants and their mothers. Many have presented excellent ideas for the revamping of NICU design and for improving protocols for family-centred care so that mothers become an integrated and central part of

infant life. My research is aligned with those recommendations in many ways. But it does not simply provide more support for those arguments. Through analysis of participants' stories I have become convinced that when we have a focus on improving professional care without understanding dyadic work, we risk replicating the exclusion we seek to avoid. For example, if we recognise that separation is distressing and remedy that by providing chairs and telling mothers they should be by the incubator as much as possible, we are still in the position of expert; and we continue to speak to the individual.

What I recommend is that we begin with the dyad and work from there. Being alongside a mother is to be alongside a mother-and-baby pair. We must be able to evaluate when we are employing a dyadic perspective and when we simply label our work as such. This means that we must understand the dyad as a transcendent perspective, one that exists regardless of circumstance. Whether a mother is rooming in with unbroken contact or she only visits 2 hours per day, the dyadic view is undiminished. Issues of distress regarding separation are windows into how dyadic processes are interfered with, but the lens of the mother as a dyadic one is no less true when mother and baby are separated than when they are together. Paradoxically, the dyadic framework is just as strong when the dyad is fractured as it is when the dyad is strong. I offer this analogy: health does not become less important when you do not have it, nor more important when you do. Health simply occupies a different kind of foreground or background position depending on how vibrant it is. The absence of health propels the desire to attain it, but health itself is not different. The idea of health is not absent when you are sick, nor is it invisible when you are well. It is a framework to understand wellbeing. So too is the dyad.

A dyadic framework also offers a practical bridge between increasingly outdated categories that assume discrete boundaries between different types of premature birth. Dyadic thinking

eliminates the need to see one group as low risk and another as high risk, at least from a psychological point of view. The dyad is equally relevant to mothers and infants regardless of where they fall on the continuum of birth. Participant mothers had many terms for how their babies were ill fitted to the categories of prematurity—a little bit prem, not quite prem, pseudo prem—which then mapped onto understanding of themselves as mothers—a little bit of a mother, not quite a mother, pseudo mother. Carrying the dyadic torch releases these diminished and confused categorisations and allows all mothers to be understood in their unique relational realities.

Much of the advocacy around issues of prematurity focuses upon tangible changes to the environment mothers and babies find themselves in. I would be misunderstanding my own findings if I suggested that participant mothers would not be in support of such things: units that include facilities for every mother to stay overnight, policies that mandate maternal consideration in decision-making, available support staff for all mothers, regardless of severity of infant medical condition would all be embraced. Beyond the NICU walls are also a host of policy implications that underpin maternal concerns and are in support of the findings. This would include: access to financial support when a child is in NICU; practical help such as transportation, parking, and childcare for siblings; expansion of paid parental leave so that mothers are not forced to choose between returning to work and leaving their child's side, as well as to ensure that fathers/partners can be present in NICU and at home; and accommodation near to the hospital for families who give birth outside of the immediate vicinity of a NICU.

The conclusions from my analysis complement and fortify the likely success of these many policy changes and endeavours. Furthermore, the shift to a dyadic understanding of mothers that is put into practice means that mothers can be sensitively supported and accurately

known even when policy changes are not forthcoming. The absence of something can be as potent as what is present, and currently a well-constructed and well-understood dyadic framework is missing. In simplest terms, even the acknowledgement of its absence could go a long way toward changing medical culture. With its inclusion in medical and social work practice, we move closer to a true embrace and support of maternal experience.

In more specific and practical terms, my recommendations target training. I recall the earliest conversations I had with medical professionals working in NICUs before I began the interviews. Having already identified my target population of participants, I was receiving information and advice from those within hospitals in order to help me create networks of referral. During this time I also visited a regional neonatal unit to see the infants who met the criteria for inclusion. In almost all cases, the prevailing medical opinion appeared to be that the mothers were hardly worth interviewing because they had so little to worry about and so quickly carried on with normal life. Similarly, the babies were small cause for concern; from a medical perspective these babies were strong and nearing full health. Most interesting to me, however, was the fact that not a single baby I visited had a parent present. When I inquired about this the reply was to say this was normal, that the babies were doing fine, and that mothers should focus their long visits in the day or two just before discharge.

I do not raise these early interactions and conversations to criticise the medical staff. Instead, I broach the topic to highlight the divide between how mothers have experienced their absence (and how babies likely do) as juxtaposed with medical assumption. This does not appear to be a case in which two parties disagree but a case in which two parties see completely different worlds. Until health professionals understand that this is happening it is likely that maternal responses will continue to be miscategorised and misunderstood, which in turn means it is likely that the best care that could be available has not yet been achieved.

Training for staff—centred upon open dialogue, discussion, and genuine interest—would seek to support doctors, nurses, and social workers in the same way that I wish to see mothers treated: upholding their value, legitimising their concerns, and acknowledging their position within both triadic and dyadic relational structures. From this position, information about the way the maternal world is structured and how mothers make meaning could advance practice in ways that I do not believe have yet been explored.

#### *X.4.2 Limitations and future research*

The most obvious limitations of my research reside with the homogeneity and smallness of my sample. While my research was robust within IPA methodological terms, that does not ensure it is generalizable for other mothers. Of course, IPA is not particularly concerned with the generalizability of findings. However, I do have interest in this question and I know that participant mothers did as well. The most common parting words mothers said to me concerned their hope that by sharing their own experience others could have a better one. I cannot argue that the experiences of 15 first time mothers of premature infants definitely represent the experiences of other first time mothers in similar situations, nor can I be certain that European mothers resemble Māori mothers or mothers from other countries. My conclusions and recommendations have focussed on issues that probably go beyond these distinctions, and for that reason are most likely germane to the discussion that all mothers are part of.

There is also a limitation of the research that is made evident by the research itself. If dyadic work cuts across labelling of infants and mothers that is unhelpful and if prematurity is now understood on a continuum, not as a sequence of categories, then my focus on low-risk premature infants is possibly an artificial construct. The implications of this are unclear. It may not make any difference or, perhaps, it means that mothers do not have as much in

common as I would have argued at the start. I do not currently believe that this qualitatively impacts on my study, but it is worth pointing out.

Study limitations are directly tied to areas of further research. Similar research with other groups of mothers would be useful, especially in an area of study where so few mothers have yet had a voice. Collecting the stories of other mothers who have had babies in NICU would test the dyadic framework idea and see how universal and useful it is. Simultaneously, companion quantitative research would be helpful to test assumptions and recommendations, as well as to move ahead with how findings that relate to meaning-making could be operationalised into real-world interventions.

Finally, further research in the area of non-pathological maternal need for the infant seems needed. As this was a theme raised repeatedly by participant mothers, the absence of scholarship in this area is noteworthy. Additionally, not only do we not have theoretical or practical data regarding maternal need for the baby, we currently have a literature that largely defines such maternal need as unhealthy. It seems obvious that there is another kind of maternal need that is not pathological and is, more likely, part and parcel of the healthy sustenance that mother-infant relationships require. More research would help test such a supposition.

## X.5 Conclusion

To conclude, I think again about the mothers and their words. I think about their wish for others to have a better experience and their prevailing belief that their deepest and most important feelings and moments were largely unnoticed by those around them. I think about how to honour that information and move it out into the world. I began this research as someone well steeped in the world of attachment theory and infant mental health. I return to a

basic premise of that world now. Infant mental health clinicians are perpetually worried about the absence of the infant's point of view, about how easy it is to forget that the baby is a human just like the adults. But the infant is voiceless in the traditional sense so the competence and influence of the baby is usually only exerted upon the mother or father. As my favourite motherhood scholar reminds us, if we—the professionals and those in support of mothers—do not notice what mothers are doing, then there is only the baby to receive and reveal it (Stadlen, 2007). And as infant mental health reminds us, we are notoriously forgetting about the baby.

I conclude that we can enter the world of the mother via the dyad. In doing so, we do not forget about the mother or her baby. In doing so, we risk nothing but our ignorance. In doing so, we gain the mother's trust and we become better at our own work.

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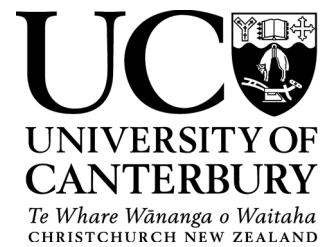
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## Appendix A: Participant Information Letter

### College of Arts

School of Social and Political Sciences  
Tel: +64 3 364 2899, Fax: + 64 364 2414  
Web site: <http://www.saps.canterbury.ac.nz/>



#### *Information Letter for Participants*

#### Mapping Identity and Connection: How First-Time Mothers Make Sense of Premature Birth

Hello,

My name is Lauren Porter and I am a PhD social work student doing research about mothers who have given birth to premature babies. I am trying to learn more about how first-time mothers come to develop a sense of themselves as mothers and all they have dealt with in the prematurity experience. I am also interested in coming to know how mothers understand their infants and their infants' experience of being born prematurely and connecting with family. For over 15 years I have worked clinically alongside mothers and children and have come to feel passionately about how all mothers deserve support and an opportunity to process their experiences.

#### **Purpose of the Study**

The purpose of this research is to come to understand how mothers without previous mothering histories make meaning of the experience of prematurity. This will be done via semi-structured interviews which will take place in a venue of the mother's choice, including the possibility of being interviewed in her own home.

#### **Participation**

My research focuses on first time mothers with premature babies born between 30 and 36 weeks gestation, as these families typically receive minimal support after hospital discharge. At the same time, it seems likely that these mothers and babies may enjoy further support and an opportunity to talk about what they have experienced. If you are a mother whose first baby was born prematurely, that baby is currently less than 5 years old and you are not currently receiving services elsewhere, I invite you to join this project.

Participation in the study is entirely voluntary. You do not have to take part in the study and you can change your mind at any time. Any questions you have will be answered and you

may withdraw from the research at any point before the research is published. The interviews will be conducted on audio tape and participants will be given access to their transcript for review and the ability to make changes before research is published. The interviews will take approximately 90 minutes. I will also collect some demographic data via a questionnaire. This data will also remain totally confidential. Your real name will not be used in any publication and all data will be stored in a secure home office.

All participants and participant information will remain confidential, accessed only by me (the researcher) and my university supervisors. The findings will be recorded in a PhD thesis which will be available through the University of Canterbury database and also potentially submitted for other publications. All identities will be protected in the final publication; any names and identifying details will be changed to protect your privacy. Even when excerpts of interviews are used, all identifying information will be deleted or disguised to ensure your protection.

I am bound by the Code of Ethics of the Board of Registration for Social Workers of New Zealand and this research has been approved by the Human Ethics Committee of the University of Canterbury

Because the experience of giving birth prematurely is often one associated with intense emotion, it is possible that talking about your experience could elicit strong feelings and upsetting emotions. If at any point you find a question too upsetting or wish to stop, we will. You may also choose not to answer any specific question you wish. I will endeavour to make sure the experience is a positive one, not one that is unduly distressing.

Additionally, any cultural and spiritual traditions will be respected and supported. If you have any specific requirements in order to be involved in the research project, please let me know.

### **Taking Part in the Project**

Your participation is important and I invite you to take part in the study. In order to book an interview and to give you all the information about the study, I request you initiate contact in one of the following ways: either call me directly or email me. My email address is [laurenporter@gmail.com](mailto:laurenporter@gmail.com). My mobile phone number is 021 721 115. If I am not available when you ring, please leave me a message and I will return your call at a time convenient for you.

Once contact is made, I will then call you to book an appointment. We will meet in a mutually suitable place of your choice, where you feel most comfortable. This can be in your own home. You are welcome to have a support person there with you.

**Questions, Concerns or Complaints**

If you have any concerns about your rights or treatment in this research, you may contact me or my supervisor, Associate Professor Kate van Heugten on 03 364 2987 ext. 6513. Additionally, you have the right to contact an independent health and disability advocate. This is a free service and the toll free (NZ wide) phone number is 0800 555 050.

I look forward to hearing from you.

Sincerely,

Lauren Porter, PhD Student, Principal Investigator

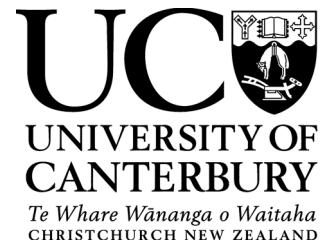
Supervision provided by:

Associate Professor Kate van Heugten,  
Department of Human Services and Social Work  
School of Social and Political Sciences  
University of Canterbury

## Appendix B: Consent Form

### College of Arts

School of Social and Political Sciences  
Tel: +64 3 364 2899, Fax: + 64 364 2414  
Web site: <http://www.saps.canterbury.ac.nz/>



#### *Consent Form for Participants*

Lauren Porter, PhD Student  
Principal Researcher, University of Canterbury

#### Mapping Identity and Connection: How First-Time Mothers Make Sense of Premature Birth

I have read and understood the description of the above named project. On this basis:

- I have read and I understand the information sheet for participants taking part in the study.
- I have had the opportunity to discuss this study further and I am satisfied with the information I have been given.
- If desired, I have had the opportunity to use whānau support or a friend to help me ask questions and understand the study.
- I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study and I will not be disadvantaged as a result of my decision. My decision to withdraw from the study will in no way affect my access to health or social services. My ability to withdraw information from the study will cease upon publication.
- I will be given an opportunity to view my interview transcript and to make changes or to withdraw all data (including questionnaire data) from the study. Should I choose to

withdraw from the study, any information I have provided will be returned to me or destroyed. I understand that by declining the invitation to review my interview data I am consenting to the information being included in the study.

- I understand that my interview will be audio-taped.
- I agree to participate as a subject in the project, and I consent to publication of the anonymised results of the project with the understanding that identifying information will be removed.
- I am aware that the anonymised findings of the research will be recorded in a PhD thesis which will become a public document available via the University of Canterbury database. I am also aware that the results may be shared, for example, in journal articles or at conferences and that I may contact the researcher at any stage if I wish to receive details of any publication of the results and conclusions of this research when it is finished. I am aware, however, that there will be a delay between the time of the interview and the outcomes of the study.
- I know that I may contact Lauren Porter (email: [laurenporter@gmail.com](mailto:laurenporter@gmail.com) phone 021 721115) if I have any concerns or wish to be assisted with access or referral to support services at any time.

Name (Please print): \_\_\_\_\_

Address: \_\_\_\_\_

Email address: \_\_\_\_\_

Phone Number: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

I have received a signed copy of this consent form: \_\_\_\_\_

## Appendix C: Sociodemographic Information Questionnaire

### *Sociodemographic Information Questionnaire*

This questionnaire will be completed, with the researcher, at the time of the interview.

*This information is confidential. Your real name will not be used in the research. Only the researcher will have access to the code sheet containing the identifying information. The code sheet will be securely kept in the home office of the researcher.*

- ✓ Name: \_\_\_\_\_
- ✓ Age:  15-21  22-30  31-36  36-41  42-48  49+
- ✓ Age and gender of first baby:
- ✓ Age of baby at birth (in gestational age, e.g. 32 weeks) \_\_\_\_\_
- ✓ Did you have any previous pregnancies? Y / N
- ✓ Age and genders of any other children: \_\_\_\_\_
- ✓ If there have been other children, were they premature? Y / N
- ✓ How long was first baby in NICU? \_\_\_\_\_
- ✓ Who do you live with:  
\_\_\_\_\_
- ✓ Marital Status (tick one):  single  married  de-facto partnership  
 divorced  separated
- ✓ Do you have your own family in the same town/area as you currently live? Y / N
- ✓ Would you describe your financial situation as causing you distress or great difficulty? Y / N
- ✓ Has your life been affected by the series of earthquakes (*Christchurch participants only*) Y / N
- ✓ Highest level of education (tick one):  0-7  8-9  10-11  12-13  
 1-2 years post secondary  Bachelor Degree  Masters Degree  PhD  
 Other: (e.g. professional qualification)
- ✓ Ethnicity: \_\_\_\_\_
- ✓ Religious Affiliation/Spirituality, if any: \_\_\_\_\_
- ✓ Current employment outside the home: Y / N