PREMATURE PERSONHOODS IN A NEONATAL INTENSIVE CARE UNIT IN AOTEAROA NEW ZEALAND

BY

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Abstract

The Neonatal Intensive Care Unit (NICU) provides medical care for some of the most unwell newborns, including those born premature. Infants born prior to 28 completed weeks gestation, classified as extremely premature, often require long admissions and close management. These infants, and those who care for them, occupy a unique position of flux. The extremely premature body is not only a locus for clinical dialogue on the reach of biomedicine, but also for wider debates over the personhood of those born at the edge of viability. This thesis is an ethnographic account of some of the ways in which neonatal personhood was strategically articulated in the NICU at various points of the infant's stay. These articulations, neither contingent nor dependent on the infant's clinical position, illustrate a multiplicity of relational personhoods that exist alongside, and sometimes at tension with, individualised dynamics of care and emotion between infants, parents, and staff. I conducted over one year of ethnographic fieldwork, including six months of intensive participant observation at a single urban unit, and over 50 ethnographic interviews across New Zealand with a variety of individuals, such as NICU parents and staff. A portion of this thesis is also comprised of autoethnographic vignettes that account for my own neonatal journey and position in the field.

I dedicate this thesis to my mum, Carolina.

Acknowledgements

The development, research, and writing of this thesis was very much a collaborative effort at all stages. First and foremost, I offer my sincerest gratitude and appreciation to the families who generously shared their experiences with me at some of the toughest times of their lives. I would also like to thank the staff at City NICU who allowed me into their place of work and encouraged all of my research endeavours.

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Table of Contents

Table of Figures

Introducing an Ethnography of Premature Personhood in New Zealand

When I first began to write this thesis, a New Zealand health standards working group began to closely examine the concept of viability in neonatal intensive care units (NICUs) across the country. The team of medical professionals and lay people are still, at the present, exploring how to standardise clinical resuscitation guidelines for those born at a mere 23+0 weeks gestation[1]. For most NICUs in New Zealand, the guidelines for resuscitation are specific to each hospital. However, typically, hospital-based guidelines recommend the routine resuscitation of infants born at 24 weeks gestation or above. A handful of NICUs may go below the national norm. These units, including City NICU[2], have set 23+0 weeks gestation as their general benchmark for providing intensive care to extremely premature infants. Nonetheless, these measures of time and gestation are still ambiguous. Medical professionals continue to operate at the borderlands of these guidelines and they justify doing so for many reasons. In unique situations, staff may attempt to resuscitate infants born at 22+5 or 22+6[3] weeks gestation. This may also occur in the reverse whereby infants born at 24 weeks (the national norm) are sometimes not resuscitated or given other intensive care. Further, these gestational guidelines are clearly porous, and considered on a case by case basis in the clinical setting. While the working group has yet to reach their conclusion, I wonder of the results and how these will be received by staff and parents in NICUs across the country. Specifically, if national guidelines or even non-negotiable protocols are set, an exploration of how this is negotiated by staff in day to day practice will be important.

At City NICU, I saw infants who would likely not have been resuscitated if born at another unit due to their birth below the 24 week benchmark. Some of these infants eventually survived to discharge, and a few survived without major disability. The simple fact that *all* would not be alive if born at a unit with a 24 week gestation cut-off is confronting, not only for parents of those infants, but also for the staff who are left to make tough decisions at the borderlands of the regulatory mechanisms. The rationales to restrict or provision resuscitation operates

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[1] The number before the '+' refers to the number of weeks completed gestation, while the number after the '+' refers the number of days in addition to the completed weeks. E.g. 23+3 weeks is a gestation of 23 completed weeks and 3 days.

[2] I have chosen to use a pseudonym to refer to my primary fieldsite to protect the identity of staff and parents who wish to not be easily identified.

[3] Infants born at 22 complete weeks and 5 days or 22 completed weeks and 6 days.

under assumptions about neonatal viability and personhood that are contentious in clinical and social settings. Wider cultural narratives of personhood, quality of life, and value of treatment interact to produce certain realities on the ground. Despite guidelines, staff use their 'gut' or experiential knowledge to determine the best course of action. At the same time, parents and other family members navigate the unique experience of having a premature infant who may or may not survive. The infant, at the centre of such experiences, becomes a bodily locus of significant sociocultural, clinical, and ethical discussions.

As I was born at 26 weeks gestation, I would certainly have been given intensive care at any unit across New Zealand, and would almost certainly have survived to discharge had I been born today. However, the story differs elsewhere, as variations in technological capability, and ideology, mean that such care may not be given at these 'later' gestations. The care of premature infants (and decisions to withhold care) is deeply cultural, and relies upon decision-making that is equally social and political. In this ethnographic account of premature personhood in New Zealand, I hope to make visible within the clinical domain, the social, political, and cultural nuances to the world of premature babies and those who care for them.

The aims of this thesis are two-fold. First, I considered how the personhood of premature babies was articulated and negotiated in the neonatal intensive care unit. From this, I hoped to more broadly explore how the case of premature infants in the NICU illuminates new ways of thinking about personhood. I argue that the care of premature babies in a neonatal intensive care unit constitutes a multiplicity of relational and often contradictory personhoods, which simultaneously create individualised dynamics of care and emotion between infants, parents, and staff. Personhood was multiple both in terms of a single infant, but also between infants on the basis of predicted futures. The many articulations of infant personhood illustrate how persons are culturally produced and differentiated based on a series of predictions. I use the term *relational* broadly and simply to denote one component of personhood multiple which constitutes, and was constituted by, networks of relationships and sensibilities.[4] As I discuss in the next chapter, scholars have critiqued the traditional attribution of personhood to different social groups (such as individualised versus relational). While I argue that personhood was manifested relationally, these articulations were multiple, dynamic, and in tension: some seemed to enable individual identities, but always simultaneously through a set of complex hidden relations. In framing personhood as relational in this context, I have highlighted how

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[4] I use the broader concept of relationality modelled from the post-relational Long & Moore to mean "interacting in ways that are co-productive, continually plastic and malleable" (2012, 41).

premature personhood (and that of others moving through the unit) was co-constituted as a multiplicity with its own tensions via individuals, groups, things, and ideas. In this way, the NICU offers a unique lens through which to examine this idea of personhood as a multiplicity. The space is highly acute and dynamic with diverse narratives of not only infant personhood, but also that of parents and staff, in a constant state of negotiation. A framing of personhood as multiple lends value to the anthropological study of infants more broadly. The infant offers a valuable ethnographic lens through which to examine personhood, in formation and in negotiation (Carsten 1995; Conklin and Morgan 1996) in a variety of environments. For premature infants, those consistently moving between politically charged categories of foetus and infant, and at the centre of narratives determining the cost and value life (particularly some lives over others), a theoretical framing of personhood as a multiplicity is particularly pertinent. As I will highlight in the thesis, this not only applies to the infants in question, but to the families and staff who care for them.

Re-working Ethnography: Introducing The Practice and Product

Preparation for this ethnographic research began far before I officially started fieldwork. Even as a teenager, I continuously reflected on my own prematurity. I wondered how my life would be different if I were not born at 26 weeks gestation. I was drawn to news stories detailing the current 'world's most premature baby' or the 'world's smallest baby born'. I considered entering the field of medicine. I often flicked through my parents' photo albums looking at myself in an incubator, and wondering just how I made it from there to here. As I became enchanted by medical anthropology and ethnography as an academic discipline, I imagined the rewarding and stimulating nature of applying these lenses to my own potential research. When I discovered that there were no extensive ethnographies of prematurity in New Zealand, I was compelled to fill this gap with an ethnography of my own.

Despite this long introduction to the field, I officially began fieldwork in late 2017 following a series of extensive gatekeeping encounters and procedures which extended far beyond gaining the approval from a single NICU to use their unit as a locus for fieldwork. I undertook the ethics approval processes for Victoria University of Wellington and the relevant District Health Board (DHB).[5] I was somewhat surprised at the relevant ease to which I was granted ethical approval by both my own institution and the DHB.[6] Of primary concern to the committee was

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[5] I have withheld the name of this DHB to protect the identity of participants.

[6] VUW Human Ethics Committee; Ethics Approval 24359. For a copy of this approval, see Appendix 1.

the status of my research with the Health and Disability Ethics Committee (HDEC). After undertaking the HDEC review process, the committee deemed my project out of scope as I was not involved directly in the care of babies, and stated that approval from the DHB and my institution was sufficient. I provided extensive reflections on research ethics within my application, including the development of provisional protocols concerning first contact with new parents[7], observational guidelines[8], and infant death[9]. In actuality, these protocols served little use during the fieldwork process outside of maintaining on-unit safety measures[10]. As it became clear, much of the ethnographic practice resisted the prescription of protocols and guidelines. For instance, in moments of fear and sadness, it was not suitable to remove myself from certain situations, as I had intended. Rather, where appropriate, I shared these fears and worries with participants. The value in ethnographic methods lies within its embrace of the fieldworker's subjectivities, vulnerability, and connections with those alongside her.

As will be explored throughout the remainder of this thesis, I spent over 12 months immersed in the 'field' of prematurity. Rather than referring to a particular locale, my field was primarily conceptual over spatial. While approximately 6 months was bounded in within the walls of a single NICU, the remainder of fieldwork spanned the length of the country using a variety of technological aids in communication. I had a Skype conversation with one rural isolated family, phone calls with families in the deep south, and coffees with parents at local cafes. I spent time in participants' homes, balanced babies on my knee, met with nurses in the cafeteria room, and walked laps of the hospital with a neonatologist. I received photos depicting chubby toddlers looking nothing like newborns I had met a few years prior, and texts from mothers on the antenatal ward giving me updates of their impending early births.[11]

Clearly, technological means of communication were of significant use during fieldwork conducted outside of the NICU. These means were also key during participant recruitment. The

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[7] In making first contact with new parents in a nursery, I required introduction by a nurse who would then confirm a parent's willingness to be approached.

[8] The observational guidelines were a written affirmation of my intention to adhere to the following rules: I would not be involve with, or directly interfere in, medical and nursing care of infants; I would continuously discuss consent with parents and staff; and I would follow all cleanliness and sterile protocols.

[9] I formulated this protocol alongside advice from staff and supervisors. The protocol described a variety of personal care measures I could take following a death. The protocol also outlined a suggested process for managing participant relationships following an infant death.

[10] Safety measures included: my notification of a senior nurse upon arrival each day; wearing my university photo identification lanyard as a visible indicator of identity; and following onsite guidelines by staff.

[11] See Appendix 2 for a table of key participant demographic information.

majority of participants from outside City NICU were recruited through a blog post shared through Facebook. I wrote this blog post for a neonatal charity on my research and own neonatal journey. I was overwhelmed with responses from both potential participants and media outlets requesting collaboration. Due to the scope of this research, I was forced to remain selective in contacting potential participants for interviews. Many participants expressed the cathartic value they found in sharing their stories, so I found it distressing that I was not able to meet with all. While some scholars have warned of the use of phone interviews and Skype calls as methods of data collection and recruitment (Garcia et al. 2009), due to the assumed impersonal nature of online communication, these methods were simply invaluable in communicating with individuals who I was unable to meet in person. In addition, the supplementation of this ethnographic fieldwork with online methods of communication aided in the resistance of the ableist assumption that interviews conducted in person are superior to those conducted online (Gibson 2019; Friedner, Kasnitz & Wool 2018).[12]

For all interviews with parents and family members, I used an unstructured style of ethnographic interviewing. The rationale for unstructured interviews was to allow participants to tell me their stories of prematurity from wherever they wanted to start, and to take the interview in whatever direction they wanted. However, for medical and nursing staff, and others working in the neonatal sector, I chose to use a more semi-structured style of interview whereby a few guiding questions were used to direct the interview. I used this mode of interviewing professionals for a myriad of reasons. Primarily, a structured interview was more expected by staff than the type of interview I undertook with parents. Staff were very familiar with researchers: the NICU itself was a common locus for medical research. However, qualitative researchers from the social sciences were rare. I found that some staff expressed preference for a more direct "question and answer" style interview as this was both easier for them, more suited to the topics they wanted to speak on, and took less time. More generally, this touches on some of the challenges I faced doing participant observation in a highly medicalised setting.

I conducted fieldwork in the form of participant observation at a single urban NICU I call 'City NICU'. As I explore much more extensively in later chapters, this unit was a tertiary neonatal unit caring for premature and other unwell infants from a very large catchment area. Patient

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[12] During fieldwork, I experienced a health difficulty which, at times, restricted my ability to meet participants in person. For this reason, among many others, technologically mediated communication was an empowering research tool.

capacity was around 40 infants, cared for by nursing staff from a pool of 200 rotating nurses, and medical professionals from a range of specialties and degrees of training. Simply put, the unit was a space of rapid change and volatility. For the six month period where I "hung out" on the unit, in primarily the same nursery, I met new people every single day. Further, the introduction, consent, and rapport processes were continual as new staff, parents, and patients moved through the unit. Given the nature of the NICU, I always treated consent to observe as a continual process – at any time, a parent or staff member was able to request that I left the room, and I checked frequently to ensure participants were comfortable to ask me to do so.[13] Although consent was never withdrawn during my time on the unit, I removed myself from the room in a few instances, based on my judgement of the situation. These instances were primarily during a medical emergency, and moments of extreme parental or even personal emotion. Here, this aligns with the conceptual aims of the proposed "compassionate turn" in cultural anthropology (The New Ethnographer 2019). Developed through an online community of fieldworkers in/from spaces of vulnerability, this turn urges for a transparency of emotion, positionality, and risk within fieldwork and in the academe. I used my own judgement to discern moments of vulnerability that I felt should remain private. Again, here I touch of some of the challenges of conducting ethnographic research in a medical setting. I speak more on these challenges in later chapters.

As the fieldwork process slowed to an official close, I began the process of 'data analysis', or what I prefer to call it 'getting to know the stories shared and observed'. I used a coding software (NVivo Version 11) to store and organise written fieldnotes, pieces of autoethnographic reflection, and interview notes and transcripts. The actual practice of analysis was less straightforward. It involved a revolving cycle of reading, re-reading, cutting up and rearranging, more reading, asking questions, revisiting 'the field', and simply an organised chaos of transcripts, handwritten notes, and photos strewn across a table. Similar to O'Reilly (2012), the process involved a lot of deep thinking that cannot neatly be categorised under the rubrics of grounded theory or traditional qualitative data analysis. Undertaking ethnographic research and writing ethnography were not two distinct phases. Rather, they were a messy and sometimes repetitive cycle of reading, talking, observing, and thinking. Not only does this produce a rich narrative which aims not at reducing participants stories to 'themes' or

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[13] For examples of the consent forms and information sheets used, see Appendix 3.

'arguments' but in sharing fundamental cultural dialogues, this also allows for the written product to simply *read easier*:

> "We might, then, like to encourage our students to craft ethnography from a process of commoning that is messy, collaborative, less-planned, and altogether-less plannable…This also involves a shedding of the constraints of writing in a framework of 'scientific' accountability. Writing in this way is guided by deep listening to stories gathered, annotated, crafted, and re-told. It demands or at least allows us to dare to write for reading, for readers who might enjoy ethnography." (Bönisch-Brednich 2008, 156)

The product of my ethnographic research somewhat then resembles that proposed above: it is fairly non-traditional in structure, and does not allow for scientific replicability. Rather, I simply re-represented the stories shared to me, while also weaving my own narrative throughout. I use the term 're-represented' to refer to the co-constructed nature of ethnography. In framing the stories shared to me during interviews for this thesis, I am, in essence, re-framing participant narratives. This speaks to the role of ethnography as inherently political. It is a *representation* of stories shared and observed with a fieldworker-conduit (van Maanen 2011). It is also for this reason that I have chosen to write ethnographic description almost exclusively in past-tense.[14] The stories told, and observations made, are representative of *that* ethnographic present, with *those* participants, and *that* fieldworker.

The structure of this thesis differs somewhat from the norm of typical doctorates in the social sciences. First and foremost, this thesis does not contain traditional extensive 'literature review' or 'methodology and methods' sections bookended in the opening chapters. Rather, I have chosen to set more in-depth discussions of the literature and methodological considerations alongside the ethnography in order to foster a more coherent overarching narrative. While the next chapter gives necessary theoretical and empirical context, it is not an exhaustive review. Furthermore, I took inspiration from Kristen Ghodsee's (2016) reflections on writing ethnographically in reaching the decision to pepper reviews of literature and theory throughout the thesis. For Ghodsee, an accessible ethnography is one which expertly integrates theory, literature, and ethnographic description into a coherent ethnographic narrative.

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[14] Writing in the "ethnographic present" (Sanjek 2014) has been critiqued for inflating the authority of ethnography, lacking dynamism, and ignoring the role of history (see Fabien 1983; Clifford and Marcus 1986). Yet some have equally argued that the present still has a place in ethnographic writing as a more appropriate means to represent ethnographic dialogue (Sinclair 1993).

This thesis includes 8 "interludes" which appear at various points between chapters.[15] I chose to use interludes both as a literary tool, and a methodological device. The interludes make space for the much more informal and conversational style of writing that I found necessary to reflect on my own neonatal journey. Using these pockets of narrative, I experiment with my personal writing tone and voice, while also guiding the reader through the key points of contemplation faced during my writing process. However, most significantly and uniquely, these interludes provide a vehicle for my autoethnographic storytelling. It is in these segues of text where I tell my own story of prematurity – a story of continual importance. In sharing the stories of others, I share my own. Autoethnography is a common method in cultural anthropology, particularly in studies of biomedicine and disability studies. I was first drawn to this method after reading Layne's "autobiographical" (Layne 1996; 2002) works on both the NICU and miscarriage where she expertly weaved her own experiences with the analysis and discussion. I also drew inspiration from Landsman's (2008) ethnographic account of mothering and children with disabilities in the United States. In sharing her own experiences, Landsman was able to provide a nuanced critique of the socio-cultural forces which shape mothers' experiences. While I integrate my own story at points throughout the main chapters, I have primarily used the interludes to tell this story both in order to foreground the stories of participants in the chapters, and simply for ease of comprehension in the wake of temporal shifts.

This brief discussion of the ethnographic methods used, and the ethnography produced, is neither a complete picture nor an exhaustive discussion of thesis methods. However, this is an important framing overview and necessary context for the remainder of this thesis. Salient points of methodological interest are weaved through the chapters of this thesis. In re-telling the stories of others, I explore my position in receiving these stories, and observing movements of individuals through a single hospital ward and beyond.

Thesis Outline

This introductory chapter has provided a high-level overview of the thesis and some of the key issues which will be discussed throughout. I outlined the methodological underpinnings of this research, and detailed the style and structure of writing used.

The next section, **Chapter 1**, provides a broad overview of the anthropological literature concerning personhood more generally to frame later chapters. I then introduce the

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[15] These have been signposted using a change in front and a stylised numerical heading at the top right of the page.

epidemiological context of prematurity as one lens through which premature personhood is understood and explained.

Chapter 2 explores how the metric of gestation is used at a fundamental level to understand and explain prematurity. Medical staff use the metric, along with other features such as a size, as a basis for discussing viability, value of life, and need for resuscitation. However, gestation also falls to the wayside as of little importance *on the ground* in NICU care. Parents and staff strategically value and devalue the metric of gestation as a marker of personhood to serve a variety of means. The concept is one feature of a wider constellation of factors that shape how premature infants are discussed.

In **Chapter 3** I take the reader on an ethnographic walkthrough of the primary fieldsite, my unique position within the space, and introduce some key characters who shaped my experience as a researcher. I highlight how personhoods were enacted and negotiated beyond the body through spatial and material means.

Chapter 4 introduces discourses of time and personhood in the NICU and beyond. I explore the ways in which 'the future' was deployed by NICU parents as a heuristic tool both during and after their infant's admission to the neonatal unit, and how parents and staff used various narratives of progress when speaking about prematurity. Unique performances of time and related concepts in the NICU serves as an example of how time is reframed and imagined to better suit present circumstances and to think about potential personhood.

Next, **Chapter 5** discusses the roles of both professionalisation and medical research on the unit as one mechanism through which premature infants are cared for differently. The development of the premature infant as a patient necessitated some key professional shifts within the early field of newborn care. I discuss how staff were key actors in negotiating infant personhood through their professional relationships, practices, and knowledge systems.

In **Chapter 6,** I critique how infants were framed as active agents in control of their own futures yet equally structured under a configuration of social norms visible in performances and narratives of infant personhood by parents and staff. These communicated cultural norms on the productive body, as well as how infant personhood was relationally mediated through a constellation of agents and types of agency.

Chapter 7 explores the various types of social categorisation used to structure engagements with both families and infants across the neonatal unit. The performance and framing of various social positions and axes of identity, such as gender, ethnicity, and class, shaped how

personhood was articulated and enacted for both infants and parents in the NICU. The NICU space was one of white upper middle class sensibilities.

Lastly, **Chapter 8** tracks the role of premature infants and those who care for them as precarious political and economic subjects where personhood is (de)legitimised through economic and political rationalisations. Economic narratives and practices present on the unit destabilise the socio-cultural position of some premature infants, and the associated labour, while reinforcing the legitimacy of treating others. This reflects wider political discussions of cost versus benefit while also illustrating cultural assumptions on the value of human life.

Through an exploration of the different ways in which personhoods were multiple, dynamic, and in tension, I make visible how personhoods were constituted by parents and staff on the basis of certain predicted futures – particularly in *how* an infant was foreseen to grow up beyond the NICU. Such predictions involved a constellation of assumptions about the body, emotion, professional differences, diverse notions of agency, economic and political discourses, and framings of social categories. The NICU was a space where infants lived, died, and existed in states in-between. But beyond the infants, parents and staff equally occupied uniquely precious and liminal states. Parenthood was negotiated in the NICU, both contingent on *and* irrespective of the infant's clinical position. Staff assumptions of social categories also worked to legitimise some parents, while delegitimising the authority of others. Further, dynamics of care, sentiment, and distinct professionalisation shaped how staff designated infant personhood, justified their working position, and approached parents. By somewhat decentring the infant when approaching infant personhood in the NICU, hidden relations and networks of personhood(s) come into view. This has implications which reach beyond theoretical and empirical interventions. Importantly, this thesis highlights key areas for development and improvement of the neonatal sector at policy and operational levels.

Interlude: From a tiny doll to *Rattus Norvegicus*

Premature babies are referred to by a variety of names. These range from diminutives to peculiar comparisons that are surprisingly accurate. I compiled a list[16] of a myriad of monikers used to refer to premature infants from both my ethnographic research, and in the stories told to me about my own neonatal journey. These names and phrases, some shocking, and others cutesy, introduces some of the juxtaposing narratives used to describe premature infants in wider society:

1. **The animal:** From *Rattus Norvegicus* to *ape-baby* and *half eaten chicken*, the animal moniker is a common one. Emphasising fragility, I've been aware of such names since I first comprehended my own prematurity. As an infant, I somewhat resembled a small "orangutan" with my ginger hair.

2. **The dead or dying:** Whether it be *train-smash* or *carcass,* these were the names that parents guiltily revealed to me as what they thought their newborns looked like. The exposed ribs and raw skin of an extremely premature baby invoke these sorts of comparisons. These sorts of names featured in my parents' experiences too: one nurse, to the horror of my mum, and amusement of my dad, used to exclaim upon arrival to the unit "How are my little carcasses today?"

3. **The old man:** These nicknames are not exclusively used in reference to premature infants. I think it's fairly common for a newborn to be told he or she looks like a *little old man* or *Benjamin Button* due to their thin skin, bald heads, and wrinkly faces.

4. **The cutesy diminutive:** These diminutives were highly gendered. For boys, it was *little dude* or *my little guy*, and for girls it was *Tinkerbell, Thumbelina,* and *little doll.* These names infer fragility as well as small size. However, medical fragility and size should not be conflated. For instance,

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[16] The following list takes inspiration from Laurence Ralph's (2014) ethnographic list detailing the Top 5 shoes worn by members of a Chicago gang.

the "*chunky sumo*" baby born at term, although larger in weight, might be equally if not more fragile, than the "*little doll"* next door.

5. **The otherworldly:** Similar to the dead nicknames, these otherworldly nicknames were often spoken to me by parents in hushed low voices. Whether the 'other world' was a different planet and the baby was an *alien*, or the other world was a womb and the baby was a *foetus*, these nicknames suggest a private and almost mystical nature to the infants.

The various types of names used in reference to premature infants are demonstrative of the ways in which such infants are conceived of in the public imaginary. More importantly, the diversity in these names highlights the contention and precarity of the infants and their position. An infant may simultaneously be called "a foetus" and "a little old man" denoting a tension between different states of being. These tensions really speak to why I understand premature personhood to be a multiplicity and *always* dynamic.

Chapter 1: Introducing Personhood and Contextualising Prematurity in New Zealand

Neonatal Intensive Care Units (NICUs) provide highly specialised medical care and treatment for premature and unwell full-term newborns. For some infants in the NICU, medical treatment may be the very difference between sustaining life, and imminent death. The ambiguity between living and dying, and birth and death, in the NICU confronts medical professionals and families with serious ethical dilemmas concerning the legitimacy of treating such extremely ill newborns. The infants themselves therefore occupy a position of flux: their bodies become sites of conflict as their personhood is debated through clinical, social, and political lenses. This introductory chapter will provide an overview of the literature concerning personhood more generally in order to frame later chapters. This chapter will then explore the epidemiological context of prematurity as one lens through which premature personhood is understood.

Introducing the Anthropological Literature on (Relational) Personhood

The concept of personhood has long been subject to anthropological debate and critique. This debate is one which presents many questions relating to the different ways in which personhood is construed and articulated. I introduce my use of relational personhood as a way of understating the intersubjective, mutually constituted, and inseparable personhood(s) of premature infants and those who care for them. Throughout this thesis, I argue that this conceptual frame is necessary to fully illuminate the nuances and intricacies of premature lifeworlds which are multiple, and encompass much more than the premature infant alone. A exploration of this concept through the lens of the NICU also illustrates how the concept can be developed as a framework which allows for a deeper understanding of personhood as a multiplicity of tensions, and sometimes, contradictions.

Émile Durkheim first prompted an initial exploration of personhood as an anthropological concept with his structural-functionalist work on *homo duplex* (Durkheim 2005). For Durkheim, personhood is comprised of "the biological and the psychological [subjective] together forming the individual, a level of existence separated from the social (Gofman 1998, 66). Personhood is not located in the individual level, but is constituted collectively at the level of culture and society. Through social and cultural participation, the "animal" individual, becomes a moral- person (Rapport 2001). Durkheim initiated the study of personhood as feature which can be approached anthropologically and sociologically, rather than attempting

to quantify the feature in the physical body, or arise at a set definition of what a person actually *is* in a metaphorical sense.

Following on from his mentor, Mauss introduces the concept of personhood as "hesitant, delicate, and precarious" (1979, 59) subject to social and cultural structures. He argues that the concept of personhood as something individualised, as opposed to relational, is exclusively found in a Euro-American setting. More generally, the approaches of both Mauss and Durkheim very much prioritise the role of culture and society in constituting personhood, and position different articulations of being a person in opposition with each other.[17]

Marilyn Strathern expanded upon the Durkheimian framing of personhood (Rapport 2015) as a concept which can be understood in terms of "dividuals" (Strathern 1988). Strathern compares ideas of Euro-American and Melanesian personhood using a dichotomy of individual-dividual:

> *"Melanesian persons are as dividually as they are individually conceived. They contain a generalized sociality within. Indeed, persons are frequently constructed as the plural and composite site of the relationships that produce them (Strathern 1988:13)"*

Strathern foregrounded more relational modes of understanding personhood. A focus on relational personhood is one which has developed significantly, and has extended far beyond Strathern's dichotomisation of Euro-American versus Melanesian models of personhood as primarily individual, and relational, respectively. Anthropologists have continued in their interrogation of the concept as a social and relational artefact – neither wholly individualised nor collective. It is something socially constructed, in, and negotiated by individuals, social groups, structures, and imaginaries: "Producing persons is an inherently social project" (Kaufman and Morgan 2005, 320) whereby a variety of practices and narratives are used to incorporate an individual into the group and afford them a particular status. It is for this reason that most anthropological engagements with the concept use ethnographic research in exploring articulations of personhood in that place, at that moment in time.

There has been a particular focus on how personhood is afforded at the beginning of life. Scholars have extensively used cross-cultural comparison to highlight the different modes of designating personhood to babies from diverse social groups. For instance, Conklin and

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[17] These approaches have received criticism for their structuralist framing, dichotomisation of 'the West' and 'the Other', and social Darwinist assumptions (see Allen 1985; Carrithers 1985 and La Fontaine 1985).

Morgan (1996) use comparison to illuminate a North American preoccupation with personhood as located in the physical body of an infant – a natural innate quality which is typically afforded at a particular moment during foetal or infant development. The concern for a biological, material, and/or corporeal characterisation of personhood is a political one, and is inextricably tied to a particular political landscape and rhetoric. The body is seen as solely material, and this materiality is thought to denote the personhood of the infant. For the authors, locating personhood as an innate element in the physical body assumes its presence at some point during gestation or at the moment of birth. It is then obvious why the foetus presently occupies a morally charged position in North American society, as well as highlighting why the process of birth is of much importance. This mode of ascribing personhood is based on singular non-retractable events: conception, passing gestational milestones, and/or birth.

The authors then compare a North American framing of personhood with the Wari' of Brazil to highlight the complexity in typifying models of personhood as relational or individual. For the Wari', personhood is something accrued over time through relationships with established members of the group. Until about six weeks after birth, a Wari' infant is considered as part of its mother's person, and from there, it is the development of social relationships which both invoke and maintain the infant's designation as a person. Wari' personhood is traversed via the formation of the individual as a social body – partaking in exchanges of bodily fluids between individuals. This is exemplary of how many anthropologists have framed "relational personhood".[18] It is by virtue of comparison that Conklin and Morgan (1996) then force a re-examination of how scholars have attempted to typify and categorise personhood(s) cross-culturally – elements of one 'model' are equally visible in others. Others have further critiqued the typification of personhood in that it creates a dichotomy between Western and non-Western models of personhood (Lamb 1997). The dichotomisation of such difference is problematic as it reproduces cultural generalisations present within the legacy of anthropology that cause harm.[19]

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[18] As illustrated by Carsten (1995), these relational modes of ascribing infant personhood are not uncommon cross-culturally. For Langkawi Malay, personhood is also processual: achieved over time through the sharing of foods and formation of kinship ties. Processual personhood and the development of relatedness are considered mutually constituted, and contingent on social exchange.

[19] For instance, the simple dichotomization of North American and Wari' personhood(s) as oppositional, not only reinforces a positioning of 'self' versus 'Other', but also ignores the nuances of individual systems, such as the role of relationships and interconnectedness in narratives of North American personhood, as discussed by Conklin and Morgan (1996).

A more recent focus of anthropological studies on personhood explores conceptions of personhood in medically liminal and unstable stages, such as at the end of life. Arguably, it is from liminal and complex ethnographic spaces where analyses of personhood deepen conceptually. Individuals in a permanently vegetative state (PVS) have been subject to recent anthropological attention following Kaufman's (2006) seminal ethnographic exploration of dying in American Intensive Care Units. In a highly medicalised environment, the nature of life is complicated when it is sustained solely though intensive technologies. This complexity is also visible in the NICU where, for some, the basic mechanisms of survival are contingent on technological intervention. In their ethnographic study of PVS patients in Israel, Bird-David and Israeli (2010) argue for a "situational" (55) framework to be used when exploring personhood – states of personhood are dynamic and in constant flux depending on circumstances and narratives used. The authors emphasise the importance of moving beyond dichotomies (classified as per: life and death; subject and object; and human and non-human) to push against an essentialising of personhood.

Ethnographic considerations of foetal personhood have also grappled with these dichotomies – attempting to move between categories of subject and object when talking about the foetus. Many have therefore used a framework of a "potential" personhood when describing the highly unstable state of being a foetus in the Euro-American political climate (such as Mitchell 2001; Lupton 2013a). For the premature baby, the blurred boundary between foetus and infant means that discussions of foetal personhood are also important here, and will be discussed later alongside the literature on premature personhood.

I centre my own understanding of personhood as something which denotes how individuals/persons/humans/selves/things are considered to exist in a certain state of being that constitutes and is constituted by certain, often contradictory, conditions in a social group. This definition is a blunt approximation of the concept with limitations in terms of specificity and theoretical depth. I employ the concept as theoretically broad and simple here to allow for the ethnography to reveal the intricacies and nuances without any prior theoretical presuppositions. Exploring prematurity in New Zealand revealed a multiplicity of personhoods that benefits from a framework of relational personhood where hidden relations, interactions, and sensibilities are revealed. I argue that personhood as multiple makes visible the rich complexity of how it is constituted in the NICU. This multiplicity was visible both in the diverse ways that the personhood of a single infant was negotiated, as well as between infants with futures predicted as very different.

Premature Personhood: An Epidemiological Lens

There exists a wealth of epidemiological data on prematurity and preterm birth. This lens, along with the clinical, was the most explicit way in which prematurity and personhood was articulated at City NICU. However, this lens also offers a useful point of departure for introducing prematurity more generally and some of the cultural values visible in epidemiological framework. I introduce a discussion of some key epidemiological data on prematurity, both as an introduction to prematurity itself, but also as an opening to how prematurity is articulated in the field. I start with the epidemiological lens as this was one of the more explicit (alongside the clinical lens) through which preterm personhood is approached.

The World Health Organization (WHO) defines a premature infant as one "born alive before 37 weeks of pregnancy are completed" (Althabe et al. 2012). These infants are then further classified as per their gestational age at birth. For instance, an extremely premature infant is one born at or before 28 completed weeks gestation while a later premature infant is one born between 34 and 37 weeks gestation. Lower gestational age at birth is correlated with an increase in neonatal mortality and morbidity. Immediately, the approach is one characterised by gestation (to be discussed later), whereby the premature person is one who is born below a particular threshold.

Population data which monitors the prevalence of premature birth suggests that over 10 percent of infants born globally are born too early, prior to 37 weeks gestation. An international study conducted by Blencowe et al. (2012) found that approximately 11.1 percent of global live births were premature. However, the study also suggested that these rates vary significantly both across and within nation-states. For instance premature birth rates in the United States exemplify the degree to which demographics, such as state of residence, shape neonatal outcomes. According to the March of Dimes (March of Dimes 2018), the state of New Hampshire reported the lowest rate of premature birth by state in the country in 2017 (7.8 percent of live births) compared to the state of Mississippi with the highest, at almost double (13.6 percent). An ethnic disparity is also clearly visible with African American, Native American, and Native Hawaiian peoples experiencing premature birth at a disproportionately higher rate than White, Asian, and Hispanic peoples (J. A. Martin et al. 2018).

For New Zealand, factors such as ethnicity, socioeconomic background, and place of residence also interact heavily to produce varied premature birth statistics by demography. In 2015, 7.3

percent of live births in New Zealand took place prior to 37 completed weeks gestation (Ministry of Health 2017). Of these, the majority were mid to late premature births, with a minority (approximately 1.2 percent of total live births) taking place prior to 32 completed weeks gestation. Compared to the United States, the geographic distribution of premature birth in New Zealand is less pronounced. The Mid-Central District Health Board, covering the upper area of the lower North Island (from Otaki in the south to Dannevirke in the north) reported the highest rate of premature births (9.2 percent) of any district health board (DHB) in New Zealand. Comparatively, the Capital and Coast DHB, which covers New Zealand's capital city, reported 7.4 percent of births in the region to be premature. Auckland DHB, which covers New Zealand's largest city, reported a smaller rate of premature birth in the district (6.6 percent). As in the United States, there also exists an ethnic disparity in rates of premature birth in New Zealand. However, this disparity is again significantly less pronounced than that reported in the United States. Of those infants born registered as Māori, 7.9 percent were premature, compared to 7.3 percent of those born registered as New Zealand European or 'Other'.

As these statistics suggest, there is a relationship between social categories and premature birth. However, for New Zealand, the most pronounced factor which shapes the likelihood of premature birth is "maternal age" (Ministry of Health 2017). For women aged 40 and over, 10.4 percent gave birth premature. Conversely, 8.8 percent of babies born to women aged below 20 years were premature. Women aged between 25 and 29 had the lowest number of premature infants - only 6.6 percent of births in this age group were premature. These statistics were visible in the representation of maternal age at City NICU whereby many mothers were either under 21 years of age, or considered 'geriatric mothers', at over 35 years of age.

An early birth may occur spontaneously, or as a result of medical intervention. Muglia and Katz (2010) have outlined risk factors, such as those mentioned above, for the occurrence or "enigma" of a spontaneous birth which occurs too early. Additional risk factors include extremes in maternal age, as discussed above, or body weight, drug use and other risky maternal behaviour, social stress and poverty, pathological physiologies of either the pregnant woman or the foetus, the presence of multiple foetuses, and infection. These risk factors also represent the degree of responsibilisation afforded to particular pregnant bodies in shaping the outcomes of pregnancy. This feature will be discussed in chapter 7. Muglia and Katz use the term "enigma" in referring to premature birth as it, in many cases, is idiopathic and somewhat resists a language of risk. Therefore while factors such as extremes in maternal age, ethnicity, and socioeconomic status are well documented in the clinical literature as increasing the risk for

premature birth (Goldenberg et al. 2008; Lu and Halfon 2003; Finer and Henshaw 2006), there exist limits to a risk-centred approach. Put simply, anyone can have a premature infant.

A more noticeable causative pathway for premature birth is the iatrogenic pathway: the use of medical intervention to induce labour, or simply deliver the infant prior to the completion of 37 weeks gestation. Medical intervention, in the form of labour inducing pharmaceuticals, or surgery to deliver the baby, is usually seen as a 'best care' practice for conditions which endanger the pregnant woman and/or foetus, such as (pre-)eclampsia, placental abruption, or the lack of foetal growth (Bronstein 2016, 14). In these instances, it is hoped that specialist care will be able to replicate the functions of the uterus in 'gestating' the premature infant outside the womb, and provide treatment for the many pathologies associated with prematurity. Central to this decision is the ambiguous concept of viability.

There is plenty of clinical literature exploring at what point an infant is considered viable outside the womb (Leeuw et al. 2000; Seri and Evans 2008; American College of Obstetricians and Gynaecologists and Society for Maternal-Fetal Medicine 2015). The primary means used to determine viability is to assess gestational age (Ehrenkranz and Mercurio 2018), and although specific gestational protocols are both country and institution-specific, the gestational threshold for viability is generally understood in the clinical literature to be somewhere between 23 and 24 weeks gestation. The indeterminateness of this clinically defined limit is indicative of the wider clinical debate: numerous factors shape whether or not viability is evident or assumed, including the cultural associations and neonatal viability and personhood.[20] Global disparities in medical care and technologies available to treat extremely premature infants means that what is viable (or a person) to some, is not viable to others. Given the most intensive and invasive treatment, such as the use of advanced respiratory support, an infant born at 23 weeks gestation may be deemed viable, receive resuscitation at birth, and survive to discharge. However, this would likely not be the case for an infant born into an environment without intensive care technologies. Moreover, additional factors such as the infant's sex (Ingemarsson 2003) and birth-weight (Ehrenkranz and Mercurio 2018) are also considered key in assessing viability and therefore couple social categories and metrics of size with personhood.

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[20] This cultural association is evident in much of the sociocultural literature concerning the concept of gestation discussed in the next chapter.

Even in nation-states with access to advanced biomedical technologies, definitions of gestational viability vary. Both gestation and viability, typically isolated to the assumed acultural realm of 'science', are deeply *cultural* concepts. Japan is known to provide active resuscitation and treatment to those born at 22 weeks gestation, while the Netherlands is known for its traditional lack of intervention prior to 24 or 25 weeks gestation (Saluja 2018). Such gestational assessments of viability are perceived as simply guidelines – dependent on the discretion of the physicians involved, weight and sex of the neonate or foetus, steroid exposure, maternal condition, and place of birth. Depending on these factors, the physicians involved may choose to either provide intensive medical care to the neonate, or to withhold such life sustaining care based on the assumption that they will not survive or will be subject to great pain and suffering with a poor prognosis. Physicians with whom I spoke at City NICU spoke of "the data" on prognosis as one factor in making these decisions. Yet the medical prognoses of babies born at the limits of viability varies significantly. As of 2012, a baby born as early as 24 weeks gestation, given the most advanced and intensive medical care, has a survival rate of approximately 50 percent. In New Zealand specifically, one centre has reported that 60 percent of infants registered as born in their hospital at 24 weeks gestation survived to two years of age (Berry et al. 2017). Statistics such as these do little to account for the actual lived experiences of those born at these gestations and their families.

Deployments of "the data" as a means to justify clinical decisions in the literature and at City NICU do not exist in a vacuum. While articulated using a variety of epidemiological, clinical, and specialty-specific knowledges, prematurity is also a mechanism through which cultural values are articulated. Although necessary and invaluable, the swiftly expanding biomedical literature on premature birth, including such studies mentioned above, does not explicitly account for the overarching assumptions on infant personhood which shape how "the data" is spoken of and acted upon in practice. The next chapter explores specifically how knowledges (and "the data") of gestation and viability are partly structured and structuring in the negotiation of personhood in the NICU.

Conclusions

Epidemiological data is one means to approach prematurity. This approach appears to categorise personhood as a neutral and natural phenomenon. However, it is enacted and understood through a range of theoretical and practical lenses that are inherently cultural. While touted as objective and replicable data, these approaches are embedded within cultural

assumptions on the body. In positioning the epidemiological data as both necessary contextual background *and* ethnographic evidence, the authority often afforded to scientific modes of knowledge production is destabilised[21] to emphasise the deeply cultural foundations of premature personhood(s) in a locus that is often foregrounded by biomedical authority. This is an important preface to this thesis due to its focus on a highly clinical realm where biomedical research is a form of professional capital, a responsibility, and way of legitimising types of care.

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[21] I touch here on the enduring popular trope of scientific work as acultural and therefore a superior type of evidence. Trevor Pinch and Harry Collins (2012) explored this assumption in their comparison of science to a 'golem' –not inherently harmful in itself, but powerful (and cultural) all the same. I also follow Jonathan Marks' (2009) call for an anthropology of science which aims to make visible the cultural and social conditions from which particular claims are produced, rather than a blind demonization of scientific knowledge.

Interlude: The Birth of a PhD Candidate

I like to think that I began fieldwork in the womb, as a foetus, predicted by doctors to be born premature about midway through my mother's pregnancy. At 21 weeks gestation, my mother began experiencing contractions. These contractions were not Braxton Hicks, or 'practice contractions'[22], but contractions indicative of impending birth. She was put on strict hospital bedrest, and prepared for a likely early birth. Over the next five weeks, my mother received a series of steroid injections, targeted at maturing my lungs and brain.

However, on the 25th of April 1995, I was born by caesarean section. During morning rounds, just as the team of doctors reached my mother's bedside to assess her condition, her waters broke, and she was rushed to the operating theatre. After spending 26 weeks and 3 days gestation, I was extracted from the womb. I doubt it took much effort given I was rather small. My eyes were fused shut, my ears just little flaps of skin with no cartilage, and I was covered in ginger fuzz. For a 26 weeker, as they would call me, making reference to my gestational age, I was also rather chunky. Weighing in at 1050 grams and measuring just longer than a Bic pen, I was described as *solid*. A 'good' size and a 'good' weight. While this is miniscule for a term baby, it was big for my gestation. Unfortunately, this wouldn't last. While my growth would begin to slow down, my big head would continue to increase in circumference. By a few months old, my weight and height sat steadily below the 10th percentile for my gestation, but my head remained well above the 90th percentile for much of my infancy and toddlerhood.

After my extraction, I was quickly intubated by a neonatology fellow, given rescue breaths by a neonatal nurse, and connected to a ventilator. Typical of notational protocols, I then received a shot of Vitamin K, albeit half the dose full-term infants receive. At the same time, my mother was being stitched up, still under a general anaesthesia, and yet to meet 'solid' baby. My dad was sitting on a chair in the waiting room eating a bag of salt and vinegar crisps. He met me well before mum, walking briskly alongside the

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[22] According to the New Zealand Ministry of Health (Ministry of Health 2019), Braxton Hicks contractions are "practice tightening's of [the uterus]. These contracts prepare the body for labor and typically do not increase in length or intensity over time (unlike 'labor contractions').

transport incubator as I was wheeled down a long tunnel under the hospital to the neonatal unit by two doctors and two nurses who were chatting about a recent game of cricket, as he still recalls today.

Chapter 2: Gestation as a Metric of Personhood

Early in fieldwork, I learned that gestation is simultaneously of the most *and* the least importance to premature infants and those who care for them. Gestation is a clinical measure: it can be plotted on a graph, and may structure best practice in the treatment of premature infants. Yet, it also communicates an underlying tension within biomedicine and the social structures which imbue it over the attribution of neonatal personhood. At City NICU, gestation was one metric used to justify both the provision and withdrawal of care. This dual role of gestation was achieved through a strategic positioning of the concept as a malleable guideline with an intentionally ambiguous relationship to the designation of personhood.

I remember distinctly the day I first met baby Alice. I had arrived on the NICU earlier in the day, and made a beeline for the mum of another baby I was following. I vaguely remember passing Alice's bedspace. However, at the time I assumed she was an older baby - she already had a laminated pink name banner sellotaped to the end of her incubator. A nurse on the unit, affectionately known by many parents as "the naming fairy" used her time off from work designing and creating name banners for each baby on the unit. Armed with a list of the newly named babies, the naming fairy crafted laminated labels using bubble letters and stickers, which are then affixed to a designated spot at the foot of each incubator.[23] Usually, this process took a few days as there was one nurse to fulfil this job for upward of 40 infants. I was then surprised to learn that this new baby, Alice, was only born a day prior. Her parents must have picked out her name either before birth or soon after. I did not pay much attention to this new infant at first. But during a quiet moment in the nursery, I had a chat with her nurse to get some more information.[24] I liked this nurse - she made me laugh - a rarity during my time on the unit. As I came closer, I was struck by the drops of condensation on the inside of Alice's incubator.[25] It reminded me of the windows inside my damp flat. Nurses had to wipe down the plastic interior periodically so they could keep their visual field somewhat clear.

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[23] The intricacies and value of this practice will be discussed at length in later chapters.

[24] As mentioned previously, part of my observation protocol required I liaised with an infant's bedside nurse prior to meeting parents. The bedside nurse would indicate if they believed the parents of the infant would accept being approached by me to talk about my research. If so, the nurse would then introduce me to the parents at the next appropriate time.

[25] I learnt that this condensation is due to the immature skin of extremely preterm infants. The thin and underdeveloped skin means that water evaporates from the body and is released as condensation. As the infant is typically in a small humidified incubator, this condensation forms in droplets on the inside of the plastic. In addition to obscuring the view of nurses and parents, the evaporation can be dangerous for very small and early infants due to fluid imbalances.

Alice was the smallest and most premature baby I saw on the unit. At birth, she weighed 504 grams.[26] Her gestation was officially classified as "23+2"[27], but as I would later learn from her mum, she may have just been at 22 weeks when delivered. Her head was very small and her ribs protruded through her skin. She had a thin cover of blonde hair all across her body, and slightly thicker over her head and brow bones. Her whole face was obscured by the tape that secured her endotracheal (ET) tube, which in turn forced oxygenated air down her trachea and into her underdeveloped lungs. Her skin was an angry red, wrinkly around her knees and elbows, but it looked soft to the touch. It was the 1st of August, but her due date wasn't till the end of November.

My decision to introduce Alice so early in this thesis is an intentional one. Born at (approximately) 23 weeks gestation, her story is indicative of the important role that gestational knowledge and metrics played in how premature babies were framed as persons and patients on the unit. Yet, the relationship between prematurity and the metric of gestation was also complex and dynamic. While gestational knowledge was one way in which parents and staff negotiated premature personhood, it was also strategically erased and/or de-emphasised in many stations.

The role of gestation as a contentious temporal negotiator of personhood has been closely engaged with across various disciplines. This literature spans a myriad ethnographic foci and highlights the values afforded to gestation as a metric of incremental and/or potential personhood for both the foetus and the premature baby. In particular, the following scholarship from the social sciences has explored the ways in which premature babies are designated personhood in the United States, Israel, South-East Asia, and Scandinavia. In each of these cases, the neonate's personhood is constituted differently and not without contention, yet the metric of gestation is valued.

An increased medical interest into the personhood of newborns prompted the development of new medical specialities and subspecialties. The designation of the premature infant as a legitimate subject of medical expertise indicates, the very least, a professional acknowledgment of some type of personhood for those born very early. Physician-anthropologist, Astrid

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[26] 504 grams is approximately 1.1 pounds. In 2017 (MoH 2019), 6.1 percent of infants born in New Zealand were classified as "low birthweight" (below 2.5 kilograms). A very small minority of these include infants like Alice born around 500 grams.

[27] 23 completed weeks and two days.

Christoffersen-Deb (2012), conducted ethnographic research focussing on narratives of personhood in a Neonatal Intensive Care Unit (NICU) in the United States. She observes how the contested narratives of personhood have structured the development and organisation of maternal and foetal medicine. A narrative of gestational viability is used to mediate the treatment of a foetus as a clinical person who demands the same medical treatment as a baby born full-term. Viability – constructed along a continuum from non-viable through to viable – structures both the level of care given to premature infants, and to their mothers. Gestational age, often taken as the primary measurable indicator of foetal viability, additionally structures *mothers'* experiences from the instant they arrive at the hospital. For women in labour prior to 20 weeks gestation the labour is classified as a gynaecological issue to be treated using the medical procedures associated with miscarriage – the foetus has not yet reached the threshold of viability in which it may be treated as a clinical person worthy of neonatal medical intervention. However, after 20 weeks gestation, the labour is managed as obstetric, and necessitates input from a neonatologist. This bifurcated logic of care also represents a transition from a sole responsibility towards the well-being of the mother, and movement towards the biomedical responsibilisation of the mother, the foetus, and the doctor. The foetus is becoming a person who necessitates intensive medical care from a specialised sub-discipline of paediatric medicine. The development of neonatal medicine assumes clinical responsibility towards the foetus prior to birth. Nevertheless, the construction of foetal personhood is much more complex. As previously discussed, obstetrical medical practice illustrates an acknowledgment of a foetal personhood – one that necessitates targeted medical care and concern. However, this biomedical acknowledgement is contingent on the passing of particular clinical milestones, such as gestational age, weight, and/or birth.

Cross-culturally, the process of birth is one way in which personhood is negotiated in the transition between foetus and infant. For instance, Jewish law, foundational to the Israeli legal system, affords personhood at birth (Weiner 2009). Before which, the foetus does not possess any legal rights as a person, and can thus be legally aborted at any gestation. Birth constructs the person regardless of the gestation at which the foetus is born. Birth as a process which ontologically reframes the foetus as an infant-person, presents ambiguities with regards to the Israeli treatment of premature infants. Weiner observes that Israeli Neonatal Intensive Care Units (NICUs) treat premature infants as persons, despite their early birth, often at gestations

which are within the Israeli legal parameters for abortion.[28] Nevertheless, the socially mediated process of 'birthing', regardless of gestation, transforms the foetus into a person which necessitates some form of medical intervention. Such intervention may be as simple as providing warmth and pain relief for the baby to die comfortably. When contrasted with the abortion of a foetus at the same gestation who is not afforded the status of 'person', the socio-cultural imperative of birth and gestational makers as integral to personhood is visible.

The values associated with gestation have also been observed by Catherine Degnen (2018) who draws on the ethnographic works of others in exploring personhood with a life course approach. Degnen argues that, for children and infants, "[personhood] in Western thought tends to be based on notions of developmental stages, biological determinism, and calendrical time (Degnen 2018, 57). Much as gestation is one manner through which foetal personhood is negotiated, infant and child personhood is negotiated via an acknowledgement of particular developmental milestones, the passage of time and the fulfilment of certain physiological markers. Yet, in the NICU, the use of gestation as a quantitative measure of preterm personhood was nuanced. Personhood was, in part, articulated using a language of gestation. However, 'gestation' was also strategically re-positioned as less important compared to other factors which made up a complex and dynamic configuration of personhood(s).

Gestation at City Hospital and Beyond

Over a period of 12 months, I returned to the realm of my birth, the individuals to whom I owe my survival, and spoke to those whose experiences resemble the ones of those who raised me. I began fieldwork keen to observe the life-worlds of those born too early. It became clear that 'gestation' (at birth) was both a structured and structuring classificatory system which was simultaneously of the most, and the least, importance to the neonatal care of a premature infant. This system vastly transcended the clinical realm, and was demonstrative of how it was positioned and repositioned as both an important and irrelevant metric of personhood.

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[28] It is for this reason, that the preterm infant, alongside the foetus, is often deployed as an illustration of anti-abortion rhetoric. Bronstein (2016) illustrated that anti-abortion movements have historically mobilised the image of premature babies as a key justification for their rhetoric. Using the gestational crossover between some abortion laws and the points at which preterm infants are resuscitated in various locations, these groups argue that there exists an imperative to also 'save' the foetus from abortion in the same manner care is provisioned to preterm infants. Groups also draw on the preterm infant in the political mobilisation of "abortion survivors" (Bronstein 2016, 151). These cases are demonstrative of how the preterm infant has been politicised, and will be discussed further in later chapters.

Pregnancy and gestation

Fieldnote: Wednesday, July 19th, 2017

I am in nursery D, the intensive care room. It's warm as usual, and I'm struggling to stay awake seated in one of the prized lay-z-boys. These soft plush chairs are rare but wanted. We go on hunts for them. If a parent wants cuddles with their baby, we raid other nurseries for an unoccupied lounger to hijack and wheel back to nursery D. Luckily for me, at least for the moment, I am free to use one. This is an unlikely treat, given I am usually left perching on a stool for the day - bearable for the first few hours, but after a while, my backside goes numb and I need to wander.

But it is this combination of heat, humidity, and a ridiculously comfy chair, which counteracts the black tarry coffee I drank on arrival to the hospital. The morning continues on much as they have the past few weeks: a triad of antibiotics are given to baby Justin for suspected necrotising enterocolitis (NEC), a life threatening disorder; the financial cost of using regular TPN versus early life TPN[29] is debated; and the new admission, 26 weeker Hana, is given a longline.[30]

As I recline in the chair, wondering what I should have for lunch, a nurse slinks up to me with a sneaky look on her face. I hadn't really had much to do with nurse Nora up until then. During my time on the unit she liaised between the antenatal ward and the unit: telling parents what to expect of NICU, and showing would-be NICU parents a real life example of what their infant might look like at birth. Nora told me that there was a woman on the antenatal ward who I might want to meet: someone anxious about the prospect of having twin premature girls and wanting reassurance that her babies would be ok if they were born now.

And thus, my own identity as an ex-26 weeker was useful once again. Nora and I headed down the long corridor which connects NICU to the OB/GYN ward. The ward trifurcates into gynaecology, antenatal, or postnatal wards- or 'postnates' as I would later know it as. I'm led into a hospital room, with two beds, and one heavily pregnant occupant. The room is lit with

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[29] Total parenteral nutrition (TPN) is a type of intravenous nutrition used when the digestive system is underdeveloped or misfunctioning. The liquid is comprised of a meticulous measure of nutrients and fats.

[30] A longline, or peripherally inserted central catheter (PICC), is a type of intravenous catheter which is threaded from a vein in the arm or leg to near the heart. This type of catheter is used when long-term access to a vein is needed or for particular medications and nutrition, such as TPN.

the same harsh white light of the NICU, and scented by the same overwhelming disinfectant. Morgan was sitting upright and cross legged in her bed when I saw her for the first time. Her black hair was in a loose ponytail, and her long sleeved t-shirt was stretched over her small pregnant belly. She looked at me with a warm and caring smile, and I was immediately at ease. I spoke to Morgan in my capacity both as a researcher, and as grown outcome of prematurity in the flesh. We talked about my project, my developmental milestones as a child, and the two girls growing inside her who would later become so important during my days on the unit. She expressed to me her fear at having not one, but two, premature babies. She called me her "beacon of hope".

From the very outset of her pregnancy, Morgan knew something was "a bit different." She suffered from morning sickness which she had never experienced during her two previous pregnancies. At 9 weeks of pregnancy, Morgan and her husband Dean found out that she was carrying twins. They were told that these twins shared both a placenta and an amniotic sac, increasing risk of premature birth, and/or the death of one or both babies. This type of twin pregnancy is referred to as monochorionic monoamniotic twins, and more colloquially called 'MoMo twins'. However, at 12 weeks gestation, a membrane was found to separate the foetuses, ruling out the prior belief that they shared an amniotic sac. But due to a significant growth discrepancy and some problems with blood flow between the foetuses, the likelihood of premature birth was still high, and continued to heavily shape Morgan's experience of pregnancy and her identity as a pregnant woman. Morgan was referred to a specialist at City Hospital, and made the weekly 3.5 hour drive from her hometown for monitoring. Her body was closely watched, measured, and scrutinised by doctors. She was eventually admitted to the antenatal ward at 24 weeks gestation, before having a C-section two weeks later upon the decision of the specialist. Jessie, weighing 635 grams, and Georgia, weighing 905 grams, arrived on the NICU after 26 weeks and two days in the womb.

For Emily Martin (2001), the processes and techniques of pregnancy are comparable to a capitalist production line. Much like a factory worker uses machines to produce products, a pregnant woman relies on her uterus to 'grow' a foetus, with the ultimate hope of producing a valued and contributing member of wider society. For Martin, obstetrics perceives of the woman's relationship with the foetus much like a worker is alienated from the object he or she produces: contractions during the birthing process are something which she has no control over. The self is separated from the uterus. Paradoxically, Martin observes a tension between the

alienation, and how the woman is responsibilised as *in-control* of the processes: "told she is doing well, or not well enough" during contractions and birth (2001, 62). This tension was also visible in how women, such as Morgan, experienced their pregnancies when at increased risk for premature birth. Gestation, acting as a technical placeholder for foetal progress, moulded pregnancy from the outset and structured the frequency and intensity of medical surveillance on the woman's body. The tension presented by Martin, is nuanced by the experiences of those women at risk of delivering prematurely.

Dichotomised narratives of control, or a lack of, were strategically rationalised by some women I spoke to. The women simultaneously speak of autonomy and identity as pregnant women, in-control of their pregnancies, and *actively* relinquishing control (and affording personhood) to the foetus as "coming when they want to", even if that is early. The latter component will be discussed in chapter 6. This dynamic illustrates a nuanced tension to that proposed by Martin, yet it is indicative of wider debates regarding conflict between the woman's person and the foetus. This tension is also visible in the literature. Feminist bioethicists working within the radical feminist paradigm have claimed that any analytical focus on the foetus is decidedly *unfeminist* (Sherwin 1992; Raymond 1987) insofar as it attributes a type of value and personhood to the foetus that is fundamentally in opposition to the personhood of the pregnant woman. Morgan (1996) expertly critiques their simplistic account of the foetus in arguing that, by viewing the study of the foetus as not feminist, we deny the experiences of pregnant women who attribute agency and personhood to the foetus. For women to whom I spoke, many felt distanced from their bodies during pregnancy because of the constant monitoring by biomedical authorities to manage a predicted premature birth. Yet this lack of control was not directly attributed to the foetus but to those who were tasked with monitoring it. Here, the conflict between maternal and foetal personhood existed more between narratives of neonatal agency (over initiating birth regardless of gestation), and the woman's desperate desire to continue the pregnancy. Women creatively managed the foetus "just wanting to come out", alongside the biomedical authority over pregnancy, with a type of gestational goalsetting.

For Morgan, as well as many other women to whom I spoke, gestation became a strategic method of goalsetting and a marker of foetal progress. Gestational goal setting was a means of asserting bodily control despite a simultaneous acknowledgment and active decision to relinquish control. This often resulted in guilt and sadness when the goals were not reached. On the NICU, women were told they had no control over their infant's preterm birth, but still spoke of their goal-setting during pregnancy as key:

"I was admitted when I was 24 weeks, and had them at 26+3...So we did really well to hang on for another two weeks" (Morgan)

Pretty much once we found out that I was pregnant at 13 weeks, it was like, we've just gotta make it to 24 weeks. So once I hit 24 weeks, we were like "Woohoo" and screaming around the house saying that "We did it, we did it!" (Abby)

"We were pretty much just hoping to get to viability because we weren't sure that we were gonna get there." (Dee)

The language of "hanging on", "making it", and "hoping to get to viability" implies a self-responsibilisation for women at risk for premature birth. The responsibilisation of pregnant women by biomedicine (and beyond) is well documented in the anthropological literature, from Layne's (1996) critique of the women's health empowerment movement in contributing to maternal self-blame, to Ivry's (2009a) comparative exploration of pregnancy in Israel and Japan, and will be discussed extensively in chapter 6. More specifically, the practice of maternal self-blame as a result of premature birth is not only present in the literature and my own research, but also in my mother's experience of going into labour early, suggesting that this responsibilisation can affect women well after pregnancy and birth. In a Huffington Post article, one mum expresses the guilt she felt after her son was born: "I'm sorry you had to be born early, and I couldn't keep you safe." (Hassall 2016). For NICU nurse Pat, maternal self-blame is something staff are often presented with:

Pat: "...like with parents thinking… 'My pregnancy is all good, why did this happen?' The self-blame is huge."

Zoe: Like thinking "Why is my body not doing what it should be doing?"

Pat: Yeah. [Pregnancy] Which is portrayed as "Absolutely natural" and how "there should be no problems" et cetera et cetera, but it doesn't happen that way. All sorts of things interrupt things. Disrupt it. And that's part of life. You know, you can't avoid a cancer or you can't avoid a heart attack and this sort of thing. You can do everything you can to try and reduce the risk, but you can't totally say "It won't ever happen to me." And yet, the birth of a child, they think "Oh, it won't happen to me." ...this is one of the things midwives say, "This is all natural" and "This is all normal" Well, yeah it is, but it doesn't negate that it won't happen. But that's what lots of mums and dads feel. It shouldn't have happened to them. So they're having to come to terms with the fact that "What did we do wrong that this happened to us?" (Pat and Zoe)

The above quote also highlights how gestation as a measure of time can still shape the pregnancy experience in retrospect, such as if premature birth was never expected or happened very suddenly. This can be as simple as going into labour before having a baby shower or a name picked out, or as complicated as only finding out about the pregnancy by going into labour. A baby shower exists as a sort of rite of passage for parents in New Zealand. Such events, which generally take place during the third trimester, are a chance for parents to celebrate the upcoming birth of their baby while receiving presents from family and friends. But what happens when a woman goes into labour early? This parenting rite of passage may be missed, or may occur months after the birth. For Sallie Han (2013) the baby shower is a ritual representation of a 'normal pregnancy' and one way in which parental personhood is produced. It is practices such as this which contribute to "gestating" the mother in routine pregnancy:

> "The baby shower is the public acknowledgement and social recognition of a pregnancy, an expectant mother and father, and a child. As such, it accomplishes cultural and social work of significances for American middle-class women and men." (Han 2013, 169)

For Abby, the birth of her daughter Molly at 26 weeks gestation meant she didn't have a traditional baby shower. Instead, she planned to hold a party once Molly came home:

> *"I never got a chance to have a baby shower cause I was 26 weeks. So a lot of friends are annoyed that they don't get a baby shower, and I'm like "Yes we do, we get a welcome home party" So I thought it would be cool if we had it on her due date." (Abby)*

Mothers on the neonatal unit showed immense resourcefulness and adaptability in working around situations such as these. For some, the fact of pregnancy had not even sunk in yet, before labour began. This was particularly pertinent when it comes to those infants born at the very edge of viability. While the metric of gestation can shape the mother's experience of pregnancy, and her own personhood, quite possibly the most significant way in which gestation is a structured and structuring force in extreme prematurity is regarding questions and debates of neonatal viability.

Gestation as Viability?

Viability constitutes a significant component of biomedical and bureaucratic literature concerning neonatal ethics (Brunkhorst, Weiner, and Lantos 2014; Nuffield Council on Bioethics 2006; Verhagen and Janvier 2015). Alongside gestation, it is a metric used to quantify personhood in biomedicine. In the literature, the metric of gestation is taken to be one

of many gatekeepers in determining the viability of a foetus or newly born premature infant. Yet, the actual relationship between gestation and viability is much more complex than I first expected. I assumed viability increased incrementally as the days and weeks passed - *which it does*. But in an email I received very early on in my research, I was reminded that just because an infant is born at 26 weeks, a multitude of additional factors interact to determine viability, and ultimately, survivorship. Further, the relationship between gestation and viability is far from linear - a factor which was reinforced heavily in my conversations with NICU staff and in following the experiences of parents. The articulation of personhood via a language of gestation is complicated by a concurrent focus on viability.

From the outset, the gestational age of a foetus is used as an initial indicator of the type of medical management a woman receives going into premature labour, and if the foetus is treated as a person and/or patient. In New Zealand, much like in the United States (Christoffersen-Deb 2012), gestational age and its relationship to viability, heavily structure the maternal experience at first indication of premature labour. However, there currently exists subtle inconsistencies across District Health Boards (DHBs) in their published clinical guidelines on standard procedure for the management of premature birth, *and* between these official guidelines and actual practice. Below are the clinical guidelines on neonatal viability taken from three DHB best-practice protocols:

> *"The gestation of possible viability is 23+0 weeks"* (Hutt Valley DHB 2018, 1)

> *"<23+0 weeks: Babies very rarely survive at this gestation and in favour of the best interests of the baby and standard neonatal practice, it is acceptable for resuscitation not to be commenced. 23+0 to 24+6 weeks. At these gestations babies are at the limits of viability"* (Christchurch DHB 2018, 19)

> *"Active intervention <24 weeks should not form standard routine care…"* (Auckland DHB 2018, 15)

These were spoken of as simply guidelines to be followed at the discretion of the lead consultant. Known to be one of the more "liberal" centres in terms of resuscitation, consultants at City Hospital provide active resuscitation to infants just under 23 weeks gestation if the efforts are predicted to be fruitful or if parents are not sure of the exact date of conception or last menstrual period, and therefore exact gestation. The assessment of an infant born below 23 weeks gestation as 'viable' challenges the claims made in the protocols mentioned above. Again, like gestation, viability is socio-cultural construct produced from, and justified by,

biomedical research and assumptions. From interviews with staff across centres, it was clear that staff assessments of neonatal viability were multifactorial, and in some cases, involved a degree of guesswork and the use of a 'gut-feeling' that contrasted the evidence-based protocols. Viability was enacted through a variety of means, and attempts at quantification. For instance a nurse at City Hospital showed me an application where features such as an infant's weight and sex, as well as gestational age, can be entered into a matrix to produce a percentage value suggesting the infant's chance of survival, and with or without major morbidity. However, the use of these apps seems to be more of an 'out of interest' practice rather than one which greatly shaped clinical care.

Beyond clinical features, the social worlds of a foetus or neonate were also assessed when determining viability beyond purely gestational age. Decision making with families was a key process in determining the course of action for extremely premature birth. Family counselling was a task generally left up to the neonatal consultants or other members of the medical team. Factors such as family composition, socio-economic status, and the personal values of both family and staff were characteristics which may shape staff assessment of viability, and ultimately, negotiations of personhood:

> *"Some [parents] have very strong beliefs: 'this is a special baby, I've tried 10 times, it's my 10th pregnancy, first one I've carried this far, it's very special, I want you to do everything you can, it doesn't matter what the outcome is for the baby, I want this baby."* (Kath)

> *"[The decision to provide active care] should be between the parents and the consultant. It should be a team approach. You know, 22+5, if [the parents] say they have a strong feeling they don't want to do anything, I guess that would be taken into consideration. But at 23 weeks, if a baby came out and screamed, and was active and vigorous, you would want to give it a go. And it's probably worthwhile giving it a go."* (Darcy)

> *"Parents these days...Especially with IVF babies, parents will say 'I want everything done, this is a precious child, I can't have children naturally' or if one IVF treatment in a lifetime is all they get. If you can afford more you've got greater success, but jeepers creepers you don't want to give up.* (Pat)

The difference in how a premature birth may be managed depending on the above circumstances highlights one way in which the viability of a foetus was assessed beyond the

clinical. The decision to provide life sustaining treatment may therefore depend more on intention and predicted outcomes - an imagined future - and less on precise gestational age.

Conclusions

The specific gestational age of a premature infant at birth is important. It is used to classify babies and to structure protocols. It provides a measure of goal setting, and a language to debate viability and personhood. Yet, the cultural and clinical value applied to gestation was dynamic and could be repositioned by parents and staff to more accurately account for their realties. Gestation as a metric for negotiating personhood supports the observations made by Degnan (2018) and Christoffersen-Deb (2012) in the use of various measures to 'quantify' and/or structure how medical staff approach the personhood of a premature infant. However, gestation was equally elevated and devalued as a metric to serve a variety of means. For instance, the number of extra days in the womb was said to matter greatly, but sometimes overlooked. In this sense, the constantly shifting configuration of a metric such as gestation in the NICU setting, sometimes subtle, sometimes dramatic, nuances Degnan's conceptualisation of a 'Western personhood' as typically negotiated in terms of quantifiable and replicable metrics. Personhood is not easily captured by a single ethnographic description. Rather, it is contradictory and multiple in layer dynamics that existed far beyond the individual and/or the relational.

Interlude: The Golden Hour

On a Wednesday morning, I received a call from the DHB medical records department, advising me that my NICU discharge notes were ready for pickup. The time was 10.30 am. I rushed to get ready and walked with purpose down to the hospital. The receptionist at the front desk took my ID, and after confirming my identity, handed me a stack of what I presumed to be the medical notes, wrapped tightly in brown paper and copiously cello-taped.

The moment I arrived home, I ripped over the bag, and tossed the notes onto my bed. I sat alongside them, and I began by looking for the notes written by the specialist upon my arrival to NICU. I was looking for those notes pertaining to the Golden Hour - *the time when stuff gets done.* For me, this involved 8 things:

1. "UAC": An umbilical arterial catheter is a central line threaded carefully through one of the arteries in the umbilical cord. This type of catheter allows for easy blood draws and continuous blood pressure monitoring.

2. "Gas": Obtaining a sample of blood for an arterial blood gas measurement. This will indicate how much oxygen and carbon dioxide are dissolved in the blood, and whether I am tolerating whatever those levels turn out to be.

3. "U&E and CBC": These stand for Urea & Electrolytes and Complete Blood Count, and are types of blood tests.

4. "Blood culture": Yet another blood test. This is where blood is taken and tested to see if it grows any sort of bacteria and/or fungus.

5. "CXM": I had to look this one up... This stands for 'cefuroxime', a type of antibiotic given in managing suspected sepsis.

6. "CXR/AXR" More acronyms… These are x-rays – specifically of the chest and abdomen.

7. "Amox/Gent": These are also antibiotics - amoxicillin and gentamicin, used to treat a broad range of infections.

8. "Px explained to dad": Explain the prognosis of my condition to my father.

And that's it. The Golden Hour. Or Golden *couple of* Hours according to my notes. As I read over these notes, I realise how medically literate I have become during my fieldwork. With the exception of task 5, I knew what the notes were talking about - what the acronyms meant, what the procedures did, and why they were performed. I was struck by a particular juxtaposition in how the same individuals have written in my notes. As indicated above, these doctors frequently use acronyms and short hand to save time. Observations are bullet-pointed; plans for action are listed; completed tasks are ticked off. However, on the same page, metaphor is used. Joking is implied. Below the surface of objective observations, specific language is used to communicate what cannot be said through numeric values and medical shorthand: Zoe is *fighting* the ventilator; condition is serious and unstable; and the use of an exclamation point indicating surprise at the fact a whole bunch of surfactant[31] came out my nose.
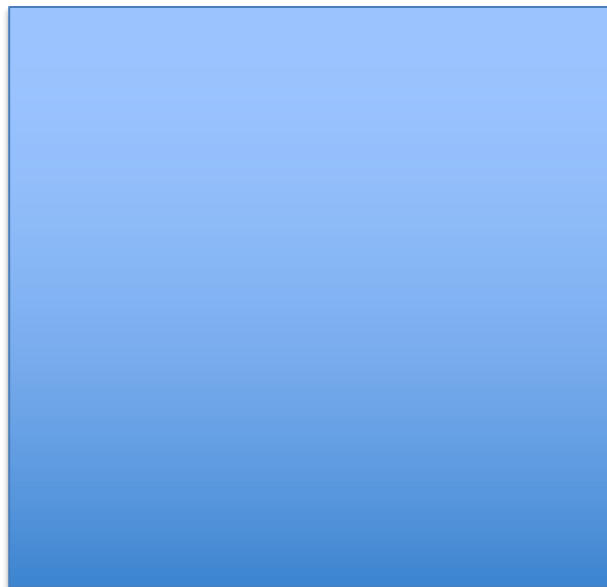
Figure 1: Brand New!

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[31] Surfactant in the lungs, "pulmonary surfactant" (Mallinath and Kotecha 2013) is a frothy liquid produced in cells to reduce the surface tension in the lungs. This prevents lung collapses and keeps the lungs working properly. As surfactant is generally produced by the foetus toward the end of a term pregnancy, premature infants may be born without (enough) of this liquid. For this reason, premature infants are often given a dose of synthetic surfactant into the lungs.

Chapter 3: Spaces, Objects, and Persons

Fieldnote: Monday 31st July, 2017

The walls were painted a light blue, peppered with animal decals. A slightly crazed looking cartoon lion held the tail of a subdued monkey, who was linked to an elephant. A long line of these animals was all connected, one way or another, snaking around corners, until they lined whole sections of the pale blue wall. If I squinted, this could be a crèche or the children's section at a public library. But below a rather sour looking hippo, the red trolley marked 'RESUS' brought the ICU back into NICU. Walls are lined with breast pumps, a resuscitation trolley, NICU success stories with photographs of healthy toddlers, and a spare transport incubator that looks much like a space station cargo capsule. If you took a half finished nursery, and combined it with a fully functioning intensive care unit, the NICU would be your end result. The NICU space was comparable to the quilts for sale in its entryway: a contrary patchwork; a pairing of two mismatched patterns; connected by thin fibres spun tightly into beauty and strength.

Today was my first day on the NICU in my capacity as a researcher. I was confident in my research: I know the literature; I've read extensively on neonatal medicine; I know who I want to talk to, and what I want to observe. But in a single moment, this prior knowledge faded into the background, and disappeared. I was introduced by a nurse to a premature baby - the first premature baby I have seen beyond photos. I noticed his small face. There was little difference between the hair on his head, and the hair which made up his eyebrows. He was covered in a peach fuzz. His little blue eyes squinted open, and flickered shut. I think he was bothered by the light. His ribcage protruded, with thin red skin stretched tightly over it, and dipping in and out as he breathed. His face was wiped by a nurse and he became restless. His skinny limbs tensed up, rigid. While cleaning his face, wiping away the secretions or "eye-boogers", the nurse spoke to him, in soft soothing tones. She told him that he is okay, and that she will be done soon. I don't know if those words made a difference to him in that instance. At the very least, it made me feel better.

Later, I was taken on a tour of the whole unit, beyond the nursery with the baby boy covered in peach fuzz. I learnt that there are two main types of nurseries at City NICU: big baby rooms and little baby rooms. The big baby rooms house a diverse range of patients, from babies

needing surgery (called "surgical babies"), to babies of diabetic mothers (called "sugar babies") to premature infants roughly weighing over 1500-2000 grams (called "feeders and growers"). I was told that these babies tend to be born at term, or at gestational age of above 28-32 weeks. In comparison, little baby rooms generally house the smallest and sickest premature infants, like the little baby I'd met earlier. Two bed-spaces in the little baby rooms were reserved for the sickest of sick - those brand new extremely premature infants who require central line procedures (such as umbilical lines, colloquially referred to as "umbies"), mechanical ventilation, and/or one-on-one nursing care. Such bedspaces had more surrounding space than the four other incubators in the nursery, to accommodate ventilators, more IV poles, and more staff if necessary. If a new infant was due to arrive from labour and delivery, an attempt was generally made to vacate one of the two most intensive bed-spaces for the new arrival.

City Neonatal Unit was a fairly large unit in terms of occupancy. Yet given that the 'space' or lack thereof, was one of the biggest complaints by staff during my time on the unit, the environment took on a cramped quality by association. The unit was made up of a horseshoe shaped corridor, with seven nurseries, and two attaching corridors. The "fishbowl" was a central feature during fieldwork, and locus of administration. Made up of full glass walls and an adjacent reception desk, the fish bowl was a central hub for staff to check patient records, view lab results, run blood gases, and look at x-rays. It was also where the doctors might have a chat about their weekend, discuss a patient in passing, or finish their coffee, feet resting on another chair. This chapter will both provide a more in-depth discussion of the physical NICU space, some of the ways in which participants, including myself, moved through the built environment during this research, and introduce how space mediated the negotiation of personhood beyond physical bodies.

Anthropologists have long been concerned with space and the built environment. In their review of anthropological engagements with space, Lawrence and Low (1990) trace a trajectory of approaches broadly concerned with how groups of people construct, occupy, and interpret certain spaces. Beginning with those grounded in ethnographic description, the authors summarize the merits and pitfalls of early structural-functionalist approaches, such as those of Durkheim (1965) and Morgan (1881). For early anthropologists, the way in which a built environment was structured "[was] seen to mirror the culture that produced them" (Lawrence and Low 1990, 456). It is precisely those characteristics of the space which is further

reproduced in the society. Space and society are mutually reproduced. However, such analyses provide an oversimplification of more complex cultural nuances - both collective, and individual – thus prompting the development of social symbolic approaches to the built environment. For Lawrence and Low, such approaches pay closer attention to the "shared mental structures" (1990, 466) which have given rise to built environments. Adding a distinctly structuralist flavour to this model, Lévi-Strauss (1974), for instance, suggests that the indigenous American Tewa mode of village organization is mutually grounded in an underlying logic of binary oppositions. As anthropologists later became more concerned with a politics of space, more recent approaches concerning the social production and reproduction of space "seek to place their understanding of built forms within the larger context of society's institutions and its history" (Lawrence and Low 1990, 492). It is these approaches, in conjunction with paying particular attention to the embodied and phenomenological nature of experiencing space and the field (Low and Lawrence-Zúñiga 2003, 2), which I have drawn from in approaching the built environment. Rather than a passive structure, the physical NICU space shaped expressions of personhood outside of the body, and manifested those expressions through various objects and narratives.

The NICU fishbowl reminded me of Foucault's panopticon. With its glass walls, occupants can not only look out, glancing at hallways and into the two high-acuity nurseries, but can also be watched. I often saw parents peering over into the fishbowl from the (dis)comfort of a nursery to see which administrator was on duty that day. Much like during a turbulent flight where I calm myself by looking at the flight attendants - my anxiety easing when I see they 'look' calm - parents looked at the (hopefully calm and collected) staff as their own mode of self-assurance. Yet, visibility was usually two way: both parties, staff and parents, monitored each other for comfort and to ensure conformity. If I was in the fishbowl, chatting to a nurse, or pestering a doctor for an interview, I often felt on-display and vulnerable. One instance of this features prominently when I think back to my fieldwork experience.

It was only a few weeks into my six month stint of participant observation at City NICU. But this one minute interaction would colour much of my behaviour for the remaining months. It was a fairly quiet day on the unit. In a nursery of six beds, only four were occupied by infants. As a researcher, this was ideal - it meant two nurses had to be rostered to the nursery, and with only two babies to care for, they were better able to take me through what they were doing. This was a privilege. I spent the day hanging out in this nursery, chatting to the nurses, trying to feel useful. When a nurse asked me to fetch a bottle of breastmilk for one of the babies, from

the famous "Milk Room", I leapt at the opportunity to actually *do* something which might help. I went into the Milk Room, feeling rather important, and fetched the named bottle. As I passed by the fishbowl on my return to the nursery, I was stopped by a senior nurse. She told me it was highly inappropriate for me to be fetching the milk. Her comment still makes me squirm. She framed her comment in reference to my own safety - I didn't know if this mother carried any sort of disease transmittable via breastmilk, did I? And while it seems highly unlikely that I would trip, fall, the bottle would break open, and the milk would spray me in the face, I can still see her point. As I think further about this now, I suspect her concern for my safety was more about the hospital's liability and how this would affect the hospital if I had made a mistake in picking up the wrong milk. I understand this too. My gripe is, however, the location of where I was effectively told off in the fishbowl and in in front of participants. As a fairly anxious people pleaser this was mortifying, But as Ruth Behar (1996) rightly suggests, participant observation is a practice of vulnerability, and not only for those observed. While vulnerability is, at once, something felt by an individual, it is also written in to certain spaces by the very foundations on which the environment rests. Discipline not only shaped spatial organisation, via surveillance, but also the wider social life of the unit.

Although *people* constituted my construction of the field, the physical space of the unit was a base layer of analysis throughout my fieldwork. I found that when situating human action, including my own, within the nuances of space, I was better able to discern the ways in which people and spaces mutually produced a certain lived experience. As I mentioned in the opening of this chapter, a fieldnote excerpt, the space was both a nursery and a medical ward. By virtue of the patient population, the space was a realm of infancy and new-parenthood situated firmly within one of biomedicine. And, even in other biomedical spaces, the neonatal space specifically is representative of infancy and new-parenthood being spatially bounded within the structured domain of biomedicine. I remember visiting a family member of mine in hospital who had recently given birth. The birth was at term, and, by all measures, routine. The newborn required little medical intervention, and he was allowed to share a room, "room-in", with his mother on the postnatal ward. For four days, mother and baby shared a single room: the mother was given support in the postpartum, and baby received the usual testing of a newborn in New Zealand. While sleeping in a hospital-issue plastic cot, the baby was wearing clothes brought in by his parents. He had a plastic name band around his foot, which jiggled as I held him close to my chest, sniffing his head.

While in a distinctly medicalised space - the impersonal plastic cot, call bells on the walls, and the plastic patient identification bands for the mother and baby were a dead giveaway - the space seemed to me, ever so slightly, more like the private realm to which pregnancy and birth are usually relegated. But this may simply be due to my point of comparison being the NICU. On the postnatal ward visiting my family member, I was able to walk freely past the receptionist, not saying who I was or why I was there. I was able to pick up my cousin, say hello, and give him snuggles. I looked at his little fingers and toes, and sniffed his new baby smell. There were call bells on the walls, much like any other patient room in a hospital, and other objects which are expected, such as a washbasin, gloves, and four uncomfortable chairs for visitors. To me, yes, this was unequivocally a medical space. It smelled of cleaning products, and I heard the occasional ringing of call-bells from the hallway. Occasionally a nurse would pop in to check on things and to work her way down the list of standardized newborn tests which are understood as routine. However, this space lacked the physically invasive technology which was characteristic of the neonatal intensive care unit.

Material Manifestations of Personhood

City NICU was a Luddite nightmare. With medical technology lining the hallways and nurseries, the unit requires its own on-site technician - a "doctor for the tech" as this individual was referred to by some nurses. In approaching these technologies beyond an Enlightenment assumption that they are, in themselves, value neutral, and offer exact reflections of the physical world (Lock and Vinh-Kim 2010), it is altogether clear that these spaces, so moulded by technological advancement, are worthy of sociocultural focus. It is to be expected that anthropological engagement with neonatal spaces has been interested in the technology utilized (Ginsburg and Rapp 2013, 320). Medical technologies, such as the incubator, are one core feature of modern neonatal care. The incubator, for instance, is a central feature of the public imaginary on prematurity, used as a receptacle for cash donations in public spaces. In her discussion of human-object relations in the NICU, Landzelius (2003) provides a skilful analysis of human-object relations which is of ever-increasing relevance given continual advancements in neonatal technology. Continuing along a Latourian vein, Landzelius highlights the importance of such technologies as objects of anthropological study and critique:

> *"Indeed, the commanding presence and sheer peculiarity of intensive care machines, coupled with their precious assignment of infant inhabitants, make it difficult to adopt anything like a distanced, dispassionate neutrality towards them." (Landzelius 2003, 5)*

For Landzelius, the incubator and its associated technologies (such as assisted ventilation), serve as mechanical stand-ins for the uterus and displace the maternal actor from her infant. These technological networks, along with the medical knowledge deployed by staff, perform functions that would otherwise be undertaken by a pregnant person: maintaining body temperature, providing nutrition, sustaining a good level of oxygen in the blood, all the while existing as a safe environment for foetal growth and development.

Yet these technologies were equally adorned with other objects, such as toys and posters. The integration of traditionally non-medical technologies into the incubator setting was a common practice in the NICU. Landzelius (2003) has additionally observed the role of such objects – such as soft-toys, name cards, and colourful blankets – in mediating the obstructed social development of the neonatal person. Mothers have framed this practice in terms of personalising the baby and their life sustaining technology. The so-called "cold and impersonal" aura of the baby encased in an incubator is humanised through the careful placing of objects that are imbued with the role of "enlivening" the relationship between the baby and its environment (2003, 329–30). Landzelius used the concept of liminality to explain the desire for families and NICU staff to provide these personalising embellishments as material dimensions of neonatal personhood that are obfuscated by the cold and clinical incubator. These objects aid in the progression of the baby from their liminal state as simultaneously foetus and neonate, to their social recognition as neonatal persons, now living outside the womb, and able to appreciate surrounding comforts and embellishments. The use of these materials is also indicative of a dynamic neonatal personhood: personhood is enacted collaboratively through familial utilisation of these material objects. However, it is simultaneously individualised through personal name cards and other materials attributed to a single baby, constructing 'the individual'.

As mentioned previously, the NICU's "naming fairy" continuously created name cards for each infant on the unit. These name cards were affixed to the end of each incubator, and were clear identifiers of 'who's who'. I was told by a nurse that these name cards are important as they help to make the environment "less *sterile*". By this, the nurse is not referring to hygiene, but sociability. In contrast to the green patient cards affixed to the side of the incubators, which also communicate gestation, birthweight, and other factors deemed clinically important, the name cards affixed to the end of the incubator are fun and colourful. The text is generated in bright bubble letters and laminated so it can still be kept clean. The use of these name cards

was appreciated by parents. I was told that these were one way that the incubators, and their tiny occupant, could be personalised specific to the perceived identity of the infant.

The use of material occupied an interesting position in City NICU – caught at the nexus of its function as an ICU and a nursery. Parents expressed their desire to personalise the bedspaces and to make them feel "more at home" with material objects. Due to sterile protocol, any 'comfort objects' placed in the incubator needed to first be placed in a plastic specimen bag. When showing me the objects surrounding the incubators, parents always spoke using possessives: "this charm is Joel's" or "these are Rongomai's books". While this not only indicates the ways in which parents assign a particular type of agency to their infants (in their ability to "have" or "own" objects), it also illustrates the role of material objects as extra-corporeal markers of personhood. Extending beyond the physical body of the infant, personhood is relationally performed via objects understood to be of significance to the family and to the infant. These materialities of personhood not only constitute that of the infant, but also that of the parents. Through the process of giving a material object to the infant, parents co-construct a relational personhood between parent and infant that is contingent on that social engagement. The personhood of the parent is reinforced through the material articulations of infant personhood.

Layne (2000; 2003), Landzelius (2003), and Han (2013) have each extensively explored the role of material objects when discussing personhood and the foetus or infant. Layne details the most explicit link between personhood and material objects in her discussion of pregnancy loss:

> "Through the buying, giving, and preserving of things, women and their social networks actively construct their babies-to-be and would-have-been babies as 'real babies' and themselves as 'real mothers', worthy of the social recognition this role entails." (Layne 1996, 321).

For Layne, material objects frequented in narrative accounts of pregnancy and infant loss as markers of (potential and/or precarious) personhood. The further along in gestation the death occurred, the more frequent were mentions of material objects. Layne highlighted the role of clothing in narratives of pregnancy and infant loss. She drew on an established literature that indicated "clothing as a marker of humanness, of personhood" (Layne 2000, 327). Clothes are an example of 'baby things' which are collected during pregnancy in preparation for the impending arrival. However, these are also used as remembrance objects after death. The

preservation of clothing as a remembrance object, or the purchasing of new clothes in memory of the deceased, is again indicative of a type of materiality of personhood. Yet in City NICU, I observed the materiality of personhood as mutual and co-constituted between that of the parents and infant, rather than a linear affording of personhood from parent to infant via an object. I saw the use of crystals, sacred stones, and other objects used as a way of negotiating infant personhood thorough the personhood of the parent.

It was the charms and stones hanging from Joel's incubator which drew me over to his bedspace. There was one necklace with charms, and two others with stones that I would later learn were sacred. After going into labour at 26 weeks gestation, Ann-Marie knew her boy would need to stay in a NICU roughly two hours away from her rural town, husband, and teenage daughter. Despite the physical distance, this family used the necklaces to stay close. Ann-Marie told me that each of the three necklaces belong to her husband, daughter, and herself. She picked up the necklace hanging in the centre, between the other two. "This one is mine" she said. I saw a purple amethyst at the end of a worn black rope. "I wear it every few days to charge it back up, then when its back, its giving a bit of my energy and stuff to him". Ann-Marie went on to explain how her husband and daughter do the same with their necklaces in order to give parts of themselves to Joel. "It makes them feel useful" she said. The exchange of necklaces not only provisioned Joel's personhood through the energy of his family, but also reinforced that of his family through the mediation of their identities both in relation to Joel and individually.

From Researcher to Researched

Moving through the unit, I was reminded of the concept of liminality taught early on in cultural anthropology undergraduate studies. The space itself, a nursery-ICU hybrid, was caught "betwixt and between" (Turner 1970) its dual function as lifesaving and nurturing. It was a liminal space for liminal people, myself included. A day of fieldwork on the unit always began with an intense hand wash. Coming in through the intercom-controlled glass doors, I was met with the three sinks and associated procedures of sterility and purification put in place to protect the babies from infection. Every day I headed straight to a sink to wash my hands for two minutes. I dried my hands vigorously with paper towels (probably more than needed). The last step, known as "gelling", involved using a potent and somewhat noxious hospital-grade hand sanitiser. This routine of "scrubbing and gelling" was an integral component of my initial orientation to the unit. A nurse explained the importance of undertaking this practice and how to do so. After only a few uses of the strong gel, I understood why some staff religiously carried,

in their scrub pocket, a travel sized moisturizer in an attempt to avoid the inevitable dry hands on continual use. Similar to the fieldwork experience of Landzelius, the "scrubbing and gelling" ritual was transformative (not only for the bacteria that resided on my hands). The practice of washing and applying sanitiser upon entrance, while serving a distinct antibacterial purpose, also marked my own visible metamorphosis into a "researcher collecting data" from "just Zoe".

Even after scrubbing and gelling I never really lost my own liminal status on the unit. When I walked down the long U-shaped hallway, with its adjacent nurseries, fishbowl panopticon, and staff hallways, I was simultaneously the *researcher* and the *researched*. Unitll now, I have written little on my unique insider status outside of the interludes which break up this thesis. However, in discussing space, I am confronted with the fact that how I moved through the space as a researcher was heavily shaped by my dual identity as a researcher straddling the boundary of an insider and outsider. While I am not, and was never, a parent of a premature infant, nor a member of NICU staff, I was previously a NICU patient.

As I mentioned in the opening of this thesis, I like to think that I began fieldwork in the womb. My prematurity is something written on my body, in the way I have moved through the world, and in how I have been supported and engaged with by others. It has guided me down this path of study, and lead me back to the space of my origin. For anthropologist Phillipe Bourdieu (2003), participant observation conventionally involves "[immersion] in a foreign social universe so as to observe an activity, a ritual, or a ceremony while, ideally, taking part in it." (2003, 281). One of the primary challenges associated with such method, he writes, is navigating the dual role of participant and observer. However, for those undertaking participant observation in a clinical setting, these dual roles of participant and observer take on a different meaning due to restrictions placed on active participation in clinical practices. For instance, my lack of any medical training meant I was unable to participate alongside nurses in their work. Many anthropologists have written further of other challenges involved in conducting ethnographic research in the hospital and/or clinical setting (Inhorn 2004; van der Geest and Finkler 2004; Kaufman 2006; Long, Hunter, and van der Geest 2008). Such reflections were invaluable in preparing me for some of the challenges I eventually faced as a participant-observer at City NICU. These discussions went beyond the mere logistical challenges of research methods, and forced me to think deeply about how I would represent the space in scholarship.

Medical anthropologist Sjaak van der Geest and colleagues have written extensively on the methodological and ethical challenges of conducting anthropological research in the hospital setting (van der Geest and Sarkodie 1998; van der Geest 1989; 2003; van der Geest and Finkler 2004). In particular, van der Geest highlighted how tensions in the politics of representation restrict what is able to be written in ethnography for fear of censorship by the hospital institution. Along a similar vein, Inhorn (2004) discussed how the social privatization of biomedicine moderates a researcher's ability to move through medical spaces, especially when these spaces are considered sensitive or precarious.

Unlike the barriers to hospital based research faced by Inhorn and van der Geest in access to, and censorship by, medical institutions, my ability to move through the NICU space was much less restricted. However, I suspect this was, in part, due to my status as a grown physical embodiment of successful neonatal care. During the consultation period with nursing management, senior nursing staff expressed excitement at the prospect of my presence at City NICU, as both a researcher and as a "graduate" of the neonatal system. Many also stated that my presence in the nurseries may be of benefit to them and their work. They explained that parents would able be to see and talk with an adult '26 weeker' who went through similar challenges and treatments as their infant on the unit. Nurses emphasized how this could put parents at ease, and give them hope for their own situation. I was pre-emptively framed as a "success story" of the NICU and neonatal work. While this afforded me the status of a unique type of insider, I also faced challenges to conducting research in the biomedical sphere as neither a staff member, parent, or current patient.[32]

I distinctly remember my 'gatekeeping' moment.[33] I was instructed by the DHB ethics group to attend one of the regular meetings for senior staff nurses. This meeting would allow me to explain my proposed research, answer any questions, and ultimately gain their approval to insert myself into their space of work. I spoke to a roundtable of approximately 15 female nurses about my proposed research. Much of the meeting involved descriptions and

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[32] As an ex-patient, I experienced a strange type of collegiality with staff which presented benefits. For instance, I was 'passed around' by nurses who wanted to hear my story and participate in my research. Yet at the same time, this also required an additional degree of emotional labour whereby I was frequently prompted to share my story and how my prematurity affects me today. In addition, as a researcher in the social sciences, I was sometimes approached with a degree of skepticism, and left to explain the value of anthropological research. I still was, very much, an outsider in the NICU. I was unfamiliar with most of the language and protocols which guided staff and parents in their daily activities. I didn't quite fit in with the staff, nor with the parents.

[33] The 'gatekeeping moment(s)' is an important phase in ethnographic research whereby the researcher is granted entry and/or approval to the field by an interlocutor.

explanations of anthropological research. I consistently reinforced that I was interested in the sociocultural aspects of day-to-day NICU life, rather than proving a scientific hypothesis. I followed by explaining why anthropological studies are still useful even though they "cannot be replicated in a lab", as questioned by one nurse. These explanations were a central part of my rapport building explanatory repertoire throughout fieldwork. From my vantage point at the head of the roundtable, I was met with encouraging smiles and kind warm faces as I went through introducing my research. But it was when I explained my unique position within the research that the warmth and encouragement in the room deepened palpably. I passed around photos of myself in the neonatal unit. Nurses fawned over these photos with excitement and discussed them in great detail: "Oh wow is that nurse Jenny in the background?" or "You were a fat baby!" Again, this snapshot illustrates the degree to which staff often directed our conversations back to my own personal journey. In sharing how I moved through the neonatal space, others seemed more inclined to take me along with them as they moved through the same space. Obviously, I was granted permission, and the gates were opened.

City NICU was quite the multisensory experience. In the short walk from the sinks to the fishbowl I experienced a microcosm of smells and sounds which permeated the entirety of the space. The cruel combination of disinfectant and antibiotics made for a pungent odour which stuck to my clothes and skin, much like a strong household cleaner. The pervasiveness of this smell prompted my swift adoption of a post-fieldwork ritual everyday: a long hot shower with scented body wash and fresh clothes to finish. Nevertheless, a walk down the hallway illuminated why the unit smelled this way. It was a medical space. Space, sounds and smells were all optimized to suit the purpose of medical care. For instance, I only once came across a nurse who smelled strongly of perfume. Wherever she walked, a the smell of her perfume followed. Within this space, smell evoked significant emotions for me, such as fear, sadness, and hope. Five months following the completion of on-unit participant observation, I returned to conduct a few final interviews with staff. Moments after entering the unit through the glass double doors, I was hit by the unit's distinct scent. This was closely followed by a feeling of emotional discomfort. The smell elicited the awkward, scary, uncomfortable, and gloomy moments I experienced sporadically during participant observation onsite. I was reminded of the intensity to which my research, and the memory of it, is embodied, beyond the simple fact that prematurity is physically written on to my body in the scars of intravenous lines and chest drains on my arms, legs, and ribcage.

As mentioned in chapter one, the little baby rooms housed the smallest and some of the sickest infants on the unit - usually those born prior to 28 weeks gestation. The little baby nursery was lit solely by two long fluorescent lights which cast an artificial glow onto the blue linoleum floors. A small square skylight sat in the centre of the ceiling with remote controlled blackout blinds often kept shut. The centrally-controlled air was warm yet dehydrating. Staff maintained the room to its own type of built-in homeostasis, the maintenance of which was key to the wellbeing of the infants. Staff exert control over all environmental factors, right down to the surveillance of noise. A small black screen containing even smaller LED bulbs monitored the level of noise enclosed in the nursery. The green LED lights formed the outline of a stylized ear, that staff and parents referred to as "The Ear". If the noise in the nursery passed a certain decibel threshold, a yellow warning outline of the ear illuminated. If the noise increased further, a red outline illuminated. Even so, rather than acting as a centrally-controlled mode of surveillance governed by management staff, The Ear was more a mode of immediate self-surveillance for those within the room and an externalisation of staff behaviours. However, given staff needed to physically look at The Ear to ascertain the safety of the noise level, the red warning outline often went unnoticed. Toward the end of my fieldwork, someone turned The Ear off completely. Staff clearly prioritised the maintenance of some environmental conditions over others: temperature took primacy over noise; sterility over temperature. Such factors aimed at prompting ideal outcomes for infants, also fostered a uniquely liminal space for parents moving through the unit.

From Liminal Spaces to Liminal Parents

Scholars have noted the almost *chronic* liminality present in NICUs: from the "maybe lives" of sick infants, to "maybe parents" (Navne, Svendsen, and Gammeltoft 2018). Many of the patients in the neonatal space are in-between foetus and newborn. For instance, those born at 23 weeks occupy a unique space whereby they would not survive without intensive medical attention to maintain the most basic of bodily functions. They still would normally require around 17 weeks of gestation to reach term. Yet, through the simple act of being born and resuscitated by doctors, kept alive by a multitude of medical technologies, the foetus is now understood as an actualised person – albeit a strange one. This liminal neonatal personhood heavily contributes both to the liminality of the space and how that related to the liminal personhood of the parents who moved through it.

A new arrival in the little baby room occurred every day or so. The sicker arrivals were easiest to identify from afar: they were placed on the right side of the room with the built-in life support

machines; their incubators were often lined with drops of condensation; usually ventilated; and some needed a one-on-one nurse. Molly was both small and sick, and the first *ventilated* baby I met while stationed in the little baby room. The periodic hiss of the ventilator was a constant reminder of her fragility. Ventilators (unlike CPAP) were often used when a baby did not have a sufficient breathing reflex.[34] When I worked alongside any ventilated infant, the sound of the ventilator dominated the auditory environment. Born only a day prior, at 26 weeks gestation, Molly was the newest baby in the nursery at the time. A chest drain protruded from between two ribs on her left side, and steri-strips covered the incision from a prior drain on her right. "Someone has decorated her" nurse Emily told me. Looking closer, I noticed the "decoration": a nurse had arranged the steri-strips on her right side to form the shape of a small star. The composition of steri-strips performed their medical function yet also reinforced an aesthetic of the nursery-ICU hybrid that was the NICU.

I didn't meet Abby, Molly's mum, for an interview until about 8 weeks later. We met for coffee at the hospital café. Over coffee, I learnt that Molly was recently been readmitted to City NICU after spending a week at a regional step-down nursery, a Special Care Baby Unit (SCBU) closer to home. SCBUs provide care to infants who require a lower level of medical intervention than NICUs. These include infants born premature from 32 weeks gestation, infants with feeding problems, or for infants transitioning from a NICU to home . During her short stay in a SCBU, Molly stopped digesting her food so was brought back to NICU to receive total parenteral nutrition (TPN), an intravenous concoction, through a central line. As I finished the dregs of coffee, I spoke to Abby about her experience leaving City NICU for the SCBU, and then returning back again:

> *"It's like moving from a five star hotel (NICU), to a two star hotel (SCBU)"*
>
> *(Abby)*

It is worth noting that such metaphors and similes were frequent in many discussions with parents. These drew heavily on cultural ideas of wealth. The City NICU was referred to as "The Baby-Hilton", making reference to a chain of high end hotels, and "the most expensive baby-

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[34] CPAP works by keeping the air passages and lungs open while delivering air with a preset concentration of oxygen (ranging from high oxygen concentration down to 'room air' of approximately 20 percent oxygen concentration). Mechanical ventilation pushes air (of a preset concentration) into the lungs through a tube in the trachea (an endotracheal 'ET' tube). It is typically used if the infant does not breathe "spontaneously". These also can be programmed to both breathe for the baby, or supplement the spontaneous respiratory effort that the baby is already making on their own (Newborn Services Clinical Practice Committee 2019).

sitting service you'll ever get". These statements often came from parents telling me how they dealt with leaving their baby at the end of the day. By framing the unit as a high-end hotel or fancy baby-sitting service, parents made fun of themselves for how upset they would be leaving the unit at the end of the day:

> *"I cried a lot the day we got home after I was discharged. Cause I went home without my baby. I know it's the Baby-Hilton and they're in good hands, but it was hard."*
>
> *(Claire)*

Over a second coffee, Abby and I talked further about Molly's first few days at City NICU after birth, and how the physical space made her feel as a new parent. She told me that this space was really something you cannot prepare for, but something learned onsite. In this manner, it is lived experience and embodiment which made someone familiar with the environment.

> *"When you get in there, it's like a whole completely different world. It's like, I'd read about it, but I didn't think it was actually like this... I just remember like all these like lines and needles and everything in her, it was like overwhelming."*
>
> *(Abby)*

For many parents on the unit, the built environment communicated a bifurcation of care in its dual function as both a nursery and an ICU. The unit took on a distinctly "homely" yet "clinical" feel, as many participants described. Wall stickers of cartoon animals stuck adjacent to posters warning about infant pressure sores from consistent CPAP usage, and colourful soft toys were placed in medical specimen bags before resting inside an incubator. This textured spatial organization may thus offer parents refuge during a time of prolonged vulnerability in a very medical space:

> *"It's like this kind of alien environment. It's not normal, it's not home. But, I felt really safe, and I felt I could be the mum I wanted to be to the boys."*
>
> *(Anna)*

For Anna, mum of twin boys born at 33 weeks gestation, the "safety" of the neonatal space facilitated her role as a mother to her babies. While clearly functioning as a "medical facility", the unit was simultaneously a space wherein domesticity was foregrounded in a largely public and clinical environment. On many occasions, I met with parents in the unit's family room. This was a room slightly removed from the medical nurseries, and a designated space for family

to congregate while visiting the unit. An assortment of children's books and plastic toys often littered the floor, while dog-eared magazines rested in piles on rows of waiting-room chairs. A small square television was permanently mounted in the back left corner of the room. When unoccupied, I informally met with parents who either wanted a break from chatting at the bedside, or who were waiting to do their infant's "cares"[35].

The family room was one place where the noises of the machines in the unit didn't quite reach. It was a haven from the beeps, alarms, and mechanical hums of the nurseries. This was a space where the needs of the family were prioritised. For a space where quiet was valued, the unit closely relied on noise. Buzzes and alarms were used daily as means for communicating the wellbeing of both babies and machines. Various probes attached to infants monitored key bodily functions such as heart-rate, level of oxygen in the blood, respiratory rate, and sometimes blood pressure. If these values moved out of a predetermined set range, an alarm would sound, and at a different pitch depending on severity of measured values. The lower pitched "orange" alarms were frequent, if not, sometimes constant. It was the higher pitched "red" alarms which usually communicated to nurses that action was needed. However, for parents, and myself in the early stages, all alarms prompted a call for action. For Abby, this extreme vigilance to such noises subsided with time and experience:

> *A: When I first got in here, they used to tell me to just ignore the beeping. Just look at your baby and if she's got colour in her face, and she's breathing, then she's fine. Don't worry about what that is saying. It's just the noise I think that makes you panic. And so now when I see people panic I'm just like "No relax".*
>
> *ZP: Oh yeah like when I first started observation I'd freak out when just the orange beeps would go off.*
>
> *A: Yeah I did the same. I used to get really upset cause no one would run over.*
>
> *ZP: And even when its red it's still like...just walk over... have a look.*
>
> *A: Yeah I've learnt to ignore the beeps and everything now.*

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[35] "Doing cares" was a phrase used to describe the practice of undertaking certain tasks to do with the infant that needed completion on a regular basis. Every 6 to 12 hours (depending on the infant's age), parents or nursing staff "did the cares". This typically involved wiping the infant's face with a gauze squares and saline, taking their temperature under the armpit, transferring the blood oxygen probe to a different limb (to reduce the risk of pressure sores), and changing the nappy. If an infant was on CPAP, "cares" also involved switching between two different types of masks, called "the mask" and/or "prongs".

We all came to learn that a loud beep is not always a bad thing. These noises do not necessarily mean that an infant is having a health crisis. For instance, the sensor might be in the wrong spot, raising alert, or the infant might be wriggling a lot and causing the sensor to interpret the movement as an increase in heartrate. However, for those newly initiated into NICU life, such noises still prompted emotions, such as worry or reassurance. The prospect of having an infant's vital signs monitored and represented by a visible and audible display, was for some parents, indicative of safety. The heavy monitoring of an infant's bodily functions reinforced the NICU as a space of bodily surveillance: both of the infant, the staff, and the parents.

In stark contrast, for a full term healthy baby, rooming-in with the mother at City Hospital antenatal ward was the norm. As I mentioned earlier, my experience meeting a new family member for the first time contrasted with how family might meet a new baby on the NICU. In exchange for intensive medical treatment of their newborn, parents forfeited any privacy when moving through the unit. In the little baby nursery, approximately 5 meters separated one incubator from the next which allowed enough room to move safely between bedspaces but also to see and hear the comings and goings of another. Of course, this spatial arrangement served the distinct purpose of enhancing visibility for staff: to check babies, watch monitors, and to supervise visitors.

The lack of privacy was a common complaint for parents who I spoke to both at City NICU and across New Zealand.[36] For Maria, this limited privacy was a significant barrier to moving through the space with ease, and in how she saw herself as a mother in the space. I spoke to Maria in the evening on Skype, where she shared her story of having a baby at 34 weeks gestation. Her baby spent 6 weeks at a NICU in the South Island. The medicalized nature of the unit kept her from mothering her child the way she wanted. The physical space challenged how Maria could fulfil elements of her identity. She found the lack of privacy disturbing:

> *"The whole environment is so medicalized. Like, how can you have any kind of bonding stuff with the baby when there are so many people around?"*
>
> *(Maria)*

For Maria, and many others, this lack of privacy was arguably at its peak during staff rounds in many units across the country. At her unit in the South Island, Maria tells me about the ease at which you can hear the doctors talk about other babies' conditions: "Every parent knows

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[36] This desire for privacy is demonstrative of the cultural valuation of the private realm, and domesticity, as key features of new motherhood.

everything about the other children in the room". For Jo, the mother of three children who all had a stay in City NICU, this was also the case:

> *You're exposed to a lot of things prior to other people's discharge. Its where CYFs[37] meetings happen sometimes, so there might be a social worker who'll come in and talk to one of the nurses about a baby, and you can't go anywhere, and you're not being nosey, but you can't not hear what they're saying. (Jo)*

I often observed these staff rounds at City NICU. Much like many parents told me, it was difficult not to avoid hearing what was being said about each baby. Some doctors were really loud. Their voices could be heard on the other side of the nursery. And while others were more soft-spoken, their voices still travelled. I am thus not surprised that parents often garnered such an in-depth knowledge of babies in adjacent bedspaces. Space, in this sense, was open and unrestricted. Yet as will be shown in subsequent chapters, the NICU space was also one of surveillance and monitoring of the infants, parents, and staff.

Conclusions

The physical space of the NICU and the objects within it shaped both how parents enacted the personhood of infants as well as their own unique articulations of their role as liminal parents and persons in the space. This chapter highlighted how personhood was enacted and negotiated beyond the body through spatial and material means. Premature infants were subject to the dual function of the space, as highlighted in the simultaneous use of comfort objects and medical technologies. Furthermore, various objects were used not only as material manifestations of infant personhood, but also conduits and artefacts of parental identities and roles. Multiple personhoods were therefore relationally negotiated extra-corporeally. "Producing persons" is social (Kaufman & Morgan 2005, 320) in the ways in which relationships perform and enact dynamic ideas of personhood. But there is also a unique materiality and spatiality of personhood, which is visible in how certain things were mobilised from and within these relations. This too, extends beyond the infant themselves in that the objects not only communicate ideas of infant personhood, but ideas of parenthood, identities, and sensibilities. These materialities also make visible the tensions between multiple personhoods. It is simultaneously distributed through and within certain objects (Gell 1998), yet there is a

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[37] CYFs refers to Child, Youth, and Family. This was the government agency which removed children from their homes if determined unsafe. This organisation became 'Oranga Tamariki – the Ministry for Children' with the change in government in 2017.

Latourian complexity in whether the materialities distribute this in and of themselves, or as extensions of human actors in the space. In the NICU, the material dimensions revealed the very acute and palpable ways in which personhood was constituted, and brought into view, as a multiplicity of tensions and negotiations beyond infanthood and parenthood.

Chapter 4: Persons in Time

Time passed both swiftly and slowly as I spent weeks seated on a hard stool nestled in the little baby room. On some days, every minute felt like an hour. My time was occupied noting down what would become the mundane goings-on in the intensive care nursery: giving feeds; doing "cares"; changing lines; suctioning tubes. I often became drowsy with the heat, dim lights, and monotony. But, there were also moments where time sped up. Yet, it never looked on the surface as if there was a loss of control. During difficult intubations or central line insertions, staff moved fast yet methodical in their interactions.

Time sped up whenever the emergency bell was hit. I saw this happen three times for Jessie. I had just arrived on the unit when Jessie has a bradycardia – a slowing of the heartrate beyond a particular threshold. These were termed "events" or more colloquially as "doozies"[38] by staff. For instance, if a staff member returned from their break, and their charge had experienced a bradycardia, another nurse might exclaim "that baby had one hell of a doozy while you were on your break". These were a very common occurrence in the nurseries, usually occurring daily. In this instance, little Jessie's heartrate slowed to 50 beats per minute. This was well below an ideal heartrate for an infant of her size and gestation. A tiny mask was held firmly over her nose and mouth, like a miniature snorkel. Air with a high concentration of oxygen was pulsed through the mask with a periodic lift of the nurse's finger over an external valve. Despite this, Jessie's heartrate did not improve, and another nurse calmly pressed a red button on the wall beside Jessie's bedspace. Each bedspace had a clearly visible red button looming over the incubator – only to be pressed in moments where more help is needed. Once pressed, the entire unit was alerted to the event by the sound of an alarm, and the baby's cot number was shown on the display monitors mounted from various points across the unit. While this prompted staff members to jog down the hallway towards the affected nursery, it also caused some parents in the adjacent nursery to perk their heads up and look over. All the while, I was seated, tucked away, in the corner watching the atmosphere shift.

Approximately 10 seconds after the alert was sounded to the wider unit, members of the medical team swiftly entered the nursery to aid the bedside nurses in Jessie's care. Her incubator was moved away from the wall, and Jessie's body was moved horizontally so she spanned the width of the incubator. Her head was positioned perpendicular to the outside edge

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[38] Merriam-Webster (2019) defines a "doozy" as "an extraordinary one of its kind". On the NICU, the term is typically used to refer to a big/long apnoea or bradycardia.

of the portholes, and the side of the incubator was then unlatched. I counted seven individuals around the incubator, each with their own tasks and focus. An NNP[39] and consultant seemed to lead the group in tandem. The consultant, Phoebe, called for the resuscitation trolley, which was brought over from the hallway outside the nursery by a bedside nurse. This red trolley contained drugs and other necessary items used in managing actual or potential resuscitations. It was easy to notice how calm everyone was: while they moved fast and with purpose, they were composed and methodical.

A bedside nurse retrieved an endotracheal tube (ET) from the second drawer of the resuscitation trolley, and handed it to Laura, the NNP. Laura then inserted the tube down Jessie's trachea using a laryngoscope.[40] Phoebe ordered a chest and abdomen x-ray to look for any underlying causes of the prolonged bradycardia, such as infection or the dreaded NEC[41], and to confirm the correct placement of the ET tube. As the minutes passed, Jessie's heart rate returned to within a normal range, and staff gradually returned to their usual duties. Another bedside nurse later suggested that someone should probably call Jessie's mum to advise her that her baby has been re-intubated. Only five minutes after this call was made, Morgan, Jessie's mum came rushing into the nursery, with an expression of worry and frustration. In the days after Jessie's reintubation, I spoke to her parents about what had happened, and their plans for the coming weeks. They spoke of their hopes for extubation, weight gain, open-cots, and transfer to a local SCBU. Morgan spoke of Jessie's "setback" as simply one part of her girls' NICU stay. This was a part that they will "look back on" in the years to come, with relief that the experience was over.

This chapter will explore the ways in the which 'the future' was deployed by NICU parents as a heuristic tool for negotiating liminal personhood both during and after their infant's admission to the neonatal unit. Parents and staff also used various narratives of progress when speaking about prematurity. These narratives both challenge *and* affirm prior scholarly claims that a neonatal stay is neither linear nor temporally straightforward. For NICU parents and staff, the passage of time was enacted creatively when moving though the unit. The concept of time was reconceptualised to account for the nuances in caring for an unwell premature infant

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[39] A Neonatal Nurse Practitioner.

[40] A device inserted into the mouth to guide intubation.

[41] "NEC" was the acronym used to refer to necrotizing enterocolitis. This is a serious condition of the intestine which can affect premature babies. I observed both antibiotics and sometimes surgery used to treat the condition.

compared to a well infant born at term. Parents and staff took a careful approach to the concepts of time and progress when looking beyond the present, into the following days, weeks, months, and even years. This first considers how the concept of time has more generally been treated as an anthropological object of study, and how these treatments form a basis for how I frame the concept in reference to prematurity and personhood in the NICU.

Sociocultural Approaches to Time

> "Time - in an anthropological perspective - is a culturally specific construct that combines ways of structuring daily activities with broader meanings about the past, present, and future" (Ssorin-Chaikov 2017, 3)

The social sciences have long been concerned with the concept of time as an object of investigation and analysis. However, interrogations of the concept, by way of cross-cultural comparison, have been subject to much of the same epistemological shifts present within anthropology and beyond. For Alfred Gell (2001), anthropological treatments of the concept have historically lacked consistency as a coherent body of inquiry. From Kantian reflections that the existence of time passing is not contingent on the individual's *experience* of time passing, through to the resultant assumptions that time is a cultural universal, anthropologists of the 20th century attempted to explain and understand the concept. For both Durkheim and Mauss (Adam 2006, 119), time is best conceived as simultaneously shared and individual. For these scholars, this concept resembles a cultural universal, yet it is varied in cross-cultural representation, interpretation, and experience. For instance, in this vein, the passing of time occurs simultaneously in two cultural groups, yet the ways in which the passage is understood is culturally specific. Nevertheless, this essentialist approach to time still implicitly relies on the passing of time as a priori, natural, and taken for granted.

The analytical importance of time as intrinsic to other anthropological objects of study is also perhaps reflected in Adam's claim that "It is at the very root of what makes us human" by virtue of our relationship to death (Adam 2006, 119). For Adam, the universality and immutability of death and/or impermanence, reached through the passage of time, illustrates humanity's attempts to manipulate one apparent universal (time) in order to avoid another (death). Yet, again, this approach is situated within a more general existential assumption that the passage of time (or even the concept of death) is universal.

Moving beyond an anthropological preoccupation in determining the universality of time, Ssorin-Chaikov (2017) focuses on time *as multiple* rather than a single governing entity. His

framing of "temporal multiplicity" (2017, 6) circumvents a post-Enlightenment desire to locate the passage of time in a universal metaphysics. While these philosophical musings further attempt to define time, Ssorin-Chaikov extends this analysis in framing it in terms of the political economy. Tethering the concepts of time and progress with explorations of the political economy form much larger trends in cultural anthropology and sociology as wider critiques of the capitalist neoliberal present, and possible futures. In particular, the move toward a capitalist economy also shaped how time was reframed from cyclical to linear.[42]

Anthropologists have primarily been concerned with how time is socio-culturally enacted in daily practice, rather than locating the practice again at the level of the universal. Some refer to the ways in which people enact diverse ideas of time as "repertoires of timekeeping" (Gingrich, Ochs, and Swedlund 2002, S2). These are further described as the various ways in which the passage of time is made part of the lived reality: whether that be in writing, through physiology, via emotions, or through a combination of other means. These approaches illustrate a trend to move beyond universalising the passage and experience of time. Further explorations highlight that the use of time to denote accuracy or reliability means that repertoires of timekeeping, and their analyses are political and infer power and authority. For instance, missionary accounts of the passage of time were employed as a colonial tool in the erasure of indigenous histories in Papua New Guinea (Schieffelin 2002). Moreover, the political mobilisation of the 'past', 'present' and 'future', as well as studies of these mobilisations, may certainly be used in the reinforcement of structural oppression or more general social change.

At the level of the individual person (as opposed to the culture or community), anthropological engagements with time have more specifically focussed on the concept in reference to the physical body. Gingrich et al. (2002) suggest the physical body as yet another "repertoire of timekeeping" (2002, S3). Much like the visible effects of aging on the body such as wrinkles and grey hair generally act as markers of time passing, the visible progression of reproductive processes, such as pregnancy, labour, and birth, are similarly the subject of anthropological approaches to time and temporality. In her exploration of embryonic stem cell research, Svendsen (2011) introduced the importance of potentiality when discussing the disposal of these tissues. There exists a tension between narratives of "biographical life" and "biological

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[42] Various technological advances and ideological shifts have prompted a framing of time as a capitalist resource (Adam 2006). Further, the subsequent desire to optimise this resource has resulted in a decoupling of time from the cyclical circadian rhythm. Time is then linear (and continuous) in its coupling with capitalist production which forces labour to be undertaken beyond the circadian rhythm. Technologies such as the lightbulb have reinforced this decoupling, in allowing for factory shift work to occur at night.

resource" (417) in the language used by clinicians working with human embryos, both those considered defective *and* viable. Svendsen articulates the role of potentiality - a mobilisation of future potentials - in how value is transferred to the embryos by involved parties. Gammeltoft positioned "potentiality-for-Being" (2013, 170) as a key focus for studies of time and temporality. Focussing on experiences of pregnancy in Vietnam, Gammeltoft explored how orientations towards the future, mediated by the past, were integral to the framing of foetuses as "children-to-be" within a wider framework of potentiality (169). Both Gammeltoft and Svendsen make implicit links between the temporal concept of potentiality, and personhood. "Potentiality-for-Being" (Gammeltoft 2013, 170) and the temporality of "biographical life" (Svendsen 2011, 417) imply a personhood that is contingent on its temporal positioning. For premature infants on the NICU, personhood was not only shaped by how the infant's futures were articulated, but also how parents engaged with narrative of progression.

Alongside anthropological engagements, critical feminist and science and technology studies (STS) scholars have also long interrogated the unwavering focus on time and progression within normative Western pregnancy and birth paradigms. For Davis-Floyd (2004) the obstetric management of birth works to communicate a technocratic model of birth that categorises the pregnant body as defective and in constant need of medical management and intervention. Obstetrical practices, like intensive technological surveillance - such as close monitoring of the length and strength of contractions - reinforce biomedical discourses on what counts as a good or bad birth. The physiological process of labour itself transports the birthing woman into a naturally liminal situation, and that hospital procedures use the liminality to transmit the core values of American society to birthing women. For instance, the constant checking of cervical dilation as a marker of labour progress acts as a method of communicating to women if their pregnancy is proceeding normally by medical standards and within a timeframe deemed appropriate by medical staff. For Martin (2001), discussed previously, notions of appropriate time and progression are also deployed to communicate the superiority and cultural capital of biomedical knowledge and the necessity for childbirth to be managed in the biomedical sphere. After pregnancy and birth, both lay and medical conceptualisations of time and progress are drawn on in the more general neonatal sphere and the NICU more specifically.

There exists a small body of anthropological literature that explores narratives of time, temporality, and progress in the context of the neonatal intensive care unit. Feminist anthropologist Linda Layne (1996) uses a personal experience of her son's neonatal journey to

refute normative assumptions regarding narratives linear progression visible within the neonatal unit and beyond. For Layne "narratives of progress permeate our daily lives" are based off a technocratic imperative (1996, 629). The assumption that technological developments are indicative of, and a stimulant to, the so-called development of the human species pushes narratives of progress into daily vernacular. Layne's own experiences as a mother of a child in a NICU in the United States challenges narratives of linear progress as the determinate for ascribing personhood to premature babies. Rather than progressively, and in a linear fashion, 'achieving' personhood post-birth through meeting certain milestones, premature babies move back and forth between these categories as they navigate through various health crises. During the NICU stay of her son, born premature at 30 weeks gestation, Layne was confronted with many questions from friends: "How's the baby doing?" and "Is he getting better or worse?" These questions imply a desire and expectation for the baby to progress along a linear track - from admission to discharge, unwell to healthy, small to standard, and from premature to term. However, as introduced previously, Layne's encounter with the NICU during her son's admission was far from linear. A neonatal journey is a "rollercoaster" yet reaching the end is a "graduation" - implying some fluctuation between the expectations of linear progress and its absence (1996, 636, 635). Fluctuation in expectations were heavily visible in the City NICU. However, while deviations away from the elusive 'standard' were generally considered the norm, as I will later argue, these deviations were nevertheless *still* predominantly couched in a language denoting narratives of linear progress.

The works of Svendsen, Navne, and Gammeltoft (Navne, Svendsen, and Gammeltoft 2018; Svendsen 2015; Navne and Svendsen 2018) have also more generally featured discussions on narratives of time and temporality in the context of premature infants. In their exploration of neonatal viability in the Danish Welfare State, Navne and Svendsen (2018) argue for the "discrete authority of origin stories" in decision making. In identifying the authority placed on an infants' - or foetus' - biographical origin ("family biographies"), the authors implicitly highlight the role of pasts in determining futures. The imagining of certain futures are adjusted and negotiated as such. Specific configurations of the future are also structured by processes and actions of the present. For Svendsen et al. (2018), the grasp of a premature infant to a parent's finger is simultaneously indicative of some sort of agency, but also a glimpse into possible future where the infant survives.

I continue along this vein in my own exploration of the concept. I do not attempt to approach time with philosophical nuance. Rather, I am more concerned with how participants'

conceptions of time were creatively employed and reconfigured, at multiple levels, to both reify and challenge linearity, and in the enaction of 'the future' in the NICU space as an articulation of relational personhood. These articulations, multiple and often contradictory, were used to foster hope when it was needed most. Further, the NICU context nuances the theoretical relationship between time and personhood through the relational co-construction of certain futures along different trajectories.

The Progress Paradigm: Time and Linearity on the NICU

A variety of narrative tools were used by both parents and staff to understand and explain the infant's position in the NICU. These narratives were couched in a language of linear progress despite staff claims that linear progress was both troubling and irrelevant to the neonatal context. Progress was claimed as anti-linear yet often referred to using metaphors which imply a unified and direct path of neonatal progression and personhood. Notions of linearity and progress heavily structured life in the NICU and the management of infant personhood. Yet, these notions were contested in parent and staff imaginaries. Further, these contestations of linearity and progress were performed in a variety of ways, including nuanced framings of hope and the future which co-constructed certain types of imagined personhood.

A member of the medical staff once told me that a particular baby was "going to script". He was gaining weight, tolerating feeds, and requiring less and less oxygen with less pressure. He was close to discharge from the unit. This metaphor of following a script was reinforced during medical rounds where staff unanimously agreed "he was doing as he should". This type of language, implying that there existed a standard course, was also encountered by Layne (1996) during her NICU experience: in questioning the progress of her baby, Layne's friends assumed a rubric of how an infant in the neonatal unit should progress. In actuality, what seemed to count as "going to script" was actually a deviation away *from* the script. Many infants had "blips in the road" while in the NICU. "Blips" included infections, brain bleeds, increased oxygen requirements and even simply a single instance of reflux. Yet, while staff considered extremely premature infants to be very at risk for these events to the degree they were considered fairly normal occurrences, such events were still referred to as "blips", "downturns", and "spirals" on a longer and more complicated journey. A journey may have deviations, a rocky terrain, yet there was generally *still* an end goal that was a point to look for, to reach eventually, or treat like a goal post. A goal ranged from the "ultimate" discharge home, to smaller points such as wearing clothes, requiring less or no breathing support, and/or moving to a less acute nursery.

A few days after Jessie's "blip in the road", which I described in the opening of this chapter, I had a long discussion with her parents in their community funded accommodation[43] where they lived for the duration of their twins' NICU stay. We sat in the art room, watching their other two children do crafts. We sat on chairs crusted with glue, arms rested on a table littered with pipe cleaners and crayons. We had a catch up, and our first chat off the NICU since the girls were born. We talked of the twins' journey, including the ups and downs, progressions and regressions, the almost circular steps forward and backward. The use of a journey metaphor often structured how this family, like others, would tell me their stories. Their babies had "slow walks" up "steep hills", and "fast tumbles" down "valleys". Their infants took side-paths, alternative routes, extensions, required gatekeepers, and signposts. Although some indicated the time it would take to "finish the journey", others accepted that their journey would extend far beyond discharge:

> *"It's a journey. We were told that right from the beginning. (Morgan)*

> *"It was a long journey – even the following few years" (Taryn)*

> *"It's one step forward, two steps backward. I thought about that a lot, because that means you'll just go backwards. I thought that can't be right. But in a way, it was." (Amy)*

In the retelling of their stories, Morgan, mother of Jessie and Georgia, along with Amy and Tarryn, in separate interviews, spoke of a movement through the premature experience, either literally or figuratively like a *journey*. The use of the word "journey" not only conveys an extended length of time, but also carries unexpected challenges and the need for hard work. Such journeys were peppered with milestones which worked to reinforce the journey narrative and the idea of linear progress. Milestones were very important in the NICU. On the one hand, they marked the passage of time across preordained, and often, rather ambiguous boundaries. Yet they also signalled the possibility of a life beyond the NICU, where an infant is not a premature baby, rather simply, just a baby. While speaking language of linear progress, the use of milestones went beyond marking off the steps needed to reach discharge.

A variety of celebratory objects were used to communicate the passing of certain milestones to parents, staff, and other individuals near an infant's bedspace. "Infant milestones" were common parlance on the NICU and also communicated certain cultural markers of infant

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[43] Most urban NICUs across the county offer off-site accommodation for parents of infants (and children) admitted to the hospital, who reside beyond a certain catchment area. The accommodation is typically community funded.

personhood. However, the specific steps taken or needed to pass or succeed a particular milestone were ambiguous in nature. For instance, the relationship between weight and progress was predominantly celebrated as a milestone.[44] On City NICU, there was a tradition for parents to celebrate their baby reaching one kilogram in weight. Celebrations involved the use of objects and practices such as cakes, photoshoots, milestone cards, and posts on social media. Weight gain was celebrated, in part, because it was part of what allowed an infant to move into an open cot, and to wear their own clothes. However, the prospect of weight gain was nuanced for staff in that it was not necessarily a positive correlate of infant "progression". A quick perusal of my own medical records was indicative of this: my own jumps in weight gain were initially treated with suspicion by nurses and doctors. The notes questioned whether I was gaining the *type* of weight desired, or whether I was simply retained too much fluid thus increasing my weight and giving me the appearance of being "chubby". Even so, an increase in weight remained still the most significant indicator of progress in the minds of parents with whom I talked. Increases in weight felt to them like easy indicators of progress as they were easily quantifiable and visible.

The "Milestone Cards" listed above were widely used both in the unit and well beyond. Infant milestone cards were available for purchase and instructions on how to make your own were found across social media platforms such as Pinterest and Instagram. For between 20 - 50 NZD, parents can purchase a set of, usually plastic, "Milestone Cards". Each card features a particular infant milestone that the designer has deemed important: these include milestones like "My First Christmas"; "I'm one month old"; "First solids"; and even "My first tooth". A fairly common trend on social media is for parents to upload pictures posing their infant with the relevant milestone card. The proliferation of these milestone cards highlights the normative pressure placed on infants to follow a particular model of infant development. Deviations from this model therefore infer a pathologisation of the infant and even their family. Infants are probably rather unaware of the pressures placed on them, and their parents, through these milestone cards. The use of milestone cards in City NICU that specifically catered to the unique needs of premature infants were a popular answer to the normative milestone cards discussed above. These included phrases such as "ET tube removed"; "Moved to open cot"; "First cuddle with mum"; and "Reached 1kg". Milestones used on these cards work to simplify the complex nature of premature infant development into singular, simple, lay markers of progress for a

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[44] The relationship between infant weight and personhood is also important. Alongside gestation, birth weight or foetal weight was sometimes used to determine if resuscitation would occur.

non-medical audience. These cards also highlight how the temporal dimensions of hope were mobilised as orientations towards unstable futures. I noticed a set of cards such as these on a workspace along the edge of nursery:

I was told by one bedside nurse that another group of nurses was in the process of organising sets of these cards to be made available in each nursery for parents' use. However, again, this nurse emphasised the danger of cards such as these, even when their content is deemed specific to the NICU. In allowing parents to publicly celebrate the milestone reached by their infant, other parents may become disheartened at the then-perceived lack of progress of their own infant who may not have reached such milestone. As Demi's mum Brooke tells me, "I know
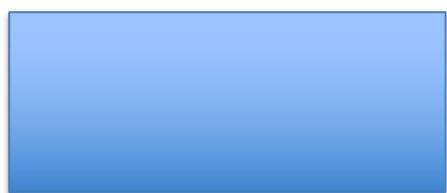
Figure 2: Milestone Cards at City NICU

it's not a race, but you still really can't help but compare." The passing of a milestone was generally something to be envied. It was a goalpost that provided the illusion of progress and stability, and was often posted on social media. I observed some participants use the milestone cards in taking a photo of their infant to post on Facebook.[45] This speaks to the degree to which the neoliberal ideology of intensive motherhood has shaped a type of competitiveness between mothers over their infant's characteristics. The infant's progress (or lack thereof) was a site of competition, pride, and jealousy, which was further spread through social media outlets.[46]

The constant threat of unpredictability and volatility in City NICU ruptured the illusion of stability indicated in commemorations of reaching milestones and the language of linearity in the development of both infant personhood and kin relations. For some participants, the formation of a cohesive family unit was contingent on the infant "reaching" or "getting to" discharge from the NICU. While also communicating the ways in which participants understood their family composition, this also illustrated the role of unpredictability in (un)structuring the NICU experience for those involved. Parents frequently used the term

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[45] This is a common trend on various social media platforms regardless of prematurity. Various Pinterest boards provide "inspiration" to parents wishing to produce carefully crafted milestone photographs.

[46] Valtchanov, Parry & Glover (2016) explored how intensive motherhood ideologies have been reinforced through the use of some social media platforms that facilitate competition between mothers. In sharing their experiences, mothers were subject to each other's judgements over parenting styles and habits.

"limbo" in describing the time spent in the NICU. Family units were in a continuous state of unpredictability in the weeks and months their infants spent admitted to the unit. The use of the word "limbo" was particularly interesting given the religious origin and its use in a space where infants die. Until 2007, Catholic theologians postulated that the soul of an infant, if deceased prior to baptism, would reside for eternity in a state of limbo and unable to reach heaven as not absolved of original sin. In 2007, Pope Benedict XVI muted the concept of infant limbo within the Catholic doctrine (Fisher 2007).

The metaphor of limbo is probably the strongest conceptual opposition to narratives of linearity. In City NICU parents considered the "limbo" both a temporal and spatial descriptor of how they related to their babies and experienced the NICU space. The physical location of the NICU was considered a spatial locus of limbo. The space itself was isolated from the outside world. Other anthropological studies of the clinical realm have also explored the concept of limbo, particularly with regards to the medical management of reproductive processes. In Becker's (1994) explorations of experiences of infertility and continuity in the United States, the metaphor of limbo was utilised by participants. For those struggling though infertility, describing themselves in a state of limbo articulated the precious and unpredictable nature of their experience, as well as the potentiality of future children. Becker argued that the use of such metaphors mitigates the cultural risks posed when continuity is challenged.

The cultural value of the limbo metaphor is further reinforced in Ivry's (2009a) comparison of pregnancy between Japan and Israel. For Israeli mothers, the politicised nature of risk in pregnancy means that pregnant women are encouraged to view pregnancy and foetal personhood as uncertain or in limbo. The Israeli government advises women to think of the foetus as uncertain until which it can be determined to be a desired (and productive) member of Israeli society. Foetal personhood is thus contingent on physical and cognitive attributes. While, the NICU parents' use of the limbo metaphor was more self-imposed that in the Israeli context, it was still political. Staff openly affirmed a NICU parents' role "as a *parent*", or the baby "as a part of the family", yet parents communicated an uncertainty of these sentiments due to the very nature of how they were seen to be becoming parents. That is, by virtue of the context in which their child had been born, their status as parent, as family, or as kin, was unstable. For one mother to whom I spoke, she expressed confusion over "not feeling like a mother" despite the daily reminders from staff. She explained the bittersweet nature of staff and other parents referring to her as "mama" and "mum" when speaking about her infant. Simultaneously, the label didn't feel accurate, yet she knew it would "all fall into place" after

the infant was discharged: she was a 'mother in waiting' as she was unable to undertake the roles and duties that she felt would reinforce her identity as a "proper mother". This metaphor of limbo highlighted how time almost stood still on the neonatal unit, despite the pervasiveness of progress and linearity narratives. This further contributed to a contention over how such narratives were enacted by parents and staff through, often contradictory, performances and relational articulations of personhood(s).

Looking Forward: The Future as a Heuristic Tool

In an attempt to avoid fits of anxiety, many try to stay in the present, and not look too far into the future. Whether that be worrying about future financial status, if we'll ever get married, or worrying about job prospects, 'the future' is a continuous and impending threat of uncertainty. To remedy this, popular self-help movements emphasise a grounding in the present, taking every day as it comes, and not worrying too much about what the future may bring. Yet on the neonatal unit, 'the future' was simultaneously, and paradoxically, looked towards yet purposefully obscured. Interpretations of the future were structured by quality of life discussions which, in their nature, were assessments of the possible futures and infant personhood.

The future was brought in to the unit in a variety of ways, yet also purposefully hidden, including the use of posters, developmental care models, and in how staff spoke of my presence on the unit to parents. Perpendicular to the main U-shaped hallway that structured the NICU, there was a long hallway of spaces designed for use by NICU parents. One side was made up of a row of doors leading to small rooms parents could use overnight for "rooming-in" with their infant as a "dry-run" close to discharge. Opposite these rooms was a kitchenette, a bathroom, and family room with a television and tattered magazines. The walls were decorated with an array of coloured posters made by the parents of long discharged NICU infants. This corridor thus housed "the wall of success stories". Posters depicted photos of newborn infants, some premature, others not, but all look very unwell. Some showed the tiny fragile bodies of extremely premature babies in incubators, and others depicted larger "surgical babies" with breathing support and/or surgical incisions. Alongside the photos were printed paragraphs detailing information of the infant's NICU stay and "key facts" such as weight and gestation. All posters also showed photos of children in the months and years following the NICU admission: toddlers finger-painting, children on trampolines, and teenagers off to school. *This* was why these posters made up the "wall of success stories". The photos offered a possible

future to parents, a site of parental normalcy, where both infant and parental personhood(s) could be actualised.

I often found parents looking closely at these posters, reading the text and looking at the photos. One parent told me she often visited these posters when she was feeling worried or felt as if her boy wouldn't ever be discharged. These posters emphasise the temporality of hope as an artefact inherently tied to the concept of time and possible futures.[47] There was a clear absence of posters which did not serve the purpose of instilling hope in parents. There were no posters depicting an infant who passed away. There was a clear erasure of infant death from the "parents hallway". Although these posters brought in the future to the NICU, these were clearly intended to only bring a certain type of future to the parental imaginary. In this instance, neonatal medicine presented itself as reliable, efficacious, and as an authority over death.

Although the future was a focal point in the NICU, it was often obfuscated in the language used by staff. "Following to script" and "Taking it step by step" were phrases I heard frequently from both staff and parents on the neonatal unit. Such phrases simultaneously imply both a desire for linear progress and looking towards an endpoint, *and* an emphasis on the present as the focal point. Many infants who occupied the most acute nurseries were embodiments of the illogical *one step forward, two steps back* idiom implying slow and incremental but eventual progress structured by periodic regressions. From a mere 2 hours old, Jessie took these steps, forward and back, until her eventual discharge. In an environment where deviations away from standard, were considered completely normal, Jessie followed the normative. This language of linear progression was motivated by a desire to not look too far into the future: one parent told me she didn't want to "jinx it" by thinking about her baby's future. Doing so was risky as, although outcomes for premature infants are improving, a 'good' outcome could not be guaranteed in this instance. A day-by-day approach was far more manageable. This involved a focus on daily tasks and small milestones which kept parents grounded in the present. Yet, although this approach was encouraged by care providers, the medical care given was heavily structured by quality of life narratives that, in their nature, foregrounded predicted futures and desired types of personhood. For Jessie, staff made clinical decisions soon after birth, such as the prescription of more frequent brain ultrasounds, to continually manage her care in way that maintained staff predictions of quality of life at the forefront of her treatment.

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[47] The temporal and affective dimensions of hope have been discussed by Miyazaki and Swedberg (2017) and Gibson (2011).

Nurses frequently told me of the increased belief in neonatal nursing that the little things that NICU nurses do will influence the child's future. The conditions of later life, the type of person an infant would become, may be shaped by run-of-the-mill NICU practices, such as frequent heel pricks, and "nesting" the infant in blankets. Moreover, care practices existed beyond the parameters of the present, and worked far beyond the provision of immediate lifesaving treatment into prophylactic measures to manage concerns of the future. I encountered this feature early in my time on the NICU.

My heels were a topic of conversation among senior nurses during my first week on the unit. As a developmental model of neonatal care is presently en-vogue in the New Zealand neonatal context, the lifelong effects of NICU care on premature bodies are a new consideration for bedside nurses. Given newborns were historically thought to accrue the ability to feel pain with age (Chamberlain 1999), less critical attention has been paid to practices which might cause pain, such as the frequent practice of heel lancing. This practice was used daily at City NICU, and involved the use of a small trigger needle to draw capillary blood from the heel for testing. Nurses at city NICU asked me if I had sensitive heels due to heel lancing as a premature infant. The assumption was that continuous heel lancing might cause heel sensitivity during infant development and beyond. Interestingly, I actually required occupational and physical therapy as a child for precisely my heels: I walked on my tippy-toes, refusing to put my heels down, and I still do this if I'm not concentrating. For the nurses, my response thus proved their assumption and the growing body of clinical and developmental research which explores such long-term effects (Page 2004; Grunau 2013). Yet, my strange heels may also be completely unrelated to heel lancing. Simply, the knowledge that I was not a heel-walker was enough proof to legitimise their assumption. An awareness of experiences of pain in the neonatal period makes up a wider academic conversion exploring the importance of a developmental approach in caring for NICU infants. Inherently, this approach seeks to prioritise an avoidance of certain possible futures, in treating present conditions.

Alongside this model, the future was brought into the NICU though quality of life discussions and the unique concerns of both parents and staff pertaining to these conversations. As previously mentioned, the medical care of a premature infant was heavily structured by a desire to prioritise ideal outcomes and ultimately to ensure the development of particular types of persons. The day-by-day, step-by-step care was *still* future focused. These imagined futures were differentiated and unequally valued. On many occasions, parents expressed their fear of possible disability. However, the types of disability were valued differently:

"One of the biggest things for me, and probably [my husband] as well…is having babies born so early, it's not like a physical disability, that you can get through, it's the mental disabilities that we're really worried about." (Morgan)

"Of course, there's a little bit of worry in my mind…will there be any side effects? Is his brain going to be ok? Everything else seems ok at the moment. But., only time will tell." (Tracey)

There existed a clear hierarchy of bodily processes and possible futures. The 'mental' held precedence over the 'physical' as a marker of success. This was also clear when I spoke with participants of my own neonatal journey – which, as I mentioned earlier, was often of particular interest to many parents I met – as I too was inherently bringing the future, and my own personhood, to the NICU. Baby Georgia was born at the same gestation I was, weighing almost the same weight I did. I think this resonated with her mum: I embodied a possible future for Georgia. As a visibly fit and healthy individual, doing a PhD and fieldwork, it was assumed that I was not afflicted with the physical nor mental disabilities which were very often feared by parents.

Disability studies scholars have written extensively on wider socio-cultural attitudes towards disability and how different disabilities are differentiated in the public imaginary (e.g. Ginsburg and Rapp 2013). In a Western neoliberal context, these views are shaped by the capitalist imperative that a productive society is built by normative productive persons. Those which do not fall within this category hinder the political and economic development of the nation-state.

The binding of citizenship to the functioning of the physical body was further reflected in the liminal position of extremely premature infants as either potentially productive members of society or "drains on the system". The apparent assumption held by parents was that an individual with a physical disability or chronic illness would move through the world easier than one with an intellectual disability, or that the stigma associated with an intellectual disability would be more pervasive than that associated with a physical disability. The existence of a hierarchy within disability or disease is an example of the extent to which sociocultural assumptions can shape which type of future is deemed acceptable and which is not. Furthermore, this is equally reflective of *where* parents implicitly located personhood in the body. In City NICU arguably the most feared disability by parents was intellectual impairments or "being slow". Vision impairments, poor lung health, and/or small stature were less feared by parents when imagining their infant's future. I never specifically observed staff

making comments differentiating the value of different disabilities and/or sequalae of prematurity, yet parents were vocal in their expressions of fear over particular cognitive or intellectual disabilities. This illustrates the continued legacy of a cartesian (and Christian) hierarchy of the mind over the body whereby the mind is considered the location of human personhood. In this framework, the integrity of infant personhood is less challenged by differences in the "physical" comparing with differences in the "mental".

Beyond exploring the differential value of disabilities as underpinned by both a neoliberal prioritization of the productive body and the bodily location of personhood, the empirical work of disability studies scholars is useful in discerning why some parents are more afraid of one possible future over another. Canguilhem (1989) suggests the increased stigma toward intellectual and/or psychological impairments over those considered to be more "physical" or somatic, rests on an inability to securely locate an intellectual disability in the physical body. This inability is in comparison to the apparent ease in which we can locate a disability, such as chronic lung disease, in the physical body of an individual. Scholars have also explored how such differentiation manifests in the attitudes of medical professionals.[48]

Yet, some parents' imagined futures for their infants went beyond what was predicted by medical staff. During the last few weeks of my observation period, I sat with Maire at Rongomai's bedside. Rongomai just moved to a big baby room, after spending months in a little baby room in a critical condition and receiving intensive care. He was wearing his own clothes, along with a CPAP mask affixed over his nose. After weeks in an incubator, Rongomai was finally in an open cot. He could be touched and held by his mother with relative ease. The bubbling of his CPAP, and beeps of the surrounding monitors later made this interview very difficult to transcribe.[49] Despite the noise, the infant's bedspace was distinctly homely. Maire has taped pictures to the plastic rim of his cot and set a labelled box of Māori picture book on a tiny cotside table. Born at 24 weeks, Rongomai was one of the "longhaulers": he spent three

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[48] More recent studies, such as those on disease prestige, develop these ideas further yet in the context of medical professionals. Dag Album (2008) explored the degree to which those in the medical profession grant prestige to different illnesses and medical complaints. Using survey data, Album complied a rank list of 38 diseases from most to least prestigious, as regarded by doctors. For a senior doctor, the three diseases/medical complaints with the most prestige are squarely somatic: heart attack, leukaemia, and rupture of the spleen. With the exception of cirrhosis, AIDS, and arguably fibromyalgia, the 8 least prestigious diseases are more akin to what is normatively considered intellectual and/or psychological, such as cerebral palsy, common in extremely premature infants, depression, and anxiety. Diseases which do not rely on objective diagnostic testing – arguably more difficult to locate in the physical body – were generally less prestigious.

[49] Much as I was advised to never conduct an interview in a cafe with loud music, I would now advise others to avoid interviewing cotside in the NICU.

months in the little baby room before his transfer to a less acute nursery down the hall. During this time, Marie tells me she had many "chats" with the medical staff about Rongomai's prognosis and his predicted future:

"So, we had a meeting with [the doctor] about the possibility that he may have some sort of disability… cause of the bleeds and being extubated intubated extubated intubated…. the high chance of him having some disability. I don't think that he will. And I don't know if that's me being naïve. And through it all, like, I never really thought that he wouldn't make it. Like we were worried, but I had a gut feeling…A lot of the staff told me they didn't think he would survive." (Maire)

Maire illustrated a different way of approaching the future in the face of one predicted by medical staff. The future is one beyond the "pretty fucking crap" journey taken through the little baby nursery. Her confidence in the future was not one I encountered again during my fieldwork. In conversations with other parents, a worry and fear over the future, bookended by a desire to not think too much *about* the future, was almost universal. Maire and Rongomai's story adds further nuance to the complicated ways in which parents and staff spoke of the future.

Conclusions

In the NICU notions of future personhoods, as well as framings of linearity and progress, were complicated by how these were contested in parent and staff imaginaries. Unique performances of time and related concepts in the NICU serve as an example of how time is reframed and imagined across different circumstances to articulate diverse potentials of personhood. These reframings go beyond changes in "repertoires of timekeeping" (Gingrich et al. 2002, S3) as cultural measurements of movements of time and temporality. Rather, these are indicative of time-multiple: simultaneous and contradictory modes of approaching time, the future, and linearity in the context of neonatal care which all interact to produce differences in how infant personhood is constituted. These unique mobilisations of the future in the NICU resemble Gammeltoft's (2013) observation that such temporal orientations towards the future are one way in which differing beings and modes of being are actualised in the imaginaries of those involved. However, these "children-to-be" (169) embody a nuanced position as occupying a complex and dynamic personhood shaped by prematurity and moving between the cultural states of infant and foetal personhood. Enactments of the future centrally position the potentials of personhood for premature infants, as "children-to-be" (2013, 169) and "Potentialit[ies]-for-

Being" (2013, 170). But, as I illustrate, narratives of the future in the NICU, more importantly, articulate *diverse* potential personhoods for different babies which are stratified on the basis of cultural ideas of the body, and that are shaped by how diverse modes of being are valued differently by staff and parents. Framings of (potential and *potentially-diverse*) personhoods are altogether contingent on temporal positioning, especially in spaces of precarity, uncertainty, and fragility such as the NICU. In a state of medical emergency or high acuity, certain orientations towards the future may diverge so as to bring focus back to the present.

4

Interlude: From Old Vents to Bagged Lambs

So here I was: sitting cross-legged on my bed surrounded by my medical notes. I had just read through the documents detailing my Golden Hour – not just an hour, but quite a few, as it turned out. As I made my way through the notes, I learn that I never really took a massive cliff-dive as predicted. My condition was serious, but I gradually gained stability. I was kept ventilated for two weeks, using the machines I now know as rudimentary. These are the ones that cause barotrauma and volutrauma – types of trauma caused by sustained pressure and overstimulation in the lungs. Plainly put, these types of trauma are as a result of too much force used in mechanical ventilation over an extended period of time. "The old vents kind of pop little holes in the lungs" I was told by a bedside nurse, as she walks me through the new ventilators. I learn that these old ventilators are one reason why there is a generation of premature infants with very specific lung pathologies. As I flicked through the notes, I was already aware that my own lung problems were directly caused by my prematurity. But the notes further make these issues clear. Two sustained weeks of "lung popping" ventilation would probably do a bit of damage.

I am struck by the degree to which neonatology has made huge technological strides since my birth. Although I am so immensely grateful I was born in the decade I was, I wonder if maybe I would be better off still if I was born today? I'm sure my lungs would appreciate these new ventilators and other technologies. Perhaps the premature babes of today will be thinking the same thing in 20 years? As I write this, the world of biomedical research has turned its gaze toward the mechanical gestation of premature lambs.

Pinned above my workstation at university is a news article detailing quite possibly the biggest neonatal research endeavour this century. The article shows two colour photos, side by side, of lambs placed inside what can only really be described as plastic bags. In actual fact, these are artificial wombs, and the occupants are *premature* lambs. The lambs were intentionally delivered premature, placed in fluid filled bags, and connected to a breathing tube and intravenous lines to sustain life. The trial succeeded in keeping the lambs alive for 4 weeks – the planned length of time for human trial. In effect, the idea is that infants born at 23 or 24 weeks would spend four weeks growing and developing in this artificial womb,

before being 're-born' at 28 weeks gestation. This supposedly would give the infants a much higher chance of surviving to discharge.

Most days my gaze is drawn upwards to the pinned pictures of lambs in bags. Over four weeks, a 'before and after' picture shows a foetal lamb growing wool, getting fatter, and basically doubling in size. It's pretty crazy really. While the researchers may have great difficulty bringing human trials into actuality, the implications of this research are huge. I think of the tiny babies born at 23 on City NICU. Would their chances of survival, with or without disability, be increased with this technology? Beyond this, is there a possibility for a foetus at 20 weeks, or even earlier, to gestate via this technology? Could a foetus be gestated entirely from conception using this artificial womb? The possibilities spill far beyond this interlude.

Nevertheless, I keep this article above my workstation for two reasons: It forces me to keep asking questions: What does it mean to gestate or to carry a pregnancy? Who is a mother? What does this mean for the ethics of neonatology? It is also simply the weirdest and most fascinating neonatal research I have ever seen.

Chapter 5: Neonatal Work and Professional Negotiations

The field of neonatology is a young medical speciality in comparison to other areas of medicine. Many of the complex lifesaving treatments and practices employed by neonatal specialists were developed within the last century. Neonatal medicine as practiced at City NICU is a field whereby medical research and development was continuously at the forefront of bedside practice. The premature infant more generally has further been spotlighted as a new type of patient, a new realm of medical responsibility, and a locus for experiment and innovation. Through these avenues, staff were key actors in negotiating infant personhood through their professional relationships, practices, and knowledge systems. I explore this by examining some the professionalising practices of different types of neonatal work within a wider context of the role of research in the NICU. Furthermore, I argue that these professional differences equally shaped how personhood was negotiated by staff on the unit.

The Profession: A Very Brief History

In 1880, French obstetrician Etienne Tarnier developed one of the first iterations of the modern neonatal incubator (Baker 2000). Originally, this technology was modelled after a similar device used to incubate newborn chickens. Maintaining the conditions in these incubators was labour intensive, requiring nurses to change out the hot water frequently. Baker (2000) highlighted the ways in which the development of this technology destabilised the status quo of newborn care. With the care of newborns traditionally left to the mother, premature infants presented a new challenge, and forced the development of a new medical speciality and medical innovations such as Tarnier's incubator and mechanical ventilation. For Baker, the practice of early neonatal medicine before the introduction of mechanical ventilation can be compared to "the American frontier before the railroad" (Baker 2000, 321). Even following the development of ventilatory technologies in the mid to late 20th century, the ever prominent position of research at City NICU still gave the space a distinctly frontier-esque atmosphere. Experimental medicine and medical research were normalised in the NICU whereby practicing medical care and doing medical research effectively was inseparable. Care clearly continued to operate under a legacy of 'frontier' medicine. Nevertheless, despite the 'lawlessness' invoked by the frontier metaphor, neonatal work was structured by distinct modes of professionalisation which additionally shaped how staff enacted infant personhood. Further, beyond the precedence of research, neonatal care was shaped by how the work was understood and explained by those doing it. Prematurity was approached differently by doctors and nurses in daily practice and

responsibilities. Such professional differences shaped the day-to-day treatment of the premature infants as patients and persons.

For doctors in the 19th century, a premature infant was not necessarily one classified as being born too early – the term "grouped together all tiny newborns…suffering from a lack of energy or vitality" (Baker 2000, 321). Prior to the development of Tarnier's incubator, infants deemed at risk, premature or otherwise, were rarely subject to obstetric intervention or considered distinct patients. The infant was squarely under the responsibility and authority of the mother. However, as Baker (2000) argued, it was the invention of a rudimentary incubator that prompted an initial change in the locus of care and responsibility for premature infants. Nevertheless, a characterisation of the medical treatment given to premature infants as 'care' is ambiguous: the early incubators were effectively used as display cases to house premature infants at fairs and exhibitions. The combination of a tiny infant, and its "artificial mother" (the incubator) was a form of entertainment and festival attraction. In spite of this technological development survival rates for very early or small infants were still poor, as were the overall survival rates for infants of the time. In France, small medical wards were specifically developed for so-called "weaklings" equipped with early incubators and wet nurses. Again, mortality rates were significant. Baker (2000) estimated a mortality rate of over 75 percent for these early nurseries. Infection risk and a lack of adequate infant thermoregulation [50] eventually led to criticism of these new nurseries. Into the 20th century, premature infants became patients of paediatricians rather than obstetricians, and eventually contributed to the development of a new medical speciality: neonatology.

In 1907, Pierre Budin published a monograph which highlighted three key responsibilities of the infant physician when caring for "weaklings": "With the weaklings, we shall have to consider 3 points: their temperature and their chilling, their feeding, and the diseases to which they are specially liable" (Budin 1907, 2). Budin's monograph more generally explored these three components of neonatal care as central to the care of premature infants and how they were to be approached professionally. These three concerns were primary responsibilities in the diverse professionalisation of neonatal medicine and nursing. In particular, the 1960s were a period of the rapid professionalisation of neonatal work. In 1960, American physician Alexander Schaffer first coined the term "neonatology" as a field of medicine devoted to the care of newborns – both premature, and otherwise (Philip 2005, 800). The field was first

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[50] Regulation of temperature.

explicitly defined in his medical textbook "Diseases of the Newborn" (Schaffer 1960) which also centralised the primary concerns of Budin as feeding, thermoregulation, and other diseases associated with prematurity as central components of professional responsibility.

The development of neonatal care in New Zealand followed a similar trajectory to that overseas. The expansion of medical services for early and/or small newborns was enmeshed with political narratives of infant personhood early on. In a comprehensive historical account of Auckland National Women's Hospital and associated services, Linda Bryder (2014) emphasised the importance of viewing the local maternity context with a global lens. Early infant hospitals, the first of which was established in 1907, "were premised on the confident belief that premature and other weak babies could, and should, be saved" (Bryder 2014, 89). This belief is inherently a political one: a statement asserting the value of a particular type of life and personhood, and one that necessitates public funding. Much like overseas, infection was a major problem in the early units. This shaped the ways in which parents were able to interact (or not) with the babies. Nurses were primary caregivers in order to limit handling and infection risk, as well as in managing feeding and thermoregulation.

Similar to overseas, neonatal care in New Zealand was also heavily research focussed. In particular, a national awareness of oxygen toxicity brought the risks of visual impairment to the forefront of global neonatal research and development (Bryder 2014, 92–93). More intensive and uncontrolled use of oxygen therapy for premature infants was found to increase risk of ophthalmological pathologies such as retinopathy of prematurity and cataracts. I suspect these early strides in neonatal research have contributed to the present narrative of New Zealand as a "world leader in neonates" as I was told on numerous occasions by those working in the sector. This narrative, in combination with the continued role of research onsite in the NICU, enhanced a framing of neonatal work as moral and political work integral to the negotiation of infant personhood, discussed later in the chapter.

Research and Professionalisation in Neonatal Work

<u>Neonatology</u>

Over the past 50 years, significant technological advances have heavily shaped practices and outcomes for those in the neonatal sector. As detailed in the previous section, it was the development of more advanced ventilatory techniques, the improved provision of thermoregulation, and more effective nutritional support which allowed for those born at the margins of viability to be deemed candidates for intensive care in the NICU. For myself, the

introduction of a new type of ventilator into the unit where I was cared for was apparently instrumental in supporting my respiratory effort. This new model of ventilator took the place of an earlier model which was known for causing more severe lung damage in premature infants. The centrality of medical research and development of new technologies is therefore felt in the deep breaths of ex-premature babies like myself.

In City Neonatal Unit, research featured in the day to day activities of both the medical staff and nurses. By extension, research was an integral component to the care of babies, and the experiences of parents and myself. When I began recruiting participants for this research, a nurse at another hospital told me that their Unit was so saturated with researchers that there would not be space for me to undertake participant observation at that location. City NICU was similar, in that I was simply one among many other researchers. Nevertheless, the majority of the other researchers I encountered on the unit were medical researchers – either established staff members doing research in their own workplace, or external researchers from other medical centres and/or tertiary institutions. There were research nurses, doctors doing their own research projects, and other medical staff who were participating in external studies. None, however, were doing ethnography.

From the outset, medical research structured medical staffs' interactions with parents. For some parents, their first interactions with neonatologists were premised on their role as researchers rather than medical practitioners. In this instance, the babies were sometimes research subjects *first*, and patients *second*. I spoke with Kylie in her home, while her young daughter played beside us. Her daughter, now almost a year old, was born at 33 weeks gestation. She spent just over 6 weeks inpatient at City NICU. Kylie giggled as she told me about her first interaction with a neonatal consultant at City NICU:

> *"Well the doctors were pretty non-existent…one time the doctor did come and sat down and everything and I was like "this is awesome" but it turned out he just wanted to do a research project on her [laughs]. Like if they wanted something, they'd be there"(Kylie)*

She was pleased a doctor had visited her on the antenatal ward, but disappointed that he had an additional motive. Kylie's experience was similar to that of other mothers I talked to. For many, while waiting on the antenatal ward for an imminent premature birth, the first interactions some mothers had with staff was in reference to data collection for research studies that needed new participants who had not been born yet. The role of research as central to medical practice extended beyond the antenatal ward, and right into the high acuity nurseries. Furthermore, the

medical research undertaken by staff also existed well alongside the commercial developments of the medical technology industry. Although arguably a commercial development, these technologies were introduced by representatives to City NICU using a language of medical research as a means of product marketing.

In addition to the various staff members undertaking data collection or participant recruitment as a part of a wider research study, commercial representatives also occasionally featured in the little baby rooms. These individuals spoke of how their companies' "latest research" resulted in "new tools" for neonatal care. It always surprised me to see these representatives from medical supply companies coming in to the nursery to pitch their products and give demonstrations to staff. It looked strange and out of place. The representatives entered the nurseries with their products and promotional materials to demonstrate how *their* research was invaluable to the development of *their* new product as opposed to others.

On one particular day, a smartly dressed sales representative from a well-known global medical and electronics manufacturer, spent approximately 20 minutes in the little baby room demonstrating a new product to bedside nurses. The product looked no different from those already in use: plastic nasal cannula affixed to the philtrum of an infant which provided a steady supply of humidified air up the nostrils to the lungs. Nevertheless, this new product, with the same product name, but termed "a second generation" version, was pitched to surpass that of its predecessor in ease of use and reliability. Bedside nurses were asked to touch and then handle a sample cannula while given a rundown of the updates, improvements, and new features of note in the second generation model. The strong foundation of research based evidence conducted by the company was touted as a primary reason for staff to "get on board" with this product development. Quinn Grundy (2018) explored a similar dynamic in her monograph on the interactions between nurses and sales representatives whereby nurses held a degree of power over the introduction of certain products. Nurses were, according to Grundy, the ideal target of sales representatives for this reason.

This claimed change in the construction of a plastic nasal cannula, among other on-site research *and* commercial pursuits, was partially reminiscent of Kaufman's (2015) "ordinary medicine". For Kaufman, the swift and continuous research and development of life-sustaining technologies, as well as the normalisation of their intensive use particularly at the end of life, arises from a system of entrenched cultural values and politico-economic discourses. In particular, the post-Enlightenment equation of scientific development *with* progress pushes novel life extending technologies to the forefront yet are simultaneously normalised in the day

to day practice of Western biomedicine. However, the neonatal unit presents a different iteration of "ordinary medicine". In City NICU, research endeavours existed alongside commercial ones, in such a way that *both* were considered research. Although commercial representatives were simply pitching new products, the products were centrally framed as culminations of the research undertaken in the sector itself. Commercial R&D [51] was therefore somewhat equated with the research conducted onsite and equally normalised.

The ever present research and commercial activities on City NICU appeared normalised to such a degree where almost all parents I spoke with had given consent for their infant to participate in at least one medical research study involving testing new products and medications or monitoring certain features of the infant. When I handed consent forms and information sheets to parents during my own recruitment process, many added these papers to an already existent pile of other forms pertaining to a multitude of additional studies they were participating in. Small laminated labels adorned the incubators of infants who were involved in various studies. Some labels even looked to mimic the name labels affixed to the end of every incubator with bright colours, cartoon designs, and bubble letters indicating that particular infant was a part of a research study.

The routinisation of new and experimental medical treatments and technologies is visible across Western biomedical practice. Koenig (1988) argued that it is this routinisation that "sustains the technological imperative" whereby the presence of a new technology necessitates its very implementation (466). Koenig draws on Fox and Swayze's (2001) discussion of the experiment-therapy continuum present in Western biomedicine. This concept highlights the often ambiguous relationship between experimental medicine and treatments considered routine and best practice. A treatment may simultaneously be experimental yet routinised and considered appropriate treatment. For Koenig, this continuum was useful in understanding the social factors which maintain the technological imperative to support experimental medicines and treatments. She explored the practice of therapeutic plasma exchange, which at the time of her research, was still a recent innovation. She followed the processes of routinisation of this practice via changes in professional configurations. The therapy was initially undertaken by physicians and then gradually moved within the realm of responsibility of nursing practice. This initial professional division whereby physicians held primary authority over research activities was not as visible on City NICU. Specifically designated research nurses worked

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[51] Research and development.

alongside physicians, external researchers, and commercial actors to implement research trials. Professional configurations were dynamic insofar as how care was coordinated and how research outcomes were met.

The nature of this field as highly research based and experimental is not unique to neonatology. Arguably, for all medical disciplines, research and experimental medicine, as well as commercial activities, have a role to play. As within the field of internal medicine, day to day practices may possess characteristics resembling both medical therapies and medical research (Fox and Swazey 2001), and may fluctuate between what is considered routine and experimental (Koenig 1988). The practice of medical care is therefore neither distinct from, nor independent of, the practice of medical research. At City NICU, the patient population, *newborn infants*, prompted a particular type of reaction from both parents and the lay community when coupled with medical research, reflecting a particular type of fragile and precious infant personhood in the public imaginary. When speaking of research studies, particularly those deemed more invasive, some parents expressed their doubts during the recruitment and consent process: the vulnerable position of the infant, particularly regarding age, was a feature which gave parents anxiety during the research process. In discussing a trial which would involve her infant receiving a different level of protein in her TPN (or the placebo), one mother told me "she's *just* a baby!" in response to her anxiety over this possible change in TPN configuration. Although this mother had second thoughts about providing consent for her infant to participate in the protein study, she eventually gave her consent upon consultation with her husband at home.

Beyond the clear visibility of research activities, the performance of neonatology on City NICU possessed similar tropes to that of medical practice more generally, including narratives of "the challenge", perspectives of medical infallibility, and clear professional hierarchies enacted on a daily basis. These features all, as I argue, work to maintain diverse professionalisations of prematurity and how personhood is approached in NICU work.

Part of the wider neonatal project is to challenge the limits of what Western biomedicine is able to achieve. While this was visible in the use of frontier metaphors in the literature, and "world leader" narratives in New Zealand, this was also visible onsite at City NICU in the specific framing of some infants. Throughout fieldwork, certain infants were uniquely framed as "a challenge". Some infants were a challenge to treat and a challenge which needed to be overcome. Alice was one such challenge. Her condition challenged the limits of Western biomedicine. A registrar told me that "She's been a challenge since day one, this one". I saw

this daily during her admission to the neonatal unit. When one issue was fixed, another arose close behind. In treating one organ system, side effects caused the deterioration of another organ system. Both doctors and nurses used challenge metaphors when speaking of particularly complex cases, such as Alice's. I will also speak to the challenge metaphors used by nurses in this section as these are more nuanced that those utilised by doctors, and I speak to some key differences in the professional management of premature infants. Challenge narratives are exemplary of the *perceived* infallibility of Western biomedicine and the degree to which we believe doctors can treat all pathologies and patients.

I sat down to an interview with nurse Anna during a period where City NICU had many challenging babies: ones which "make you question your ethics" as Anna framed it. Our interview was peppered with beeps from adjacent incubators, and we frequently moved around the room as she checked on the babies. Due to the complexity and acuity of the patient population on City NICU at that time, our conversation was naturally steered towards a discussion of the ethical issues associated with treating very complex premature infants, and particularly those born at the edge of viability. For Anna, the seemingly relentless active medical intervention given by doctors to certain infants was heavily problematic: "We just keep, going keep going, keep pushing these babies cause they're babies and they're cute and they're moving their limbs… cause they [the doctors] think that they can do everything… 'we're doctors, we can do it'." Again, the cultural capital given to Western biomedicine was centred on its perceived infallibility in conquering death and disease.

I was interested to hear more about how Anna framed the professional differences in approaching these "challenge cases". From interviews with parents and other staff, I was acutely aware that the 'doctors *cure*, but nurses *care*' assumption was widely held – at least for those I spoke to. I asked Anna to speak more to this difference and how this shapes managing the challenging infants:

> *"[there's a difference in] Every situation. There's even a difference of opinion between consultants. [Doctors are] all like 'yeah we can get this baby out of here' but with what life? And I don't know, like I just think, there's a baby involved." (Anna)*

These sentiments were a common theme in the conversations I had with nurses over professional differences. These sentiments speak, not only to assumptions on the abilities of Western biomedicine, but also to the type of care work which is understood to be bifurcated between medicine and nursing: curing versus caring. Anna illustrated a point of professional

conflict between doctors and nurses, each undertaking what they believe to be the ethical and moral work in their profession. 'Pushing' some babies, and not others, is demonstrative of the authority held by staff in assessing "what kinds of children are desired and unwanted" (Gammeltoft & Wahlberg 2018, 8). Further, this speaks to the moral power wielded by staff in making such decisions using various political and economic rationalisations of personhood, discussed in the thesis. Yet, discrepancies in professional power meant that some voices were louder than others.

In observing daily medical rounds, it was clear that hierarchies were an additional mode through which both neonatal medicine was practiced and performed, and how different attitudes towards prematurity were articulated. The presence of professional hierarchies and complex power dynamics cuts across medical disciplines and is obviously not unique to neonatology. The hierarchical nature of the medical profession in general has been the focus of both social scientists and medical researchers alike. For Lempp and Seale (2004) the inculcation of medical hierarchies is a key component of the 'secret curriculum' taught during undergraduate medical education. Medical students are socialised early on to respect authority and the expertise of those professionally ahead. As outlined by Crowe et al. (2017), this socialisation into a distinct professional power dynamics continues well into postgraduate education as junior doctors train in their desired medical specialties and subspecialties.

Morning rounds were a hub of activity on City NICU. There rounds involved an exchange of information valuable to both staff and parents. The feat of "making it to morning rounds" was one which many parents aspired to. This was a feat because rounds could occur at any time and were easy to miss. Rounds were a chance for parents to receive a run-down of their infant's condition, as well as, for many, being the only time they would see their child's doctor. A huddle of consultants, registrars, and nurses systematically moved through the unit, spending anywhere from 30 seconds with a "run of the mill baby" to upwards of 20 minutes with a "challenge baby". The condition of the infant heavily dictated the atmosphere and dynamic of that particular staff visit to the bedside. For instance, Isabella was well within the "feeder and grower"[52] stage when I observed the team rounds one morning. Her goals were simply to "keep doing what she was doing" which meant she needed to continue feeding and gaining weight. This round was one of the shortest I ever observed. Approximately one minute was spent at her

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[52] This term was used to describe babies that were typically no longer receiving significant breathing support, and the focus was on nutrition and weight gain.

bedside while the consultant checked her weight in her notes and gave Isabella a metaphorical "gold star" for her weight gain efforts and lack of bradycardias. Satisfied with Isabella's progress, the consultant moved the team along, very much reminiscent of 'follow the leader'.

The next cot contained Alice, a challenge baby. Two days prior, Alice received extensive surgery to resect a perforated section of her bowel. She left the surgery with a small stoma.[53] In addition to the stoma, Alice was still ventilated, fully sedated, receiving all nutrition through a central line, and monitored closely by a nurse at a one to one ratio. It was clear that she was a complex case for staff to manage. Rounds always slowed around Alice's bedside, and sometimes other consultants from around the unit would join the discussion of her care. Her parents were usually present, but they sometimes deliberately chose to leave the room so as to not be privy to certain discussions on their daughter, particularly those regarding the possibility of withdrawing intensive care. Upon arrival at Alice's bedspace, a consultant opened his presentation to the group by loudly exclaiming that "this one has had some mischief along the way". By "mischief" he is presumably referring to the number of complications in her clinical condition, particular those which occurred over the past 24 hours.

"Yes" Alice's bedside nurse for that day replied. "She's had quite a few doozies this morning". A fair amount of back and forth ensued, as the nursing manager on rounds and the consultant conferred intensely over Alice's clinical management. Occasionally, a registrar piped in or a question was directed to a visibly stressed medical student. It was very obvious that there was some disagreement over how Alice should be managed in the coming days and weeks, and the tension was palpable from my perch close by. I was already aware that disagreements occurred. Some nurses I spoke to frequently expressed their exasperation with the rounding process for this very reason. Another bedside nurse Steph came over to chat with me about the visible tension we could see in the group. She whispered "I don't know why we [bedside nurses] bother going on ward rounds. Nobody listens…". Mid-sentence, she was cut off by a consultant moving to the next bedspace and who wanted her attention.

Later that day I spoke more with Steph about the hierarchy during ward rounds. She told me that they often "get heated" particularly with complex cases such as Alice where multiple organ systems require medical intervention. Aside from professional hierarchies (between registrars and consultants), she explained implicit hierarchies *between* consultants due to their

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[53] A portion of intestine is brought through the skin of her abdomen to allow for faeces to pass into a plastic bag affixed to the skin, therefore bypassing the colon.

"portfolios". Beyond sub-specialising in neonatology, the consultants each had their own particular area or 'portfolio' of neonatology which interested them. For one, nutrition had primacy, but for another, neurological management was the most important and worthy of focus in the wider clinical setting.[54] This was necessary, Steph told me, in order to keep the discussions holistic. However, this might then cause conflict when one organ system is prioritised over another by a particular consultant and their portfolio. For an infant such as Alice, with multisystem organ involvement, it was clear to see why tension ensued on the road to devising an appropriate clinical plan. Nevertheless, these hierarchies existed well beyond consultants and their portfolios. Imposed professional hierarchies, such as those between doctors and nurses, were also visible in the type of care work deemed appropriate for each profession.

Nursing

The differences in scope between neonatal medicine and neonatal nursing were both structured and structuring in the ways in which staff spoke of premature infants and their care. Such professional differences aided in the construction of divergent professional ontologies of prematurity: different modes of knowing and understanding prematurity which in turn shaped practice and narratives of personhood. Alongside differences in training and underlying epistemological assumptions, these divergent ontologies were produced via a layering of sociocultural, political, and economic factors.

In a seminal monograph, Renée Anspach discussed how the different "positions" held by doctors and nurses shaped how knowledge was constructed and applied in the treatment of infants receiving care in the NICU (1997, 1). The various duties assigned to professionals (both medical staff and nurses), not only structured their clinical interactions with the infant, but also in how infant personhood was approached. Jessica Mesman (2005) elaborated on Anspach in her comparative exploration of prognostication in American and Dutch NICUs. During her fieldwork, Mesman found notable differences in how the prognostic picture was formed for each infant based off some professional differences. Such differences existed both between NICUs and *within* NICUs. Moreover, in extending Anspach's discussion of divergent "positions", Mesman argues that any discussion of prognostic differences must closely examine "circumstantial elements, the NICU's local history, and [the] individual knowledge

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[54] Again, this speaks to the differential valuation of the mind versus body, and some implicit assumptions over where 'personhood' is considered to be located, as discussed in the previous chapter.

and experience of those involved" (Mesman 2005, 49). Drawing on STS analytical frameworks, Mesman situated her argument in the assumption that "prognostic knowledge is not simply waiting out there to become applied in practice, but [via various social and cultural layers] is constituted in the very same practice as it is used." Therefore, it is through this framing that the role of certain professional differences (as an example of the various social and cultural layers present) in prognostication, and assumed futures, are made visible.

My observations in City NICU were similar in that different roles necessitated different knowledges, and therefore, different practices and approaches to premature birth. Nevertheless, that is not to say that there was not any crossover between roles – there certainly was. Rather, it is to say that, as mentioned in the previous section, medical professionals exhibited a specific way of *doing* prematurity. Epistemological differences shaped practice, as well as through assumptions held both within and outside of nursing, specific framings of neonatal care work, and via local workplace politics.

"I think we've broken her" Alice's bedside nurse Janine told me about a week after her abdominal surgery to repair the bowel perforation. She was extubated, put on CPAP, and had been moved back to a bedspace reserved for babies with less acute needs. In an interview with her mother before the surgery, I was told this abdominal issue is fairly common in an infant born at her size and gestation. Her mum told me during the interview that the hope then was that the perforation would heal itself and wouldn't require the stoma surgery. Obviously, the surgery became necessary as the perforation in Alice's bowel did not close on its own, and it had continued to leak bowel contents into her abdomen. In the week after her surgery, when I arrived on the unit and saw Alice off the ventilator and in a different bedspace, I thought that she had improved over the weekend. However, as I spoke to Janine, I learnt that she was soon to be reintubated. A routine blood gas had revealed high levels of carbon dioxide in her blood. This was an indication of a deterioration in her condition, either due to poor breathing effort or infection. I also learnt that the move to the new bedspace was organised to accommodate a new infant, rather than to reflect any improvement in Alice's health. A new infant was due to arrive later that day, who would require the bedspace she had previously occupied. Alice and her incoming ventilator just had to be managed in a less acute bedspace.

This type of language was used by many nurses in reference to different babies. I met the new occupant to Alice's old bedspace a few days after she was born. Her name was Hana, and she was born at 27 weeks gestation to young parents Angel and Hemi. At 15 years of age, Angel was the youngest mum to participate in this study. I leant from Hana's bedside nurse Lea that

Hana had recently been extubated and put on CPAP. Apparently Hana had struggled in the last 24 hours since the extubation. I observed much of the day spent testing and re-testing Hana's blood gases alongside making small changes to the concentration of oxygen delivered through CPAP. Finally, well into the evening, Lea returned to the nursery, white print out in hand, and proudly exclaimed "We've fixed her!" to the two other nurses in the room. The small piece of paper was emblematic of that day's success whereby Lea had been tasked with administering a long list of treatments to Hana in the space of her 12 hour shift.

This event was yet another instance of how I witnessed nurses use metaphors of *breaking* and *fixing* babies in their day to day practice. These metaphors were used alongside those of "decorating" and "growing" babies. Nursing tasks, such as applying steri-strips to the incision from an old chest drain was referred to as "decorating" – the steri-strips were applied to the skin in such a way that they closed the wound, and also formed the shape of a star on an infant's ribcage. Neonatal nursing as a profession which "grows babies" was also a metaphor used by some nurses themselves. I found this particularly amusing when one nurse exclaimed "We grow babies" all the while holding a syringe containing high-fat infant formula to be passed through a feeding tube into the stomach of an infant using gravity. Just as the incubator acted as an artificial womb, giving infants a place to gestate outside the body, nurses grew and developed premature infants through complex configurations of treatments and therapies.

Beyond more clinical nursing practices, such as gavage feeding, administration of medications, suctioning of ET tubes, and the like, nurses also performed additional care-based tasks more traditionally associated with infant care. While parents were always prioritised to perform care work tasks when possible, in many instances, these needed to be undertaken by nurses. Nurse Sarah was faced with a decision when it was time to change Jessie's linens: moments prior, Jessie had what was known on the unit as a "Poonami" (or a "Poosplosion"). Her sheets were heavily soiled, and the plastic inside wall of her incubator needed to be wiped clean. Sarah told me that one of her favourite tasks is picking out matching sets of linens in making up a fresh incubator. She took me to the cupboard where they keep the linens, and I saw shelves full of soft cotton sheets and quilts. These ranged in colour, yet notably absent were reds and browns – such colours may hide any bleeding that needs to be noticed by staff. Sarah grabbed two pink sheets, a towel, and a dark purple quilt to drape over the incubator. She then proceeded to make up Jessie's incubator, with the aid of another bedside nurse, while questioning whether the parents would like this new combination of sheets. The process was a blend of the type of care work stereotypically associated with the feminine domestic domain and that of nursing. The

dual stereotype of care work as characteristic of nursing and mothering is indicative of the highly gendered nature of neonatal nursing, and nursing more generally. Much has been written about the gendered assumptions in and on nursing (Davies 1995). The historical dominance of women in nursing sustains and is sustained by assumptions on a presumed necessary relationship between femininity and nursing: the care work inherent in the profession is stereotypically considered the work of women, such as the role of emotional care work, assisting with feeding, and making up beds or incubators. This assumption is further deepened in the realm of neonatal nursing insofar as infant care is considered the epitome of female care work.

Nurses handled the infants day in and day out. They were present for milestones and setbacks. They spoke to babies and responded to their cries. They conducted the close care work associated with "growing" babies. As a parent told me, while the nurses were there all the time, "the doctors breeze in and out". Therefore it is clear then why nurses held different assumptions about what was best for an infant, especially one considered a challenge case. This speaks again to the assumptions of caring versus curing, as discussed in the previous section. These considerations are examples of "everyday ethics" (Das 2010) which challenge nurses beyond the more critical "life and death" dilemmas we assume typical of neonatal ethics (Strandås and Fredriksen 2015, 902). Routine examinations sometimes caused stress for nurses when observing what they interpreted as pain or discomfort in the infants.

Stressful situations occasionally necessitated specific care practices for the nurses themselves. At a bureaucratic level, nurses were encouraged to attend "debrief sessions" following a particularly complicated situation or sudden death of an infant. However I was told that these sessions are typically not particularly useful – "it's just a whole lotta *talking*" one nurse told me. "A bit touchy-feely" another chimed in. A debrief was scheduled for later that afternoon following a series of sudden and/or unexpected infant deaths which had occurred in the past month. All nurses closely involved in those cases were required to attend. The nurse manager rostered on popped her head in the nursery to remind the bedside nurses of this. Her reminder prompted a collective groan in response from the bedside nurses. A week later I spoke to Anna, a bedside nurse frequently rostered into the little baby room. We talked about these debriefs, including the one from a week prior. She told me she much prefers her own way to relaxing and 'debriefing': coming home to dinner on the table, a large glass of wine, and a hot bath. Collective selfcare is also important, Anna explains:

"I think we support each other a lot in here. And we do cry…and we do drink wine [laughs]. We wouldn't really be doing it [coping] on our own. It's part of the job, but obviously it affects you when a baby dies that you're looking after or that you've grown attached to…gotten to know."(Anna)

A specific type of dark humour was also used by nurses in challenging situations as a means of self-care. To begin with, some of the metaphors associated with this dark humour upset me. Yet, towards the end of my fieldwork, I found myself making similar jokes at home. These usually prompted shocked and confused reactions from my housemates. The use of dark humour in nursing has been well documented both in academic scholarship (Ghaffari, Dehghan-Nayeri, and Shali 2015; Buxman 2008; Dean and Gregory 2004) and in popular culture (Robbins 2015; Kim 2015). For Buxman (2008), the use of "gallows humor" (67) in nursing can provide a stress release for both nurses and patients during stressful or painful events. Yet this humour also helps to create a type of emotional distance between nurse and infant, and is indicative of a strategic detachment. The use of workplace humour is also understood to reduce the risk of burnout in medical and nursing fields.

Alongside everyday ethical issues, nurses navigated complex workplace politics and hospital bureaucracy in their day to day NICU activities, such as chronic understaffing, a "mean girl culture", and wider underappreciation of the nursing profession. I was told by other researchers and DHB staff that City NICU workplace culture is well below ideal. This was repeated by many nurses I later spoke to. The environment had a distinct reputation for workplace toxicity, especially within the larger population of nurses in the unit. A "mean-girl culture" shaped the experiences of some nurses as they moved through the unit. Some bedside nurses explained how bullying is particularly pervasive from senior nurses and nursing management "on a power trip" exerting their dominance over younger nurses and those less advanced in their professional development trajectories. I found this interesting given the assumptions expressed by the same nurses that their profession is one based on *care*. Clearly, *care* was in reference to patients and their families, and in clear tension with internal professional relationships. I also witnessed significant internalised sexism in the ways in which this bullying was explained: "it's cause there are so many girls in a small space…too much feminine energy" a bedside nurse explains. I was told it would be better if there were more male nurses who worked in City NICU. During fieldwork, I only came across two male nurses – out of 200 rotating nurses. I asked a bedside nurse why there was such a dearth of male nurses in the neonatal unit. The response given was that "They [the men] go do ED [the emergency department] or psych [the

psychiatric ward] . It's all crying babies and boobs up here. It scares them off." This is amusing as, for the nursery I was based in, the babies could not really cry. This type of gender essentialist explanation was almost always the justification given for the disproportionate number of female nurses in the unit. In this manner, the subject of neonatal nursing, the infant, was an embodiment of not only ethical considerations on personhood in the treatment of unstable babies, but also in the wider political rhetoric about the highly gendered and the somewhat precarious state of the nursing profession.

Conclusions

Professional differences in approaches to premature infants were a common feature of City NICU. These speak to the divergent manner in which the fields of nursing and medicine have been professionalised and centralised. Overarching the fields of neonatology and neonatal nursing also exists a constant orientation towards research as a central component to this speciality. This highlights the legacy of experimental medicine and research endeavours as central to the practice of premature care, but also in how staff related to the infants. Further, the experimental nature of medicine more broadly (Kaufman 2015), makes room for the diverse approaches and techniques utilised in the neonatal sector. Although staff seemingly attempted to separate their research activities from their clinical care, the practice of research was so much intertwined in daily NICU practices, that it is difficult to separate the two entities – they are practiced concurrently and simultaneously within the wider treatment of infants as patients, persons, and loci of professional debate. In the distinct professionalised manners through which doctors and nurses engaged with infants, the doctors and nurses performed and enacted dynamic interrelating modes of premature personhood which were sometimes contradictory and in tension. Not only were the professions different in terms of varied techniques, priorities, bodies of expertise, and responsibilities to parents, the professions also differed within themselves on the basis of individual identities and sentiments. Therefore, both infant personhood and parenthood were constituted by staff differently in the process. Parents continuously negotiated between different professional, and individual, registers and practices while premature personhood was continually configured as multiple across these differences.

Chapter 6: A Language of Infant Agency

"Babies are like old people when it comes to breathing. If they have the opportunity not to, and to have someone or something else to do the work for them, they'll take that opportunity." (Nurse Rebecca)

I had spent much of the night talking to Rebecca as she worked away in the little baby room. I was observing my first night shift. This was a shift where I was introduced to a different type of atmosphere in the NICU. The heat and lack of natural light made me sleepy, as did sitting in a soft lay-z-boy recliner. It was quiet and there were no parents around. Rebecca told me that some nurses prefer night shifts for this reason: with parents at home in bed, nurses are left to do their jobs without interruptions. It reached midnight, and I had only seen one parent over the past two hours. A mother came in to change her infant's nappy, take a few photos, and quietly chat to the bedside nurse before she left for the night.

Throughout the remainder of the night shift, I noticed that Rebecca talked *to* the babies a lot. Not just *at* them, but as if she was talking *with* them. She had little conversations with the babies, made inside jokes with each baby, coached them through procedures, and congratulated them on their progress. I was particularly struck by how she profusely apologised to an infant while doing a routine heel prick. Occasionally, as we talked, a non-ventilated baby let out a small cry or squawk. Ventilated babies could not make the same noises as endotracheal tubes went right through their larynx and prevented vocalisation. These squeaks were framed as interjections in our conversation: an infant "putting their two cents in." Sometimes an infant kicked an arm or leg up into the air. Rebecca also framed these little actions as interjections. I was interested in how Rebecca approached what she understood as these frequent interjections. I got to talking with her about the personalities of the babies currently in the nursery. According to Rebecca, each had clear personalities from birth: "You don't think of a 26 weeker having a personality, but they really do!" She told me about having "stroppy girls" and "laid back boys", and how the former tended to do clinically better than the latter.

I frequently encountered narratives of infant agency which were indicative of staff and parent co-constructions of infant personhood. These narratives of agency included material manifestations, such as the use of personalised objects. The specific narratives of agency, both produced and reproduced by parents and staff, were sometimes at tension with each other. This chapter explores the ways in which premature infants were framed as having a particular type of agency and personhood that was performed by parents and staff through narratives of infant

self-determination over their own clinical trajectories. Infants were further framed as possessing a uniquely unstable type of agency that underpinned such narratives of self-determination. However simultaneously, the performances of self-determination were structured by particular norms of personhood. This chapter critiques how infants were framed as active agents in control of their own futures yet equally structured under a configuration of social norms visible in performances and narratives of infant personhood by parents and staff. These communicated cultural norms on the productive body, as well as how infant personhood was relationally mediated through a constellation of agents and types of agency.

Diverse Theories of Agency

Anthropological approaches to agency have each shown diverse and nuanced framings of the concept. Early discussions gained prominence in the late 1970s during a period of change in the discipline. A range of anthropologists began to critique the traditional reliance on structural-functionalist approaches which posited 'culture' as a single entity and as a system of organisation. These concerns characterised the longstanding debate on structure versus agency in anthropological analysis (Moore 2012). Furthermore, these debates have given rise to a very large body of literature which has continually attempted to understand and explain agency and who, what, and why something or someone may or may not possess it.[55]

Early anthropological analyses of agency fit broadly within the category of "practice approaches" (Ahearn 1999; 2001). Working within the practice framework, Bourdieu emphasised the way in which human actions and practices mutually constitute wider structures. Within his "theory of practice", Pierre Bourdieu (1977) argued for the inseparability of individual agency from wider structures and vice versa. The two are continually restructured in relation to each other, but neither are entirely distinct nor immutable. Bourdieu's conception of agency is grounded in a materialist determinism: the ability to shape or change wider structures is itself structured by class. Thus, in a sort of circular system, structures are continually reproduced by social agents by virtue of social dispositions being structurally reproduced. The individual dispositions which structure and are structured by practice are so naturalised and embodied that they go unnoticed. The hope is that these dispositions fit within the moral "rules of the game" and maintain the wider structures (Bourdieu 1990, 66). For James

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[55] Although a comprehensive tracing of the concept is beyond the scope of this thesis, I provide a snapshot of some key theoretical approaches and their empirical application. I have chosen to focus specifically on the approaches below as they illustrate some of the large differences in how anthropologists have sought to explain the concept. My own framing of the concept takes elements from a variety of theoretical bodies.

Laidlaw, Bourdieu in effect argues that the "existence of reflective, intentional, self-responsible" agents simply serves to reinforce the structure itself (Laidlaw 2013, 9). For Laidlaw, Bourdieu's discussion of agency is rather circular. Marshal Sahlins (1985) operated within a similar dialectic to Bourdieu. However, for Sahlins, the 'structuring structures' of importance are less about materialism (of importance to Bourdieu), and more about cosmology (Sahlins 1985). Furthermore, Sahlins also focused on historical processes and individual action as mutually constitutive of cultural systems, particularly in reference to Oceania.

Sherry Ortner (1989) too used a "practice" approach in discussing her vision of a structure and agency dialectic. For Ortner, social agents are "loosely structured" by their relationship to culture (Ortner 1989, 198). This relationship to cultural structures and symbols both enables and restricts how individuals move through the world. Individuals are not completely unaware nor totally organised by wider structures. Rather, Ortner implies a sort of partial awareness of these structures . According to Laidlaw (2013), agency is, for Ortner, a type of power employed specifically to challenge the partial view of these structures. Also, as critiqued by Laidlaw, Ortner's framing of agency seems to rely on the concept as something exercised toward *changing* the structures. There is an emphasis on temporality in agency as an inherent aspect of will and resistance.

Critiques of the practice approaches offer a theoretical moment away from the dialectic of structure versus agency. Both Laidlaw and Saba Mahmood's (2011) concepts of agency inherently offer critiques of Ortner's emphasis on enacting social change. Exerting agency may simply be about maintaining the status quo or not about exerting power for the aim of resisting structures. For Mahmood, agency is visible *in* the subscription to structural norms and not dependent on resistance. The exertion of agency is not oppositional to conformity or adherence to structural values. For Laidlaw, agency is more about responsibility (or lack thereof):

> "…as matters of blame and responsibility, as an aspect then of the relational processes whereby stretches, phases, or stages of people's ongoing conduct are interpreted as acts for which distinct agents (of varying shape and size) are accountable." (Laidlaw 2013, 197)

Laidlaw emphasises agency as a mode of exerting, accounting for, denying, or being free from responsibility. He offers this as a critique to the shortcomings of Latour's actor-network theory (ANT). For Latour (2007), objects and non-human animals *have* agency by virtue of their ability to shape action and causation. Agency cannot be isolated to a singled human entity and

is dependent on other "networks" of agency. For Laidlaw, Latour attributes agency to causation rather than intention: anthropologists designate agency to objects by highlighting their role in changing human action rather than the objects possessing an a priori *intention* to change action. ANT designates this quality *to* the objects. An additional critique of ANT offered by Laidlaw and many others is that the framework flattens ethical life. Laidlaw's focus on responsibility as a key feature of agency is therefore an attempt to rectify this. Responsibility is not just in reference to oneself, but to collective responsibility, ethics, and material relations.

My study exemplifies how the agency of another can be enacted and performed by someone else for particular purposes. Nurses, parents, and other staff afforded agency to premature infants. Nevertheless, this was not just about conceptualizing a self-responsibility in the infant, particularly regarding their own clinical trajectories, but it also exemplified how relationships to individual and collective responsibilities were dynamic. At once, agency was both attributed to and directed away from infants, parents, and staff members through various modes. Further, the performing of infant agency by parents and staff with infants highlights points of tension where the conceptual performance was altogether still structured under certain constraints. Multiple articulations of infant agency are co-constituted by many actors in an intersubjective negotiation of (acceptable) personhood(s).

"Tough Little Buggers"

"I think she's just nosey" Abby told me as we peered into her daughter's incubator. The baby moved her head to look back at us. Molly's eyes were open wide, and her brow furrowed as if to tell us to give her some privacy. *Fair enough*, I thought. She spends her days in a clear plastic box, as if on display, so it made sense that she was telling us to "bugger off" so she could snooze in peace. Abby and I continued talking of Molly's traits, her qualities that were seemingly present from birth. I learnt that she's been "nosey" from birth. Just hours after her birth, a few weeks prior, she first "interacted" with her parents by staring right at them, and then proceeded to look all around as if trying to take in her new surroundings. At this stage, Molly was just over one kilogram. She was beginning to fill out, gaining some weight, and tolerating feeding. She was doing all the things she is supposed to do. As I considered this, I was struck by how frequently I, among parents and staff, talked of infants' traits, quirks, habits and personalities. Molly was "nosey" while Jackson was a "mellow wee fella". Jessie was "feisty" while her twin sister Georgia was "calm and chill". These infants were heavily individualised in day-to-day narrative and practices. The individualising language not only attempted to stabilise precarious personhood of the infant through positioning them as

individuals with their own unique perspectives of the world, but also illustrated the performance of a type of emotional labour and communication by staff and parents in the relational mediation of that personhood. This personalisation was also in direct tension with some of the complex narratives of clinical self-determination that diminished infant agency. Furthermore, these infants were designated a type of agency (in the form of self-determination) over their own clinical positions, yet this type of agency was somewhat bounded by particular social norms that shaped who was deemed an acceptable 'person' and why.

As an anthropologist, I have not been concerned with determining whether these babies actually possess the capacity to be "nosey", "a stroppy girl", or a "wimpy white boy". Further, I have not engaged with more philosophical explorations of whether they should be deemed persons a priori or if they have the ability to determine if they will live or die. Rather, I am concerned here with how self-determination, personhood, and agency, of premature infants has been understood and performed by those who care for them, in such a way that it communicates a variety of cultural norms.

For Bird-David and Israeli (2010), the personhood of PVS patients in Israel was distinctly reinforced through the re-telling of life stories (both those historically accurate, and imagined). In sharing stories of lives lived and imagined futures, those who care for PVS patients manage the liminal status of a severely incapacitated individual kept alive by technology, and who can no longer participate in such discussions. As mentioned previously, the telling of imagined futures was a prominent feature of narratives of time and progress for extremely premature infants in the NICU. These stories of imagined futures reified the position of an extremely premature infant as an active participant in the environment. Nevertheless, these were more clearly future-focussed and contingent on temporal narratives of development and progress which equally highlighted a potentiality of personhood. In the day to day however, the position of premature infants was more discussed in terms of their personalities: their natures, emotions, quirks, and individualities.

I met many "grumpy teenagers" during my time spent on the NICU. At one month old, I remember Jessie, positioned in her incubator, on her stomach, one tiny arm lifted to cover her head. "She's like a grumpy teenager" Morgan explained, giggling at the sight of her daughter in this posture. I think back to my own teenage years: alarm blaring; commanding I get out of bed and ready for school; lying on my stomach holding a pillow firmly over my head in a futile attempt to block out my alarm; grumpy and in a similar posture to Jessie. We projected the persona of an irritated teenager onto Jessie as she snoozed, probably unaware of our presence.

That persona was in stark contrast to her tiny monitored body, and her face obscured by the damp CPAP mask strapped around her head and under her chin. She kicked up a leg as if to participate in the conversation and assert her presence. Again, I found myself subconsciously designating a persona to this tiny human before me. In keeping with her "feisty" nature, I saw her kicking up her leg as if to tell me to bugger off. It was as if she was giving me a swift kick away from her incubator, or practising her first punt at a non-existent football. Much like Jessie's, another infant Xavier's sleeping habits were characterised as uniquely *his*: "He didn't like it when he was in his incubator" his mother Amy told me with a laugh. "They [nurses] kept tucking him up, and he would just push everybody…he had a real personality right from the get go." Xavier's actions, pushing away the nurses, were framed as early indicators of his personality, even at a young age. Both Xavier and Jessie were cast as being acutely aware of their own environments and engagements as such.

Furthermore, while the presence of these traits was understood by parents and staff as indicative of infant personhood, they were equally framed as in direct opposition to an infant's extreme prematurity: "you don't think of a 26 weeker as having a personality". Again, this refers back to cultural assumptions on infant personhood – that it is reached at particular point during gestation – a point which may take place after birth if an infant is born extremely premature. Despite the complex relationship between personality and personhood, parents and staff implicitly referenced personhood when discussing personality. Explanations of personality were instrumental in how personhood was understood. The discussions of Jessie's feistiness, Tiarie's nosiness, and Georgia's chill disposition, are exemplary of a particular mode of understanding personhood such as that discussed by Scheper-Hughes and Lock (1987). For the authors, Euro-American conceptions of personhood traditionally emphasised the acknowledgment of individual experience, self-awareness, and self-perception in the world (Scheper-Hughes and Lock 1987, 14). Nevertheless, I understand the performance of these traits and characteristics on City NICU went far beyond the basic ascription of a persona to the infants.

The framing of infants as possessing certain personality traits also communicated how the social and emotional roles of those caring for the infants were performed dynamically in this context, and how neonatal agency was relationally embedded in that of others. In speaking of, and to, the infants as if they possessed unique traits, parents and staff operated under a logic that they were not only aiding in the social development and inclusion of the infant through doing so, but also, particularly for parents, enacting emotional needs and carework. When I

observed parents speaking to or about their infants with regard to their perceived personalities, it was as if parents were in a way performing their infant's imagined futures. In doing so, parents illustrated their emotional needs and desire for their children, for them to be "nosey", "chatty" or "feisty" far beyond their admission to NICU.

However, parental and staff performance of these characteristics was sometimes complicated by the intensive clinical care needed in the maintenance of basic physiological functions, such as cardio-pulmonary support and related management. For instance, ventilated infants were often given sedative and/or paralytic medication to maintain successful ventilation. These medications paralyse the respiratory muscles so that an infant's respiratory effort does not interfere with the prescribed ventilatory pressures and volumes. When I read my own medical notes, I saw that I apparently had a habit of "fighting the ventilator" and a "high tolerance for opiates" which meant they needed to increase sedation and paralytics in order to get me to breathe "with" the ventilator. Despite my weakened state, the language used in my medical notes – "fighting" and "pushing back" the ventilator – implied I possessed a type of autonomy and vitality over my physiological position. Even as a sedated and paralysed infant, staff enacted my active participation in the world around me, and went beyond the clinical vernacular in doing so.

Nevertheless, for some time, I assumed that the performance of personalities to infants would cease, or at the very least, *lessen* in the context of heavily sedated and/or paralysed infants. I formed this assumption as the practice seemed in direct tension with a typical Euro-American norm of defining personhood, such as one premised on the ability to experience self-perception in the world, as explained previously (Scheper-Hughes and Lock 1987). I presumed, via the purpose of the drugs administered, that these particular infants were neither aware of themselves, nor their environment, and therefore staff and parents may not use the same language when talking to or about the infants. However, when I encountered three ventilated infants, who at the time, were all sedated and paralysed, my assumption was both challenged and reinforced.

It was an extremely busy day, and the unit was pushing past its patient capacity. I was seated in the little baby room surrounded by six premature infants, including three ventilated, sedated, and paralysed infants. This was the first time I had seen three babies requiring this acute degree of neonatal care. Previously that morning, I'd been talking with nurse Sarah about her perspectives on infant personalities more generally. She told me all about the apparent difference in personality between girl infants and boy infants, which I discuss in the next

chapter. After the arrival of the three new infants, and the intense workload associated with their care, we went back to talking about infant personalities. However, the presence of ventilated babies changed the tone of Sarah's discussion. It was less chipper, more sombre in nature. She told me that the drugs given to the infants "masks their personalities". Her words confirmed the belief that they have intrinsic personalities that could be hidden by the medications.

Continuing along the ethnographic trajectories of Bird-David (2010) and Kaufman (2000), Koksvik (2016) explored ventilated patients in a different setting: the Norwegian adult intensive care unit. Similar to the sedated and paralysed infants discussed previously, these patients were unable to speak or move due to sedation and were generally critically ill. Their paralysed and sedated status further highlights the limitations of essentialising categories of personhood, especially based on place. For Koksvik, patients such as these highlight the complexities present in rigid and typified models of personhood and specifically those which prioritise a Cartesian demarcation of the mind and body: "[Personhood] exists in the context of a network of relationships that include and engage other people, artefacts, employment of senses, and speech." (Koksvik 2016, 140). In effect, relational performances and negotiations of personhood(s) were multi-sited and dynamic on the adult ICU, similar to that of the NICU.

Nevertheless, a language of personalisation was still used in reference to the ventilated and sedated infants. This was despite their lack of perceived "interjections" in conversations and the view by some staff that their personalities were "masked" by the drugs used to sedate and relieve pain. Ventilated babies were unable to audibly cry like Jessie or Xavier. They were positioned by nurses on their backs so not to compromise their ventilation tubes. Yet they were still referred to as "strong" or as "survivors" by parents and staff. However, these words were less like the very individualised words used in reference to the other babies (nosey, feisty, chill). Rather, such words spoke more generally to the clinical position of the infants in question: they were critically ill yet *surviving*; sedated and paralysed yet *strong*. However, this is not to say that I didn't observe deviations: feeders and growers for instance, were talked of as strong "sumo" babies. Alice, ventilated and sedated, was still "cheeky". In coming out of her drug induced paralysis, her left eye first opened before her right and so, in blinking, she winked at us and showed her "cheeky-side". Nevertheless, the more general differences I observed in the language used highlights the role of movement and cries in the designation of personalising traits. It seemed that the more active an infant, the more they wriggled, cried, or positioned themselves in a funny way, the more specific personalising language was used. In

particular, the crying of an infant invoked diverse and dynamic categories of personalising language.

Tears are almost inevitable in the care of infants. With the absence of spoken language, or the dexterity to use signed communication, newborns cry to communicate their hunger, discomfort, and/or frustration. It will typically, at least in my own experience with infants, prompt swift action from the caregiver. Yet, in the little baby room at City NICU, crying was spoken of differently. For one, the cries of an extremely premature infant sounded a bit different to those of a full-term baby. An infant at 28 weeks gestational age generally cried with must less gusto than the surgical babies born at full term in the nurseries across the hallway. For parents, the cries of their tiny infants sometimes prompted tears of their own. For some parents, the cries of their infant were perceived as cries of discomfort or pain thus prompted their own tears of sadness and helplessness. These infant tears were often understood by parents as something negative. This negativity was reinforced by their medically fragile position and the inability for many parents to just reach in to the incubator, pick up, and soothe their infant. Moreover, the cry of an infant was something to be avoided as it was often perceived as a marker of pain or discomfort. However, nurses and doctors often encouraged these cries. As mentioned above, noises or movement from an infant was often framed as an interjection in the conversation, the infant "putting their two cents in" and participating in the nurseries' social life. The infants "chatted to each other" and "set each other off". Some nurses spoke back to the infants in soothing tones. But generally, the cries went unnoticed – often it was hard to hear the tiny cries over the steady noise of CPAP or the groans of mechanical ventilators in the high acuity bedspaces. When I talked to staff about the cries of infants, many took these cries as signs of infant strength rather than suffering. In vocally expressing themselves, via cries, the infant clearly has enough energy and lung capacity to do so. A crying infant is particularly "chatty" and "feisty" – expressing his or her strength and deviating away from the foetal-infant imagery. The infant was framed as having the ability to communicate with staff, albeit understood as a rudimentary mode of communication.

This was clearly a point of importance for some parents, and continued far beyond discharge. I sat with Lisa in her living room, trying to keep baby Paxton from grabbing my hot cup of tea off the coffee table. At around 16 months old, Paxton was definitely getting the hang of moving around the room and exploring his surroundings. He was very much 'present' in our discussion. I remember laughing while transcribing a section of the interview where Paxton grabbed the dictaphone and babbled into it like a toy microphone – a definite highlight of the day. I had

been speaking to Lisa about her experiences with nurses on the City NICU. Paxton was born at 26 weeks gestation and therefore spent a long time in the NICU. He spent over 4 months on City NICU before his transfer to a regional SCBU in his transition home. Therefore, Lisa had a lot of experience with nursing staff across difference units. We talked about her preference for nurses who spoke to, and about, Paxton "like he was an actual person" rather than the reduction of his personhood to his medical status. This was important for Lisa, and many other parents I spoke to, as for them, their infant was far more than their clinical state. Speaking to the infants was one way in which parents and staff were able to reinforce this.

However, for some staff, the personalising of infants was far less important. A neonatologist explained to me that the most important part of the infant, for the clinician, is their diagnosis and/or other key clinical feature such as prematurity. Additional factors, such as infant name, sex, and family composition, are all secondary. Perhaps this explains why I occasionally observed an infant go by their gestation rather than their name during ward rounds. "This 23 weeker required some packed cells overnight" communicated slightly more information than "Alice required some packed cells overnight". Clearly Alice's gestation was more pertinent information here, over her name. Beyond the little baby room, the use of pathologised monikers was also widespread. Term infants who required surgery were collectively called "surgical babies". At the individual level, an infant with gastroschisis was referred to as such: "the gastroschisis baby". In some ways, The infant *is* their disease and some personalising features were subsumed by the state of their physical body.

For Koksvik (2016, 128), this is exemplary of Foucault's (1994) "clinical gaze". Koksvik discussed how the biomedical model is critiqued for its reductive framing of health and disease. Individuals are reduced to organ systems, pathologies, and techo-assemblages, thereby overshadowing additional factors. For Koksvik (2016, 129), "this places intensive care in a rather awkward position, as it remains, arguably, one of the most extensively techno-scientific clinical units of the modern hospital". The NICU occupied a unique position within this awkwardness: at once a highly clinical space, where the clinical gaze takes precedent, yet also a space where personalisation held a particular type of moral value.

The importance of naming was highly dynamic and volatile for many parents and staff I spoke to, despite being of generally less importance for many clinicians. For anthropologists, the naming of an infant communicates clear social, cultural, and political norms and values, as well as illustrating agentive parental power (Bruck 2009). Personal names are often imbued with meaning – whether that be in their aetiology, or in the context through which they were given.

The complex relationship between naming and personhood is important here. For Linda Layne, the context of naming in pregnancy loss highlights some key nuances to Western naming practices when "social birth has been decoupled from biological birth" (Layne 2006, 32). In an environment where the foetus is highly politicised, Layne framed the naming of a miscarried foetus as a political act and dynamically tied to narratives of "person making". The different contexts in which a miscarried foetus was deemed "deserving of a name" (a narrative identified by Layne in the pregnancy loss support rhetoric) highlights the diversity in which we afford particular moral and social statuses to the foetus depending on gestation and the nature of the pregnancy. The example of premature birth at City NICU illustrates a similar tension in the process of naming as a person making process.

On the one hand, assigning a name to an extremely premature infant helped parents to normalise their situation. Naming was an opportunity for parents to more closely identify their infant as *their* baby. For many, infant names were given soon after birth, the fear being that an infant may pass away without a name. But for others, naming was a little more complicated. At a logistical level, an extremely early birth meant some parents had not even thought about names yet. In an example of this, one set of twins were nameless for many weeks – their birth was such a surprise, and not one, but two names needed to be chosen, The choosing of a specific name may also be complicated by an early birth, such as my own. My parents had a general idea of what they wanted to name me throughout my gestation. However, when my mother was put under a general anaesthetic for her emergency caesarean section, my father was left with the responsibility of giving me a name. "Zoe…" he decided on. "…It's because it means life in Greek" he has always told me. His choice of name was specific to the circumstances of my birth, and I most likely would be going by something completely different if I was born to term.

Yet additionally, choosing a name and designating that name to a very unwell infant risks a degree of attachment that may be feared, I'm told by a beside nurse. This nurse continued to tell me about the naming process, using the example of the yet to be named twins I mentioned above. She seemed almost irritated that they hadn't been named yet. She found it "weird" that they hadn't been named as, for her, this was a key step for parents in "personalising the babies" and clearly exhibited a fear of attachment or even an early sign of postnatal depression. This also exhibited an explicit pathologizing of perceived parental detachment from the infants and was a clear example of local norms dictating how parents should feel and behave in relation to their infants.

Affording Agency

Beyond personalising premature infants on the NICU, parents and staff also rendered a sense of autonomy to the infants. This autonomy was described of as both over their own clinical trajectories and as social actors within the NICU and beyond. However, this autonomy was a bounded one – at tension with wider social norms. From the outset, many parents openly talked of their infant's early birth as something which the infant initiated or had ultimate control over.

For whatever reason, the infants "just wanted out" or "were just coming out". Spontaneous premature births were framed as infant initiated. The cause of which was grounded in the perceived wants, needs, and desires of the infant: "she wanted more space", "he was done cooking" or "she was just really impatient". This idea is also visible within tikanga Māori whereby a foetus possesses a type of agency over the birth (or miscarriage) process (Jutel 2006). This type of agency is equally visible in the vocabulary used to refer to the foetus as te pēpi, meaning 'the baby. The more general framing of early birth as infant initiated is also in direct tension with the narratives of maternal bodily failure associated with premature birth and miscarriage whereby blame is directed at the female body. These narratives of foetal and infant agency direct blame and responsibility away from the pregnant woman and/or mother. These points of tension seemed to exist side by side, where there was often a dual acknowledgement of both mother and infant agency in regard to preterm birth.

Infants in City NICU were spoken of as having a hand in their own clinical trajectories – from mundane day to day changes in care, to significant changes such as the decision to withdraw care or cease resuscitation. Furthermore, the language used by parents and staff was not unique to premature infants. I encountered a similar language used with reference to very unwell full-term infants. Throughout her 5 weeks of life, Alice went through stages of "wanting to try less oxygen".[56] Her oxygen requirements ranged from a high concentration through to a lower (albeit still fairly high) concentration of oxygen delivered via a ventilator. If Alice remained stable, every few days staff would reduce the concentration of oxygen she was receiving. Most often, her breathing was supported through mechanical ventilation, but occasionally she was trialled on CPAP. The decision to either reduce oxygen concentration or change apparatus was framed by bedside nurses as one directed by Alice – based on if *she* wanted to try less breathing support. Moreover, if the lower oxygen concentration or pressure was ill-tolerated, the decision

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[56] Although staff spoke of "trying less *oxygen*", it is worth noting that this also denoted discussions about the type of breathing apparatus (CPAP versus mechanical ventilation).

to move back up was discussed as directed by Alice herself: "she wasn't ready and wanted to go back [to ventilation or higher oxygen]". I encountered this language employed by both bedside nurses, medical staff, and parents, who spoke of the infants as "having a say" in the degree to which oxygen support was given.

When Alice required less oxygen, she was a "clever baby" while if she required more, she had "fallen off her perch" or was "making trouble". Her fluctuating clinical requirements were not only talked of in terms her physical health, but were also imbued with social meaning, and metaphor. In the nursing notes from my own NICU stay as a premature infant, I was referred to as a "very clever girl" for only requiring a "whiff"[57] of oxygen via nasal cannula at 3 months old. For both Alice and I, oxygen requirements were spoken of and written about in such a way that communicated more than the clinical picture. Requiring less oxygen was linked to personal traits of the infants, such as bodily awareness and intelligence. Yet this also again reflects the agentive power of those who care for the infants. As previously mentioned, designating personality traits also communicates their wants, needs, and desires for the infant's future.

Common infant behaviours were also framed as markers of infant authority over nursing knowledge and practice. In particular, I encountered certain narratives used to explain infant feeding practices that placed value on the perceived autonomy of the infant *over* nursing-based care. Once it was established that a premature infant is able to digest breastmilk or formula, they were primarily fed through an oral-gastric tube (OG) – a long flexible plastic catheter threaded through the mouth and into the stomach. This was used to provide nutrition at a steady rate prior to infant development of the "suck-swallow-breathe" reflex. When receiving an OG feed, it looked as if the infants had absolutely no control of the nutrition entering their small digestive systems. Using gravity or a mechanised pump, the milk would flow at a set rate and volume. For the nurses, this method was useful as it allowed for a measured volume of milk to be administered and then recorded in a fluid input/output table. Some of these infants had reflux, or milk that would come back up their tube. The nurses called them "cheeky monkeys" as if the children were doing it to entertain themselves. While this is arguably an example of a basic physiological reflex, it was spoke of using a distant language of agency and infant autonomy.

For Georgia, Jessie's twin, this was a frequent occurrence. On a Thursday morning, Georgia's feed took much longer than Jessie's. For her bedside nurse, this was a time consuming

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[57] A "whiff" usually refers to air with an oxygen concentration of, or slightly higher than, "room air".

endeavour. With an eye-roll and shrug, her bedside nurse explains why Georgia is doing this. "She's full" I'm told. "She's one-upping us by forcing her feed back up" she then laughs and looks affectionately at the infant. As if on cue, a bubble pops out from the end of the open syringe – "a burp!". Georgia is framed as being cheeky in this endeavour – "one-upping" the nurses in showing them she can control her own nutrition and can "outsmart" nursing knowledge and practices through subtle contractions of her stomach. Burps, of course, are not intentional at that age, but were cast as such.

The role of the infant in "guiding their own care" has been increasingly appreciated by nursing staff as an important component of their practice. This resulted in the development of cue-based care techniques, and their incorporation into the NICU. Again, while serving physiological cues which are not necessarily intentional, the use of cue based care was spoken of using a language of agency: it allowed infants to "guide their own care". Cue based care is a type of developmental care which places importance on infant behaviours as communicating physiological needs through cues. Feeding is an area where cue based care has been well researched and implemented in the care of premature infants (Shaker 2013b; Altimier and Phillips 2013; Newland, L'Huillier, and Petrey 2013; Gelfer, McCarthy, and Spruill 2015). This practice places value on infant cues to structure feeding as opposed to a "volume-driven" approach which can be stressful for parents and detrimental to infant neurodevelopment (Shaker 2013a; Kirk, Alder, and King 2007; Giannì et al. 2016). Nursing attitudes towards cue based care also illustrates a cognisance of care techniques beyond the intensive and medical techniques characteristic of NICU care:

> Nurses believe they can deliver nursing care in accordance with infants' cues and needs, beyond that provided by advanced medical technology, and incorporate parents into that nursing care (Jen-Jiuan Liaw, Shu-Yueh Chen, and Ying-Ti Yin 2004, 282)

This also highlights the trend towards individualised medicine and patient centred care in the biomedical sector. Within the context of an increasingly neoliberal healthcare system, the framing of medical treatment as patient-centred, not only works to deliver medical care that is individualised and catered to the person, but also arguably directs responsibility away from the cannon of 'evidence based medicine' (EBM) and towards the patient. For instance, if a cue-based care approach, although increasingly considered evidence-based, fails to deliver certain clinical outcomes, the fault rests in the body of the infant in their (lack of) cue expression, not within the underlying assumptions that drive the cue-based approach.

For nursing staff I spoke to about City NICU and beyond, the increasing introduction of cue based care was an exciting development in nursing practice. Yet it represented more than just a culmination of the extensive research on neonatal neurodevelopment. In the language used to refer to cue-based care, staff implicitly designate the infant a type of authority over care.

"I think that is something that is kind of changing more and more, about listening to the baby, and not thinking that we've got it right all the time." (Nurse Practitioner; Northern New Zealand)

"[With feeding,] they run the show" (Registered Nurse; City NICU)

The image of an infant "running the show" and pulling the puppet strings, is important both as it subjectified the premature infant more generally, but also as it directed a type of mild blame away from medical treatment and toward the infant if a treatment or approach failed to work. Rather than simply an object of medical care, the infant was framed as in control, in combination with the expertise of medical staff and EBM. Such agency also, more potently, was spoken of with regard to much bigger changes in infant care trajectories such as the withdrawal of care or the decision not to resuscitate at birth. The withdrawal of care was not a decision taken lightly by staff. This manner of infant death was spoken of almost as a dance between narratives of infant agency over their clinical trajectory, and the clinical expertise of medical staff.

At 5 weeks of age, weighing over 1kg, Alice's intensive care was withdrawn so she would die. Nurses moved her from the main nursery, down the hall, and into a single room down an adjacent corridor. This spatial demarcation communicated the withdrawal of care to the entire staff and other families. This was the last time I saw Alice. I learnt later that she spent the next day still receiving intensive care, while family travelled to visit, and a professional photographer was brought in to take family pictures. Alice was dressed in clothes for the first time, and the sounds of her monitors were muted. I learn that her intubation tube was removed, along with all other monitors. For the first time since her birth, she was free of all lines, wires, and tubes. She was then held by her mother as she breathed on her own without support. She survived in this manner for almost two hours, before taking two final last gasps. I'm told that a nurse then checked for heart sounds, followed by a member of the medical staff. Death was confirmed. Alice's body was then bathed and dressed in fresh clothes. I'm not sure what happened next. Presumably her body was taken somewhere. I was told by one nurse that some

parents like taking the body outside, or near a window so that the spirit or soul can leave the confines of the NICU.

The withdrawal of care appeared medically orchestrated. Even the language used, in that "staff *withdraw* care/treatment" implied an active medically-mediated process done for the purpose of alleviating suffering when all else fails. Close medical and nursing management was visible from the spatial demarcation, right through to the removal of the ET tube and the administration of morphine.[58] Two nurses told me that they are usually tasked with taking a very active role in the withdrawal of care. They will say to parents: "Okay, I am going to take the tube out now" rather than waiting for a parent to indicate that they think it is time. A nurse practitioner tells me that the decision to remove the ET tube is one that should be left with staff, not parents. The symbolic authority over removing an ET tube was understood as too traumatic for parents to wield, and thus it is always up to staff to verbally express their intention to remove the tube, and the responsibility left to the infant to "declare themselves" as ready for death. Interestingly, this was one of the instances where responsibility was actively diverted away from parents.

> *"But also saying to parents 'I'm going to take the breathing tube out now'… not letting them make that decision, it never should be, from my point of view. It never should be the parent's decision to say 'I'm ready now' cause most parents won't make that decision. So, you get them up for a cuddle, and they can stay there all night and all day. And then you say 'Right, your baby is starting to…it's not suffering, but we need to move this on'…taking that responsibility so it's not their choice [the parents] and so they don't feel responsible. That's how I see it." (Darcy, Nurse Practitioner)*

A nurse told me that the removal of the tube does not always lead to the immediate death of the infant. It can take hours, or even days, for an infant to die, all the while their blood oxygen levels drop and their brain and other organs are deprived of oxygen. The duration is why, I'm told, that morphine is often administered. "It helps calm them" I'm told by a beside nurse. However, a known side effect of the opioid is its ability to suppress breathing and lower blood pressure. "It's not euthanasia, but we *do* help them out a bit" I'm told by another staff member. Obviously, this implies at least some medical authority and power wielded over the biological processes necessary for death to occur. In addition, the use of morphine as a pain relief is also used in part to aid the family. While also "calming the infant", the medication reinforces the

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[58] For pain relief.

assumptions of a palliative care model for parents, that their infant "is not suffering" as they die.

However, simultaneously, staff designated the infant agency and authority over their immanent death, and relinquished their own control. The infants "call[ed] the shots" over dying. The infants "declare[d] themselves". They were framed as communicating to staff that they were ready to die or signalling through organ (dys)function that continued active treatment was futile. They did this through not responding to treatments that another baby in another situation might otherwise respond to well. In this manner, the medical decision to withdraw care was corroborated, if not fully initiated, by the infant themselves.

> *"So ultimately, it is about the patient [the baby]. They have made their minds up…The baby has made their mind up that they are really poor, and that there is nothing we can do" (Darcy, Nurse Practitioner)*

Infants as agents of their death and the processes that lead to it again directs a degree of responsibility away from medical practitioners, knowledge, and technology, and thus also an admission of the limits of biomedicine. If an infant "declares themselves" despite the best efforts of medical staff, can biomedicine be blamed as failing to save the infant? This narrative of infant agency both illustrates the limits of biomedicine, while also directing blame and responsibility away from the biomedical institution. However, while this type of agency was made visible in the infants, it was still a bounded agency restricted by the medical institution and beyond. Infants could declare themselves yet were also "pushed too hard" by the medical institution. They instigated their own death yet were "helped along the way". Infants exercised agency but such agency was somewhat structured by the overall aim and goals of the NICU work.

Off the NICU, the complex relationship between infant agency and the agency of others was also visible. During the interview process, I navigated prioritising input from both parents and infants in telling their neonatal stories. Parents told the stories of their infants, while so telling their own stories. Simultaneously, we often designated power to the infants in telling these stories during the interviews. From the moment I stepped into ██ house for an interview, the subjects of the interview – their twin boys – were at the forefront. Their home was toasty warm, a nice reprieve from the wind chill circulating outside. Seconds after sitting on the sofa, ██ handed me a one year old. His warm body eventually settled on my lap facing inwards while he attempted to pull my glasses off my face. As we began the interview, he became wriggly,

and was keen to scoot off my lap and onto the floor with his toys. We took a break from talking and I plopped the infant on the floor. He swiftly bum-shuffled over to his twin, who wore glasses, and tried to pull them off his head. This was with little success as infant glasses are much like goggles, two lenses strapped to the head. I was then presented with the other infant, who quickly curled up on my lap, his head rested on my chest. I felt his breathing deepen and slow as he fell asleep. This interview continued, with the occasional interjection from one or both boys – a cry or squeal reminding us why we were talking. Every squeal I interpreted as the child telling their part of the story and thus highlighting my subconscious desire to somewhat centre the infant in the telling of stories rather than homogenise each into a singular 'premature infant' narrative.

This desire to centre infant stories was similar for staff and parents on the NICU who go went to great lengths in also re-telling infant stories that centred infant agency. Upon admission to the NICU, each family was given a memory book for their infant. These were A4 sized booklets with space for parents and staff to write diary-like entries on day-to-day goings-on and bigger events that they deemed important for memorialisation. They were much like the popular 'Baby Books' that parents of healthy babies use as scrapbooks to record key information, milestones, and photos of the infant's first year of life and beyond. However, these memory books were specialised for babies in the NICU – much like the specialised milestone cards discussed in a previous chapter. These books were designed for both parents and staff to make entries when they wanted. In reading some entries, a certain writing style was clearly visible that centred the agentive power of the infant in question. Staff used second person possessive pronouns in these entries: "You came off the ventilator at 6pm but got a bit tired on CPAP so was re-intubated at 12am" or "You loved your second bath today, much more than your first! You looked comfy in the clothes Mummy said you wanted." These entries were clearly written *directed* at the infant – framed as the infant reading these entries as an older child or adult and implying a hope for their survival to do so. The infant was squarely situated as the subject of this neonatal story – with supporting characters such as "mummy", "granny", "big sister Charlie" and "Doctor Jay". The hope was that the infant would someday read the notes, and again, specific temporal framing of hope and the future, was brought into the NICU.

As I read these entries in some memory books, I was reminded of my own medical notes. Unlike the infants on City NICU, my mother did not receive a memory book. Therefore, I spent time reading my nursing notes instead. However, these were written a bit differently to the

memory books and clearly served a different purpose but also illustrated a type of infant agency through a language of personalisation:

"Zoe is a lovely wee girl, settled all day, although repositions herself regularly"

"Zoe clearly enjoyed her first bath as much as her parents did! She is now sleeping soundly in her cosy clean incubator"

"Clever girl mainly on room air this duty, only requiring a whiff with handling"

Taken from Zoe's Nursing Notes (1995)

These nursing note entries were taken towards the end of my NICU stay, and differ heavily from those taken in the first few weeks. I was referred to as "the infant" much more in the first few weeks, with only sporadic references as "Zoe". The use of my name only increased later in my NICU stay. In the early notes I was much more objectified:

"Infant condition serious and unstable"

"Infant showing little respiratory effort"

"Large bilateral IVH diagnosed in infant this shift"

Taken from Zoe's Nursing Notes (1995)

These notes are short and snappy. Almost no personalisation is present in the notes from my first few weeks. The only exception is "Zoe *fights* the ventilator and requires more sedation than average" illustrating some degree of individuality. Early notes were much more concerned with my clinical state, while later notes were less clinical and more individualised. Simultaneously, for the infant memory books I was privy to, the entries towards the end of the NICU stay tended to be longer and less clinical than those written earlier, quite possibly as the infants were close to discharge anyway and required less clinical care. While this may simply be indicative of those in my 'sample', I find it intriguing that this dynamic was reflected in my own medical notes.

At City NICU, I did not read an infant's nursing notes, unless the parents showed me. From the two occasions I was given a few nursing note to read by parents (they wanted my opinion on what some words were), it was clear there was variation in how nurses wrote their notes. In one note, a ventilated infant was referred to using their name while in another, the infant was "baby". Some nurses added smiley faces after their names, others did not. However all, from what I was able to read, somewhat decentred infant agency: "bradycardia required bagging"

and "parents gave bath". This decentring of infant agency is in accordance with current New Zealand nursing documentation guidelines that instruct nurses to "be factual, objective, consistent and accurate" (NZNO 2017). On a list of "don'ts for nursing notes" the guidelines further specify that notes should never "make assumptions or use subjective/ judgmental language". My own nursing notes, particularly those towards the end of my admission, illustrate many assumptions. For instance, it was assumed I was "clever" and that I actually "enjoyed my first bath". These were ways in which my agency as an infant was assigned by staff who cared for me through their mode of notetaking.

A Bounded Agency?

The narratives of personalisation and agency which I observed in City NICU operated clearly within a diverse set of social norms and values. Simultaneously, infants were spoken of using a language of agency and authority. However, the performance of these features was structured, sometimes bounded and at tension with social norms, professional values, and parental agency. Points of tension included nursing notes and memory books, questions of authority over death, diverse framings of infant traits and characteristics, and the way in which professional authority was both acknowledged and somewhat deferred to the infant.

Upon questioning during interviews, it was unclear whether staff always viewed the performance of infant agency and personalisation as simply bringing to the open features they saw as inherent to the infant (but were unable to express themselves), as a practice used to provide comfort to parents, or as a type of self-care work in dealing with the emotional labour of nursing. I talked with Kath, a nurse practitioner, about the use of personalising objects, such as name tags, on the unit. For Kath, the purpose of the coloured incubator labels I discussed earlier was primarily for the benefit of parents, in her view. These labels help to give parents ownership of their infant, and allow for bonding that is deemed appropriate by staff. This example serves to illuminate one way in which these performances of infant agency and personhood, sometimes via personalisation devises are done so for a myriad of reasons, and operate within boundaries of what is acceptable and what is not.

Conclusions

These dynamic and often unstable narratives of neonatal agency and personhood are also indicative of Kaufman's liminality that is "prolonged and chronic" (Kaufman 2000, 76). Yet for premature infants, who according to cultural criteria, still display markers of social participation and individual responsibility, their agency and personhood is clearly bounded

within the walls of the NICU and social norms associated with newborns, especially those considered medically fragile. Practices of designating agency to premature infants in the NICU were highly complex and often bounded and at tension within a particular set of constraints. Staff and parent models of infant agency are therefore open to manipulation, restructure, and creative (de)valuing to suit certain needs. In particular, NICU nurses made visible elements of infant personhood and agency through narratives of infant self-determination. Staff and parents enacted the will and responsibility of infants, while equally denied other aspects of their agency. Similar to the idea of agency as formulated by Laidlaw (2013), agentive power in the NICU was visible in the ways in which staff and parents rendered infants as possessing intention over their clinical position, traits, and communications. Yet here, agency as responsibility is intertwined with an Ortnerean (1989) vision of agency as entailing power and intention, and equally operated in the NICU in dynamics of interrelated and co-constituted agencies mediated through relationships and narratives. Narratives of agency were important aspects across a multiplicity of premature personhoods in continuous tension, negotiation, and often, contradiction.

5

Interlude: Feeding and Growing

I only spent a few days on the CPAP snorkel. It seems this was one of the breathing device I either really didn't like, or just couldn't get the hang of. According to my nursing notes, I often found a way to wiggle my chin out of the chin strap. This small piece of Velcro is an important part of the CPAP headset. The soft Velcro strap is placed under the chin of an infant to keep his or her mouth closed. With a closed mouth, air pressure from the nose mask is maintained, allowing for the lungs to stay both inflated and oxygenated. As an infant, this chin strap was apparently bothersome, and nurses would find the strap looped across my mouth after having untucked my chin from its grasp. This incidence is mentioned quite a few times in three days' worth of nursing notes. This is maybe one reason I moved to nasal cannula so fast – the pressure of CPAP was being maintain anyway, so I may have well as moved to something a bit more comfortable, right?

After a few weeks equipped with my new nasal cannula, I was moved to a much less acute nursery. I was now officially in the feeding and growing stage of premature NICU care. Over the next days and weeks, I was fed both orally and through a tube. I became fat enough to maintain my temperature better so I was moved to an open cot, and could wear the clothes my mother brought in size 000000. In each successive photo taken during that time, I lose a piece of medical technology – from umbilical line, to PICC, to IV, to tube free and so on. Yet the nasal cannula persist. I learn that this was one of my biggest barriers to discharge – even at three months, I still had a penchant for apnoea's, particularly at night. Maybe I was just too tired to breathe. Nevertheless, my parents were keen to get me home, oxygen and all. I was discharged from the unit just over three months after my birth, at just under 40 weeks adjusted. While I would be readmitted a few days later, my discharge was the first time in three months my parents left the hospital *with their baby.*

Chapter 7: Personhood and Social Categories

Staff used various types of social categorisation to structure engagements with both families and infants across the neonatal unit. While some of these categories were explicitly and intentionally employed to shape care practices, others were much more subtle yet reflected much broader cultural assumptions on what types of lives and persons are acceptable. Furthermore, the performance and framing of various social positions and axes of identity, such as gender, ethnicity, and class, shaped how personhood was articulated and enacted for both infants and parents in the NICU.

The following is a semi-fictional vignette[59] which illustrates some key themes of this chapter. In particular, this vignette not only highlights a composite of experiences faced by diverse parents, but also some of the ways in which both babies and parents are socially positioned as worthy of particular types of interaction, status as persons, and identity as parents.

Maria woke to her alarm at 5am. She'd had a horrible sleep, waking every 30 minutes or so to check her phone for any updates from the nurses on the night shift. Her wife Louise slept through Maria's alarm, and was tucked up in a fleece blanket. She'd fallen asleep with her glasses still on and her open book still resting on the pillow. Louise returned home late last night following a double-shift at the restaurant. Maria then decided to let her sleep a little longer. She took advantage of the quiet moments and headed to the bathroom for a quick shower. She scrubbed her face hard and lathered on moisturiser. The NICU has dried out her skin badly. Freshly washed and dry, she downed an instant coffee and a piece of fruit. Worry tightened her stomach and her breathing deepened as she thought about the plan for her infant today.

Her anxiety was forced to the side as one of the twins raced down the hallway toward her. Bella's hair was ruffled, and her cheeks were still flushed from sleep. She latched on to Maria's leg like a small monkey. Soon Jacob had followed his sister, and was firmly gripped onto Maria's other leg. She was trapped by her two babies, but needed to escape to visit the other

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[59] This vignette uses composite characters to construct a cohesive narrative account based off the experiences of many participants, some of which have anonymity beyond the use of a pseudonym. In this sense, the vignette is *semi*-fictional. I have drawn on the work of Kirin Narayan (1999) in my decision to explicitly state the semi-fictional nature of the vignette from the outset, to maintain ethical accountability to the fieldsite. Anthropologists have justified the use of composite characters as a way to represent many views at once (Angrosino 1998), and for the purposes of anonymity (Ralph 2014).

one that she left behind the night before. Her heart ached at the thought of leaving her twins yet again. They had run out of money to pay the pre-school fees so the twins were left in the care of Louise's aging grandmother 30 minutes away. Since the birth of her baby boy 4 months ago, her twins had grown, passed milestones, and added to their limited vocabularies all the while Maria focussed on the new baby.

Louise appeared in the kitchen. She noticed a new line on her wife's face, right between her eyebrows. Her fringe was long over her eyes, well in need of a cut, so she pushed it back firmly, securing the hair with a clip. Maria opened her eyes wide at Louise, a signal for help. Louise then detached their babies off Maria's legs, bribing them with a movie so they comply. She returned to the kitchen once the kids were settled watching a film.

"So you definitely can't come?" Maria asked. Louise responded with a pained "I told you I can't. My meeting with the boss….it….I need my job." With a sigh of both frustration and understanding, Maria touched Louise's shoulder, before sneaking away so the kids wouldn't notice she'd left. She was halfway to their new, empty, people mover before she ran back to the house. She reminded Louise that the twins' grandmother can only take them from 8am today rather than the usual 7am. "I'll make it work" Louise called out, as Maria ran down the path to escape her crying toddlers who noticed her departure.

Maria drove the 40 minutes to City NICU, and cursed herself as the fuel light illuminated. Petrol would have to wait till her wife was paid. The nagging discouragement over their finances was however, subsumed by the anxiety she felt over the days and weeks to come. Today Maria will learn if her baby can breathe sufficiently without the ventilator. For reasons that she didn't understand, he often skipped breaths or stopped entirely. Something about reflexes or scarring, she'd heard. She wasn't quite sure. The ventilator had showed he'd been breathing over the mechanical breaths provided. This was an indicator he might be ready for CPAP, the nurses had said. She could tell they were concerned though, if his trial on CPAP didn't work, as the registrar on-call had let it slip that they were running out of options. She'd overheard another mutter something about quality of life.

As she arrived at the NICU, she felt a strange mix of relief and tension. She could now see her baby, but she'd left two others at home. She was in a space where she was watched closely by the staff…not to mention the nosey other parents she could always tell were eavesdropping during rounds. She found all the questions about her "husband" frustrating,

as well as those who questioned why she doesn't "look like her son". While she had carried the baby, her wife provided the egg. They had both wanted to be involved in the process even thought it had strained them financially. Maria has often wondered if their roles in the pregnancy were reversed, the outcome might have been different.

As she entered the nursery, she noticed that the all familiar ventilator was moved off to the side. It was unplugged and disconnected. She panicked. "He was extubated just after rounds. Isn't it great…he's doing fabulous!" Becky the bedside nurse exclaimed. "Oh….um… awesome" Maria responds, flustered, and kicking herself for missing the big event that she had lost so much sleep over. She had left her two other babies at home, with a stressed wife, to make this, and her boy's cares weren't for another hour. So she decided to head down to the hospital café for a tea and maybe a treat. "Leaving already?" Becky queried as Maria hoisted her handbag up to her left shoulder. She was hit with a pang of guilt as she explained that she was just going to go out for a tea and will be back in 20 minutes.

She looked apologetically at the incubator, checked her phone for the time, and settled on a hard stool next to her baby. "I think I'll actually just stay here" she mumbled. Her bum quickly became sore from the stool and she craved the tea, but her baby was there, breathing on his own, and for a moment, all was well.

Babies as Gendered Persons

Two week old Jackson, much like any infant born at 24 weeks gestation, sometimes "forgot" to breathe. Sporadically throughout the day, the shrill beep of a monitor alerted us that he was having an apnoea and bradycardia[60], referred to as an "apnoea and brady" by the nurses, due to his premature birth. His bedside nurse walked over to his incubator to have a look. She gave him a little rub on the chest and a touch of the feet, and he promptly began to breathe again.

Jackson's apnoea and bradycardia has a clear clinical explanation. This explanation was located in the physiological development of his heart, lungs, and central nervous system. However, on the ground, in lay conversation and using humour, these events were discussed differently. Jackson was simultaneously a premature infant with an impaired respiratory reflex, and a "laid-back little surfer dude" who was simply "too lazy" to breathe. "The boys are like this" I was

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[60] An apnoea of prematurity means "breathing has stopped for more than 20 seconds" due to an immature or impaired respiratory reflex (Stanford Children's Health 2019). Bradycardia refers to a slow heartrate, and often occurs with an apnoea (Kids Health NZ 2019).

told by nurses: "They often forget to breathe because they're so chilled out and relaxed." For Thomas, another baby born extremely early, his frequent episodes of "forgetting" to breathe took on a gendered and racialized lay-explanation: "he's a wimpy white boy" I was told by another bedside nurse. In isolation, these explanations were curious, maybe a little amusing. Yet, when the twins Jessie and Georgia eventually joined the nursery, along with Alice a few days later, this gendering via medical events was more explicit. Alice, more affectionately known by staff as "Thumbelina", often made the other girls "jealous" as parents and nurses often proclaimed. If Alice went into respiratory distress, drawing attention from doctors and nurses, Jessie was usually close behind with her own respiratory crisis. "She [Jessie] got jealous of all the attention that Alice got" Jessie's mum Morgan told me. "They gossip [Alice and Jessie] and they set each other off" another nurse chimed in. These episodes happened a few times, usually involving some combination of Jessie, Georgia, and Alice, going into respiratory distress within a few minutes of each other. Sometimes, it was all three at the same time "gossiping like little girls". In observing the care of two boys and three girls, who occupied a single nursery, it was very clear their personhood was negotiated and articulated by parents and staff via a complex and dynamic language of sex and gender.

Anthropologists have extensively deconstructed the concepts of sex and gender in framing both ideas as cultural categories and mediums through which personhood is articulated. Although gender is being increasingly framed as a uniquely cultural category in the public imaginary, the category of sex remains somewhat acultural for many people – based on 'natural or 'biological' indicators which are typically viewed to be immutable and inherent to the individual person. Little variety is assumed within a binary view of sex. However, various anthropologists have argued for the sex binary as an equally *cultural* distinction much like the gender binary. Both features are neither cultural universals, nor do not allow for variation of construction and expression. Even the dichotomisation of sex as oppositional or different to gender is both deeply cultural, and criticised. For Butler, the very category of sex, as subsumed by the category of gender is problematic insofar as the category of sex remains a normative ideal (Butler 1993; Bloodsworth 1995). However, in this thesis, I have intentionally chosen to discuss sex and gender as separate (cultural) categories as such demarcation allowed me to highlight the ways in which participants analytically frame the categories as distinct.

Furthermore, sex, like gender, is typically considered as a constellation of features that have been used to categorise individuals as 'male or 'female'. Differences in chromosomes, external genitalia, and hormone levels are traditionally used to assign sex in a binary manner by medical

authority. Katrina Karkazis (2008) examined the role of the medically orchestrated sex binary in the management of intersex individuals. Karkazis highlighted the ways in which deeply-cultural types of knowledge, employed under the banner of biomedical research, are used to manage intersex individuals in such a way that often forces categorisation as male or female. For many physicians, the presence of features which resist categorisation into the sex binary are deemed a pathology of development. The framing of intersex as a pathology has further contributed to harmful cultural norms that it is something to be biomedically managed.

A binary view of sex also reinforces a particular constellation of gender norms and stereotypes which shape experience. These norms are visible at the outset of conception in the gendered framing of gametes. For Emily Martin (1991), human gametes – already culturally categorised as those deemed of a male or female – are further gendered in the language used in reference to the actual germ cells. In medical textbooks and the wider public imaginary, the egg is referred to as a passive entity that waits for "activation" by the sperm. In contrast, sperm are "on a mission" to "penetrate" the egg and actively initiate conception (Martin 1991, 490). This type of language illustrates how, at the level of the gamete, cultural assumptions of sex and gender pervade American medical education.

Various cross-cultural explanations of human conception have also illustrated how cultural framings of sex can begin much before birth, sometimes right at conception. Marilyn Strathern's (1988) fieldwork in the highlands of Papua New Guinea highlighted how the foetus and infant are seen to have both male and female biologies: the mother's blood, and father's bones. Exchanges of bodily fluids and ritual work to mutually articulate individual sexes. Sandra Bamford's (2007) exploration of sex and gender with the New Guinea Kamea also exemplifies a unique framing of male and female biologies at the moment of conception. The foetus is made via struggle between gendered fluids in the uterus. If the maternal fluids are more powerful, the infant is considered female. However, the infant is not actually gendered until around five years of age. Young male and female children lack differentiation. Gender, like personhood, is negotiated through the development of relationships and exchange.

These points of ethnographic comparison emphasise the degree to which both sex and gender are culturally constructed entities from a range of knowledge systems. Further, both sex and gender are things which can be performed on the body though relationships, framings of diverse biologies, and both binary and non-binary frameworks. In City NICU, a medicalised framing of infant sex was tied closely to cultural narratives of a particular type of gendered personhood.

From the outset, sexual dimorphism shaped the way some staff approached the premature infant, both as an object of medical treatment, and as a social body. There is a fast developing body of medical literature exploring the relationship between foetal/infant sex and neonatal outcomes. One nurse told me with certainty that male premature infants tended to have higher rates of mortality and morbidity compared to female infants of the same gestation and birthweight. Various studies corroborate this statement in suggesting male infants have a variety of poorer pregnancy, birth, and neonatal outcomes. These range from higher a rate of NICU admission for males compared to females (Melamed, Yogev, and Glezerman 2010, 340), through to higher rates of morbidity and mortality for male infants (Kent et al. 2012; Ingemarsson 2003; Hintz et al. 2006; Cooperstock and Campbell 1996; Bacak et al. 2005; Itabashi et al. 2009; Naeye et al. 1971; Khoury et al. 1985; Perelman et al. 1986). Nevertheless, according to Kent et al. (2012, 124), the correlation between the male sex and poorer outcomes "appears to lose significance at 27 weeks gestation". Therefore this relationship is most potent for those born extremely premature.

Little is known as to why this difference has been so clearly and repeatedly documented by medical research. Khoury et al. (1985) suggested this to be a result of slower lung maturation in male foetuses given male premature infants have a higher rate of mortality and morbidity associated with Respiratory Distress Syndrome of the Newborn (RDS). Alternatively, some research suggested that the increased rate of male premature birth, along with the associated morbidities, is as a result of placental differences between male and female foetuses or due to differential sex based metabolization of antenatal steroids (Vu et al. 2009; Clifton 2010). Nevertheless, these studies themselves rely on the assumption of basic and immutable sex differences, and ignore the potential behavioural effects of such claims in the NICU. For Cordelia Fine (2011), the hypothesis of a neurobiological sexual dimorphism which shapes behaviour can produce the sex based behaviours the hypothesis is testing. In effect, the assumption that there are, or might be, male or female brains naturalises associated behaviours. The wealth of studies exploring sex-based reasons for neonatal mortality then may entrench the type of sexed and gendered personhoods enacted onto the babies.

Clearly, from the these biomedical studies, we can also therefore infer that medical assumptions about sex also shape the type of personhood designated to the foetus prior to birth. A sociocultural approach further illustrates how the foetus is explicitly gendered in the womb, based on assigned sex, within broader narratives of foetal personhood. Ultrasound technology is a common means of assessing the health of a developing foetus. However, as found in the

literature, the ultrasound also provides a visual means through which the foetus is constructed as a person.[61] Further, it also provisions an additional source of information deemed very important: the sex of the foetus. Although not fail-proof, the ultrasound gives fairly reliable information about the sex of the foetus based on the external genitalia visible through the scan, and how this is interpreted by staff to be indicative of a particular sex. For Larkin (2011), both the clinical and parental preoccupation with determining foetal sex serves to reinforce binary assumptions on both sex and gender.

> *"By insisting on the primacy of naturally sexed bodies, even while deflecting attention from bodies onto images, commodities, and discursive behaviours, the popular discourse surrounding ultrasound imaging of fetal sex and the distribution of the images of fetal genitals produced in the ultrasound examination uniquely reinforce and authenticate the binary sex system as the "biological" limit of gender and sexual variation, as that line beyond which only the abject lies." (Larkin 2011, 286)*

The gendering of premature babies in the NICU may therefore begin prior to birth using ultrasound. When I first spoke to Morgan on the antenatal ward, a few weeks prior to the birth of twins Jessie and Georgia, she referred to her babies [62] as "these girls". Even prior to birth, their sex shaped the language Morgan used to talk about her babies. However, for Morgan and her husband Dean, finding out the sex of her infants was not as exciting as popular media and discourse led her to assume as these scans also revealed a worrying growth discrepancy between the twins. The practice of repeated ultrasounds was simultaneously exciting and scary for the couple. The 18 week ultrasound, usually the point at which foetal sex is determined, also revealed an increase in the growth discrepancy which would ultimately result in their premature birth.

Soon after their arrival to the NICU, small green cards were affixed to the outside of each incubator next to a porthole. These cards registered key information regarding the occupant of the incubator: infant name; doctor and surgeon; national health indicator (NHI) number;

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[61] The use of ultrasound technology to visiblise the foetus is therefore highly political as an act of affirming foetal personhood and displacing maternal personhood (such as Han 2008; Petchesky 1987). The ultrasound may also serve as an instrument of selective reproduction, both on the basis of prenatal genetic diagnosis and in determining foetal sex. These features, among many others, have been examined extensively by medical anthropologists and sociologists alike on a global scale (Mitchell 2001; Georges 1996; Howes-Mischel 2016; Ivry 2009b; Morgan and Michaels 1999; Harris et al. 2004; Gammeltoft 2007; Taylor 2008). Abortion on the basis of foetal sex, although technically illegal in many countries, is aided through the use of ultrasound technology.

[62] I use the term 'babies' and 'infants" here rather than 'fetuses' in order to the use language used by participants. No pregnant woman I spoke to referred to 'the foetus'. It was always "the baby" or "the infant" during gestation.

birthweight; date and time of birth; name of parents; gestation at birth; exact dose of vitamin K given at birth; date of Guthrie test(s); and infant sex. I noticed these cards were often filled out in phases, as if the social categorisation of the infants was something revealed over time. Infant weight, gestation, time of birth, and sex were filled out first, followed by the names of the infant, parents, and doctors. For Jessie and Georgia, most of their information was filled out faster than I observed otherwise. Staff 'confirmed' their sex soon after during their first physical examination. An "F" was written next to the word "Sex" on each green card. If an infant was in fact deemed male, an "M" would be written there instead. Little space was given for sexual diversity. If external genitalia was classified by doctors as "indeterminate" or "ambiguous", the space would be left blank until further testing could be conducted.

The presence of this marker on the incubators highlighted the role of sex in NICU care. One nurse told me that the label "M" or "F" on each incubator is helpful in bedside nursing as it allows a nurse to choose the appropriate manner of cleaning the infant during a nappy change. Perhaps this nurse was having me on here, as I was also told that this information is almost always simply be acquired by "looking at the infant" (something nurses obviously do often), hearing their name, or during the shift change handover discussion between nurses. It is only when there may exist some external ambiguity that the card might come in handy. Even then, this ambiguity is something which is communicated between nurses during shift change. It therefore seems that this space on the green cards served simply as a placeholder for recording key information. Nevertheless this placeholder sets sexual bifurcation as standard – either "M" or "F" were the only markers used.

Binary assumptions on infant sex were further visible in the attention given to exploring sex-based neonatal outcomes. In particular, sex was used as a factor in determining survival estimates for extremely premature infants. I was first introduced to the Extremely Premature Birth Outcome and Outcome Estimator interface early on in my fieldwork. Alice had recently arrived on the NICU. As mentioned previously, I had never seen such a premature infant before (born at 23 weeks). Given her critical condition, I asked her bedside nurse Rachel about "her chances" (this was the way many parents spoke of their infants outcomes, which I began to use as well). Rachel then whipped out a cell phone, from the deep pockets of nursing scrubs, and brought up a website for me to look at. The US National Institute of Health collected extensive data on premature birth outcomes between 1998 and 2003 (National Institute of Health n.d.). This data was then used to devise an outcomes calculator which gives mortality and morbidity estimates, based on inputted characteristics, for premature babies. A key characteristic that

shapes the estimates is infant sex: of which you can select either "Male" or "Female". Again, the sex binary is linked to neonatal outcomes, and found right in the pocket of a bedside nurse. We inputted Alice's characteristics into the matrix: gestation; birthweight; sex; singleton birth; and antenatal corticosteroids. The characteristics generated an 11 percent chance of survival without moderate to severe disability. While this estimate presented a grim picture, it was more than double the chance of survival for a comparable male infant, as generated by the outcomes calculator.

These objects – the green classification cards and online outcome estimators – allowed for little sexual variation and thus reinforced a binary framework of sex (and personhood), especially given the reliance on external genitalia as the preliminary determinate for sex on the NICU. Medical literature has suggested that extremely premature infants classified as "XX female" are at an increased risk of appearing virilised in comparison to those born full term (Ogilvy-Stuart 2004). I did not directly encounter cases like this during fieldwork. However, I was told by a few bedside nurses and past parents of instances when infant sex was initially indeterminate due to extreme prematurity. Extreme prematurity can result in what is referred to in the medical literature as "pseudo-ambiguity" regarding the external genitalia for both male and female infants (Greaves, Hunt, and Zacharin 2008; Callegari et al. 1987; Victorian Agency for Health Information 2017; Kaye et al. 2000). As mentioned previously, I was told that, on occasion, this occurs at City NICU. "The issue", as it was referred to by one bedside nurse, is generally quickly resolved with a more extensive examination of the premature infant. The infant can then be placed in the appropriate category: designated "M" or "F" resolving any confusion. Even a transient existence outside the sex binary created something which needed to be swiftly resolved as it forced a confusion for medical staff that they apparently could not cope with. A reliance on clinically determined sex differences further set the stage for gendering of the infants, proliferation of traditional gender roles based off assumptions on what sex and gender mean, and a type of gendered personhood which is co-constructed through assumptions on sex.

Nevertheless, as mentioned briefly in the previous chapter, the sex of the infant was of secondary importance to one neonatologist I interviewed. Immediate medical needs took precedent over features such as sex, infant name, and family details. Gender was one component of a variety of social categories that shaped how infants were talked of as persons:

"With the competing interests of 45 other NICU babies, the focus is very medical-centric and on the immediate health needs of the baby, and the organisation of the team to ensure that those needs are met in a timely fashion" (Neonatologist, City NICU).

The sex of and infant was at once important and not at all. The "M" of "F" were important identification and classification markers of both sex and gender. Such classification began prior to birth for some parents, with increased cultural value afforded to the foetal ultrasound as determining sex and signposting this as a milestone of normative pregnancy. Upon birth, the physical exam was used to assign sex – as either male, female, or in some cases, ambiguous. There was little space left for further ambiguity. Material objects, such classification cards and survival matrices reinforced the sex binary, as well as the pathologisation of ambiguity in its classification as a "Disorder of Sexual Development" (Balsamo et al. 2012). The resultant gendering was further used as a mode of performing infant personhood, in that, these such performances were very often gendered.

Beyond the Clinical: From Gendering to Gender Roles

At City NICU, as previously described, each incubator and open cot was affixed with a computer generated coloured label communicating the baby's name (in addition to the green information cards). These labels also included cartoon stock images, of the designers choosing. I observed palm trees alongside the name 'Kimberly', a car next to the name 'Jackson', and a fairy princess next to the name 'Maya'. The names were coloured in a variety of shades ranging from blues, yellows, greens, pinks, and purples. I learnt from staff that these nurse made labels were a fairly recent introduction at City NICU. During my own NICU stay as an infant, my mother hand crafted a label for my incubator, and later, open cot. She used a piece of card to colour my given names in felt pens. Each letter received a different colour to create a rainbow effect:

When I spoke with a Nurse Practitioner from a NICU in a different part of the country, I learnt similar incubator labels are common across New Zealand. However, unlike my own, the labels tended to communicate a quality assumed of the infant's person, that was deemed important for the family:

"It's not done by somebody at home. So it's done by the bedside nurse. And she takes a picture in conjunction with the parents from a whole lot of pictures, or something online, or something related to their family some of the farmers want their little boys to have tractors or, you know, something to do with [a local rugby team], or a ballerina, and then its coloured, by the printer, and then the nurse individualises it, and its printed and laminated, and then it goes on the end of the bed." (Neonatal Nurse Practitioner, Northern New Zealand)

The nurse observed that in her unit "farmers want[ed] their little boys to have tractors". Not only does this clearly illustrate how a gendered personhood is relationally constituted, it may also speak to the nature of this unit in serving more rural communities than the more urban City NICU. Also unlike City NICU, these pictures were chosen in conjunction with parents and the decision to use gendered stock images was a more collective one.

I found the presence of soft-toys in both open cots and incubators a rare occurrence on the unit, but particularly in the high acuity nurseries. As mentioned in Chapter 3, infection control took precedent over the decoration of incubators with so-called "comfort objects" such as soft toys. The use of this protocol illustrated a clear shift in the protocols from two decades prior. My own incubator was occupied by a soft toy rat which dwarfed my small body. In photos, I can see that the rat was wedged between the plastic edge of the incubator and the soft bunches of blankets rolled outward creating a raised nest for my body. The rat was dressed in a blue and suit with a green bowtie. The tail could be pulled for a short musical number. Ever present in photos, the rat gradually seemed to shrink in size as I grew bigger alongside.

The soft corduroy of my soft-toy rat was striking in contrast to the soft toys I saw at City NCIU. Unlike my own, these were enclosed in plastic specimen bags, perched at the very end of the incubator, and far from baby's reach. Similar to name tags and sheet sets, many soft toys were equally gendered, either in colouring or form. For instance, in a single nursery on one specific morning, I observed a plush (plastic enclosed) green dinosaur alongside a male infant, a small doll in a yellow dress perched next to a female infant, and an anthropomorphised brown tractor-trailer toy adjacent to another tiny male.

These incidences of gendering via objects on a single NICU, while on a much smaller scale, speaks to the wide reach of how neonatal patients are gendered globally through the proliferation of explicitly gendered NICU practices made popular through news media. Two specific articles from online lifestyle news outlets gained popularly across social media for

their portrayal of the NICU space. In addition to increasing public awareness of the neonatal sector, these articles illustrated a gendering of infants that was deemed publicly acceptable and even endearing. A NICU in Chicago, Illinois routinely celebrates Halloween by dressing patients in costumes. The photos in a Huffington Post article (Bologna 2017) depicted infants dressed as male boxers, pink rabbits, peacocks with a bow, wonder woman and superman. The public Facebook page for the Chicago hospital (Advocate Children's Hospital 2018) also uploaded pictures of costumed infants with captions such as "Ella is a majestic unicorn" (dressed as pink sparkly unicorn), "Caroline is having a blast under the sea" (dress as Ariel from The Little Mermaid), "The force is strong with Nyxon" (dressed as a Star Wars Jedi), and "Erik is ready to protect his city" (dressed as Batman in blue). A HELLO! Magazine article (Barcelona 2017), which was shared significantly across social medical platforms, shared pictures of nurse-led graduation ceremonies for premature infants at a NICU west of Charlotte, North Carolina. Infants were posed for professional photos in personalised graduation caps coloured pink or blue. The wealth of comments that referred to the photos as "precious", "cute", and "hilarious" highlights the manner in which this attribution of gender through clothing went unquestioned by public consumers. The undisputed nature of such gendering was mirrored in City NICU.

Nevertheless, the presence of gendered objects and practices such as those discussed above are not unique to the neonatal sector, and feature in pregnancy and infant care more generally. Sallie Han (2013) explored some of the ways in which infants are rendered persons through practices associated with pregnancy. She discussed how infants are gendered in the womb through language of the sonogram and through the accumulation of gendered objects. She highlights the distinction between baby "gear" (large items deemed necessary e.g. car seat, crib, and highchair) and baby "stuff" (smaller items of lesser importance such as toys, clothes and décor) (Han 2013, 163). The author observed how the purchase of these objects is often gendered – men purchase *gear* and women purchase *stuff*. Furthermore, she also highlighted the way in which these objects communicate the gender of the infant prior to birth, through colour and form. How the infant is related to is shaped by gender norms even prior to birth. Parents' consumer practices served to reinforce the gender binary from the outset. While the gendering of premature infants is therefore far from novel, gender stereotypes reproduced in the NICU represent an amplified mode of person making whereby objects not only reinforced gender roles, but also reified how precarious states of personhood were managed through material objects.

Beyond material objects, a gendered vocabulary was also visible in how parents and staff spoke of male and female infants on the unit. The opening of this chapter gave specific examples of the gendered language used by parents and staff in reference to the infants they cared for. This language was used both in reference to day-to-day infant care and regarding more critical high acuity care. For instance, as highlighted in the opening vignette, the fairly frequent desaturations and bradycardias that affect an extremely premature infant were spoken of differently between Jackson and Jessie, as I observed on multiple occasions. While Jessie's desaturation was attributed to her feistiness and cheeky nature, Jackson's apnoea and bradycardia was spoken of in reference to his "laid back surfer dude" attitude.

The use of gendered language in explaining the medical events of premature infants has not to my knowledge received any academic attention.[63] As previously discussed, clinical research suggested that female premature infants have a higher likelihood of survival compared to male counterparts of the same weight, gestation, and birth characteristics. I observed a distinct correlation between the ways in which these sex based assessments of risk are enacted on the unit (discussed in the first section of this chapter) and the gendered language used to refer to male and female infants. Female infants, predicted as having better outcomes, were referred to by both parents and staff as "feisty", "stroppy", and "angry". "Girls are fighters" I was told by a bedside nurse. In contrast, male infants are "lazy", "laid back", "wimpy" and "chill". Not only was this language used to explain medical events, it is exemplary of how the sex based survival data is explained through narrative. Gender was a mode through which diverse narratives of survival and strength were articulated.

However, the language used to refer to female infants illustrates an interesting tension. This is a tension which is similarly present in contemporary stereotypes of femininity in adulthood. Female premature infants were simultaneously deemed feisty and angry yet also dainty and delicate – "like tiny Thumbelina". While expected to fulfil the assumptions associated with increased predicted survival, performances of gender and personhood were still located around gender norms that characterised the female body as cutesy, fragile, inferior, and in need of

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[63] However, some linguists have explored the exchange of gendered language between young children and their parents (Endendijk et al. 2014; 2019; Friedman, Leaper, and Bigler 2007; Judi Mesman and Groeneveld 2018; van der Pol et al. 2015). Endendijk (2014) found that when reading a specially designed picture book on gender to their children, parents engaged in "gender talk" that involved reinforcing particular gender roles and stereotypes. When reading to their sons, fathers in particular emphasised gender appropriate tasks and behaviours in their discussions with the sons. Although my study is contextually associated to both the NICU and to infancy, the data shows that the use of gendered language extends far beyond hospital boarders into the private realm of parenting at home.

protection. Similar to the performance of agency, the use of gendered language and objects on City NICU was equally justified by staff as for the benefit of the parents: name tags reduce "sterility" and other objects "help personalise them [the infants]". However, staff made no reference to the *gendered* nature of these practices. In addition, these practices and language were equally used by parents away from the NICU or before their arrival. Therefore the reproduction of such gendering cannot be attributed to staff alone – especially given the literature which suggests parents play a role in reinforcing gender roles and stereotypes for their children. Such language and practices were another way in which parents and staff worked to attribute agency and personhood to the premature infants. These actions are personhood-affirming – albeit also gendered in nature.

Anthropologists have more widely observed the dynamic relationship between gender and personhood across the lifespan and cross-culturally. A brief discussion of these is important in highlighting how understandings of gender are culturally constituted often alongside, and within, those of personhood. In their aforementioned comparative exploration of Euro-American and Wari' personhood, Conklin and Morgan (1996) observed that processes of sexual development and associated gender roles are enmeshed with the development of an individual as a person in Wari' society. Full personhood is achieved once male and female youth undertake specific practices associated with their sexual development, such as sexual intercourse for females, and warfare for males. Nevertheless, as highlighted in chapter 1, this personhood is dynamic: not partaking in sexual intercourse or warfare may result in a loss of personhood for female or male members, respectively. For the Wari', personhood and gender roles are inseparable – one maintains the other. Sarah Lamb (1997) examines a similar relationship between gender and personhood for Mangaldihi men and women in West Bengal. Trajectories of personhood here are equally gendered:

> *"These contrasts [between men and woman] can be said to begin with differences perceived in the biologies of the two sexes, differences magnified by practices in upbringing and marriage. The contrasts can also be said to derive from patrilineality and virilocal postmarital residence, which favor the continuity of men and the transformation of incoming women. These perceptions and practices continually led to contrary treatments of the genders: the most important connections of males were made but once and intended to endure throughout and beyond their lifetimes, while those of females were repeatedly altered-first made, then unmade and remade, then often again unmade." (Lamb 1997, 290)*

These studies illustrate how experiences of personhood as a continual or dynamic state are therefore shaped by various social categories. For females, marriage is a distinct process of reshaping personhood – a reframing of kin ties considered integral to her development as a person within the social group. Again, gender is a diversifying characteristic for men and women. Assigned gender shapes how an individual is accepted within a social group through the enactment of gendered practices and roles. Further, this also illustrates how social categories, such as sex and gender, offer a useful lens through which to view the diverse ways in which personhood is articulated in both the NICU and beyond.

Anthropological studies of this relationship have primarily looked beyond the Euro-American context, and focussed significantly on older children and adults – such as the studies discussed above. Less explicit attention has been paid to the relationship between gender and personhood for the foetus or infant. Scholars have mainly observed the foetal ultrasound, specifically in determining foetal sex, as one way in which the foetus is 'made' an infant (and a person) in the womb (Taylor 1998; 2008; Han 2013; Roberts 2012; Gammeltoft 2014). Analyses of 'gender reveal parties' equally illustrate the importance placed on foetal sex in imaginaries of the foetus as a member of society.

Scholars have highlighted the role of ritual in the gender reveal party as one manner in which a gendered foetal personhood is actualised. Florence Pasche Guignard (2015) argued that these parties are premised on a ritualised dynamic of secrecy and disclosure. Private knowledge, foetal sex, is made public through the cutting of a cake or the popping of a balloon. For instance, a plain cake is cut to reveal a pink or blue dyed interior. Another means made popular via social media technology is the marketing of a black balloon filled with the buyers choice of either pink or blue confetti. The balloon is popped in front of an audience of family and friends to reveal the (predicted) foetal sex. Videos of the process are shared frequently on social media. This speaks also heavily to the role of social media in both signifying and mediating moments deemed special or important to share in daily life (Ross 2019; Gershon 2014; Miller 2015; Edwards 2012). Janelle Applequist (2014) further explores the ritual of the gender reveal made public via the social media platform Pinterest. The portrayal of party ideas on the platform, whose primary consumers are women, highlights how these parties, and associated consumables, fortify the gender binary and communicate what it means to be a baby boy or girl even prior to birth.

There exist clear implications from the study of sex and gender in the NICU, for both studies of gender and personhood, within anthropology and beyond. Parents heavily contributed to the

reinforcing of gender norms for infants. This is also prevalent beyond the walls of the NICU – despite a growing body of push-back in activist sectors. In City NICU, parents and staff performed infant gender as a manner of performing infant agency and personhood. These features were enmeshed and shaped by more general assumptions on infant gender. Yet, these were shaped in a way that was context specific. For instance, the use of gendered objects was reconfigured to more accurately fit into NICU life, such as the use of plastic bags.

I suggest that one reason these norms were so pervasive in the unit is due to their role as personhood-affirming. The language used and practices employed, although gendered, provided an opportunity for parents to treat their baby as they would if the infant was not in a precarious medical position – treat them just like any other baby. The heavy commercial presence of infancy as gendered means the tools available to parents (particularly in the adornment of the bedspace) are often explicitly targeted towards 'boys' or 'girls'. The clinical presence of sex, and pathologisation of sexual ambiguity, allowed for limited variation in how sex and gender are configured. Such gendered narratives were also used alongside an intersection of other social categories to articulate different types of infant personhood that were contingent on the diverse performance of familial social positions.

Ideal Parents, and Ideal Babies

"It's all crying babies and breastfeeding" I was told by Jaime, a bedside nurse. "That's why there are barely any male nurses in NICU. It scares them away…it's a very woman-focussed space." This was Jaime's explanation for the dearth of males who worked as nurses at City NICU. However her comment also revealed another view of the neonatal space: that it is female centred, and a space where mothering is prioritised yet burdened. On the unit, *parenting* was very much synonymous with *mothering.* For a myriad of reasons, fathers often took a secondary role while on the unit. Primary responsibilities, including the burden of care, were generally undertaken by the mother. For this reason, and as will be explained further, this section will primarily discuss the social positioning of women as parents on the unit. The lesser representation of fathers' voices in this chapter reflects the more limited participation of fathers in this study – both as interview participants, and in their presence during my period of participant observation.[64] The experiences of mothers on the unit, and the ways in which certain

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[64] This relative absence is illuminative in itself: as the NICU space was one of mothering, so seems that of neonatal research. Amy Mackley and colleagues call fathers the "forgotten parent" in NICU research (Mackley et al. 2010, 200). The maternal experience is often prioritised, both in research and in practice whereby the mother's perspective is taken as "gold standard" for communicating parental response to having a child in the NICU

families were framed by staff, highlights both how female personhood and agency was sometimes reduced to, enabled by, or constructed with their role as mothers and parents, and how their social positioning shaped renderings of infant personhood.

For many mothers in the NICU, their physical body framed much of our early discussions on their pregnancy and their introductions to motherhood. Even from pregnancy, some women framed themselves as already failing at motherhood: "my body wasn't working and I felt like I was failing as a mother already". Participants used a language of early parenting when they spoke about their pregnant selves in retrospect. Much like expectations around good parenting were pervasive at City NICU, these seemed to extend prior to birth: being a good parent begun prior to birth, or even prior to conception. Thus, how parents were judged in the NICU was closely tied to their actions prior to birth and the features of their lives which existed prior to conception. Although an analytical melding of pregnancy with parenthood has political implications, I treat pregnancy as a type of early parenting, of the foetus, as this is how many parents spoke of the stage in retrospect. Further, this also illustrates the far reach of expectations surrounding parenting and the responsibilities involved. The actions of the pregnant woman were framed as both instrumental to the type of person she would birth, and to the type of mother she would be to that person.

Pregnancy: Making Parents?

> *"You wonder if maybe you ate better, or you were the right BMI, that might have made a difference…you feel guilty"*
>
> *(Rose, mother to Alex born at 29 weeks)*

From conception, biomedical rhetoric designates a great deal of responsibility over the developing foetus to the mother. The close clinical surveillance of pregnant women reinforces the notion that the pregnant body is at risk, and that the conditions of pregnancy greatly shape the infant she will birth. This section discusses the ways in which the pregnant woman's physical body is afforded utmost importance in shaping the outcome of the pregnancy, both in the clinical literature, and in public health rhetoric. As a result, mothers at City NICU experienced pressure from medical professionals to manage their bodies in a particular way

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(Arockiasamy, Holsti, and Albersheim 2008, 220). Nevertheless, the value of fathers' voices cannot be understated, especially in traversing the spaces considered traditionally feminine, such as childbirth and rearing. While this chapter primarily focuses on mothers' experiences, simply by virtue of the participant sample, explorations of fathers' experiences (as unique to mothers) are an important and necessary avenue for future research.

when they were pregnant. Women spoke of their pregnancies much like they spoke of the expectations and parental responsibilities toward their babies. A positive birth experience and healthy infant was promoted as within their control. Guilt and self-blame ensued when the desired outcome was not reached. Guilt was specifically located both in a perceived "failure" of the body and in a failure as a mother to 'produce' a contributing member of society. Raspberry and Skinner (2007) encountered a similar relationship between the pregnant woman and responsibility but in terms of genetic disease. Some women in their study experienced guilt and self-blame over their genetic material, similar to the experiences of women at risk of premature birth or who had experienced premature births. The authors used the concept of "embodied historicity" in referring to the highly temporal nature of how the genetic diseases and their heritability has been understood. Locating an embodied historicity, as a type of relational personhood, in the condition of the premature infant provides an important link between the origin of the infant and the potential feelings of self-blame and guilt of the mother. For some mothers I spoke to, the body of their infant was not only the locus of maternal responsibility, but also an index of the conditions of their pregnancy.

Drawing on a significant body of clinical literature, public health rhetoric has promoted the instrumental role of maternal health in positive birth outcomes. In New Zealand, the Ministry of Health continually produces a variety of maternal health promotion outputs, including advertising and written publications targeted at both pregnant women and medical professionals. These outputs mainly give recommendations on topics such as maternal weight, alcohol and drug consumption, diet and exercise, and stress. In these publications, appropriate weight gain during pregnancy is linked closely with positive outcomes:

> *"It is normal for women to gain some weight during pregnancy due to the growth of the fetus, placenta and amniotic fluid. However, too much extra weight during pregnancy can lead to adverse outcomes for the mother and/or baby."*

> *"Healthy eating is especially important during pregnancy as it supports optimal fetal growth and development. Physical activity along with good nutrition will contribute to a healthy pregnancy weight."*

> *(Ministry of Health 2014a)*

This excerpt from a Ministry of Health publication targeted towards medical professionals highlights the importance of maternal self-management in maintaining a "healthy pregnancy". Factors such as diet and exercise are promoted as instrumental to foetal health and therefore

the responsibility of the pregnant woman. Promotional material directed at pregnant women also reinforces the importance of self-surveillance and appropriate health management in achieving a positive neonatal outcome.
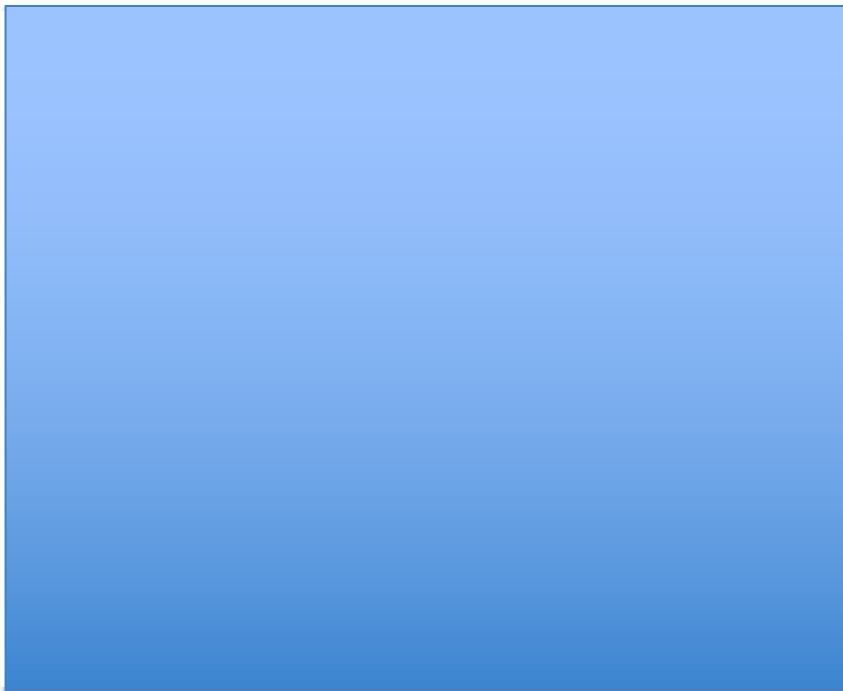
Figure 4: MoH Guidelines on Pregnancy Weight Gain

Figure 4 (Ministry of Health 2014b) illustrates how weight management for pregnant women is portrayed as crucial to a healthy pregnancy and birth. Management strategies, such as weight recording and diet plans, are given to help control how much weight a pregnant woman gains. These publications and dialogues frame weight management as for the benefit of the pregnant woman and foetus. In both documents mentioned above, little attention is given to the wider social and cultural contexts which shape weight during pregnancy. The authors imply that pregnant women have equal access to the weight management resources outlined, such as wholegrain bread, fresh vegetables, home cooked meals, and designated time to exercise. In addition, the reliance on BMI to quantify healthy weight means other factors such as muscle mass and ethnicity are not taken into account in these publications. Heath promotion materials such as these further set such features of a healthy pregnancy as integral to the birth of a healthy infant. The woman is given responsibility over maintaining a healthy pregnancy and the ability to produce and mother a healthy infant.

The above is a clear example of the way in which women are responsibilised to control neonatal health outcomes, and by extension, the different ways in which neonatal personhood will be articulated. This speaks heavily to a multi-disciplinary body of literature that has explored how discourses of responsibility are deployed as a mode of neoliberal state control. For Nikolas Rose (2001; 2006; Rose and Novas 2007), control is exerted over subjects of the neoliberal state via discourses of the body. The individual must, and should, manage and therefore control their own health through bodily surveillance and other practices deemed healthy. This at once gives the illusion of body autonomy while also reducing the state's responsibility to citizens. Rose's discussions have been further developed and applied to a variety of social contexts. Trnka and Trundle (2014; 2017) warned against reducing the concept of responsibilisation to a structure and agency dialectic. Rather, they argued that discourses of responsibilisation are best viewed alongside, and in conjunction with, "a matrix of [other] dependencies, reciprocities, and obligations" (Trnka and Trundle 2014, 150). Using this framework, it is hence important to understand the above discussions of pregnant women within a wider context whereby women are not only met with responsibilities towards themselves and the state, but also the foetus as an individual person. These expectations arise from state rhetoric, as well as the expectations of peers and the individual. Furthermore, the presence of the foetus as part of this configuration of responsibility deepens the moral imperative associated with 'the healthy citizen'. The pregnant woman is not only under a neoliberal moral obligation to pursue and maintain health for the sake of being a productive individual, but also has an equally

important obligation to parent another productive citizen. However, as argued by Trnka and Trundle, it is necessary to look beyond these discourses of state mediated responsibility in a vacuum of obligations. For the mothers of premature infants in this study, their pregnant selves were retrospectively responsibilised via a mechanism of self-blame after birth. Yet, this self-blame was also nuanced by the staff narratives that a premature birth is an event beyond anyone's control.

Expressions of guilt and self-blame were common features in my interviews with mothers of premature infants, especially when the premature birth was understood as a result of an issue with the woman's reproductive system. There included instances of cervical incompetency, placental insufficiency, and structural abnormalities such as a bicornate uterus[65]. The language used to describe these causes was one of deficit. "Insufficiency", "incompetency", and "abnormality" were all words used to describe why some women went into labour early. For many, these were communicated as the diagnoses:

> "So it turns out I've got a septate [bicornate] uterus. It's a bit shaped like a love heart… I'm waiting for surgery for mine. They'll take away the septate, and then … cause apparently that causes prem or miscarriage"
>
> (Jacs, mother to Luka, born at 27 weeks gestation)
>
> "They pretty much told me I had cervical incompetence. So once baby would reach a certain weight, my body would think that I was going into labour.
>
> (█████)

Even for women who had no definite or documented cause of premature labour, a sense of bodily failure and associated guilt was common. These were more to do with possible differences in lifestyle during pregnancy or features such as maternal weight. The maternal body was very much framed as "an agent of quality control" (Rapp 1990, 115), possessing a moral obligation to produce, and parent, a healthy infant. Many women spoke of what they could have "done differently" during pregnancy as something which they thought about often now as a parent to a premature infant. However, many also expressed that the conditions of birth were simply beyond their control:

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[65] A bicornate uterus is a deviation from what is considered a typical shaped uterus. It is often referred to as 'heart-shaped" (Healthline 2019).

"I still think about what I could have done differently to prevent her…to prevent what happened. I went through a stage of blaming myself. But that was stupid cause nothing I could have done could have prevented it."

(Kirsty, mother to Eden, born at 33 weeks gestation)

This conforms with the common message I heard nurses tell mothers on the unit that premature birth is often something that "just happens" and is not something "to beat yourself up about". However when these statements are taken in conjunction with ideas from health promotion materials, the message is altogether confusing. During pregnancy, the woman is told to behave in a particular way to reduce the risk of negative outcomes. Yet following premature birth, staff attempted to alleviate the resultant maternal guilt through emphasising that premature birth is an event somewhat beyond control.

Performing Parenthood

Parenting was performed on the unit through a variety of interactions, tasks, and experiences. These often differed extensively from those understood to be traditional tasks of parenthood, yet also communicated certain norms on how a 'good' parent should behave, and how the intricacies of parenting might shape infant personhood. Here I work alongside a wider trend in anthropology to simultaneously examine how particular cultural categories of kinship, specifically motherhood, are destabilised, but also explore the ways in which the categories are reinforced and reproduced. Parenting practices on the neonatal unit highlight the dynamic power of these kinship categories: such practices both challenge and reify parenting norms beyond the biomedical context. Further, parents were positioned under different social categories of ethnicity, gender, and class, which further shaped cultural assumptions on infant personhood, such as how the social characteristics of families are used to justify care insofar as those characteristics are assumed to shape infant personhood.

While I use the term parenthood to indeterminately refer to those who themselves identify as parents – whether that be a mother, father, or other caregiver – it is necessary to acknowledge that the term is heavily gendered and that the role of parent encompasses much more than childcare. Some have argued that the term 'parenthood' fails to acknowledge that "mothers are still people who do most childrearing and have [the] most responsibility for children." (Phoenix, Woollett, and Lloyd 1991, 5). As discussed previously, the terms mothering and parenting were used rather indiscriminately on the unit simply by virtue of the fact that the vast majority of parents who spent time on the unit were women. However, I have chosen to use

the term parent as it is an attempt to take into account the dynamic nature of care that I observed on the neonatal unit. While the majority of individuals I spoke to fit squarely within a normative biological category of 'mother' – that is, they provided the genetic material and carried the infant – there also exist many additional embodiments of parenting that are beyond such normative categories. However, I use the term 'mother' when used by participants as it often denoted a uniquely gendered aspect of the parent role. The personhood of the women in my study was very much intertwined with their, often relatively new, identities as mothers.

In addition, it is also important to acknowledge that parenthood encompasses far more than child care. Rather, a variety of additional roles and responsibilities intersect in the social construction of a (good) parent. Anthropologists have also acknowledged the degree in which the role of a parent, and the practice of parenting, is particularly value laden and oblique as far as what is deemed 'good' and 'bad' parenting (Faircloth 2013). Parenting an extremely premature infant is both familiar and different to parenting a healthy infant. For instance, both infants require feeding. However, different methods are often used. Both parents are scrutinised by other individuals. However, such scrutiny is often on the basis of vastly different measures of 'good' parenting and often make reference to social categorisation of parents.

At the intersection of disability studies and anthropologies of kinship and reproduction, scholars have explored how parenting, and mothering, a medically fragile and/or disabled infant shapes the role and identities associated with being a mother and/or a parent (such as Gammeltoft 2014; Rapp 1996; Singh 2019; and Timmermans & Buchbinder 2015).[66] Many such shifts greatly resemble those experienced by parents of premature infants in NICUs. In New Zealand, these shifts also operate within a legacy of colonialism and enduring institutional racism. Gail Landman (1998) highlighted the experience of parenting an ill and/or disabled child as transformative in defining what it means to be a parent or mother. For instance, parenting in this context often means relinquishing a degree of authority to medical professionals. Successfully deploying 'parental' knowledge over that of medical expertise is deemed a "special hallmark" of parenting a medically complex or fragile child (G. H. Landsman 1998, 83). This also highlights the way in which different knowledges and

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[66] In their respective ethnographies, Gammeltoft (2014), Rapp (1996) and Timmermans & Buchbinder (2015) explored some of the ways in which cultural attitudes of disability and/or medical complexity/fragility shaped experiences and identities of (potential) parenthood in the contexts of selective reproduction and newborn medical care. In the field of disability studies, Shailen Singh explored how he internalised his son's diagnosis within his identity as a father. Further, these studies have, in part, highlighted the processes of identity transformation that take place when parenting a disabled or unwell child, that differ from parenting an able-bodied and/or neurotypical child.

authorities may conflict in the treatment of such infants or children. Landsman observed how these diverse responsibilities of parenting often begin in the NICU context. An examination of parenting in the NICU context is therefore important as this is often the initial space where such diverse roles and responsibilities emerge. In particular, narratives of attachment and detachment are central in anthropological explorations of both personhood and parenting in the Neonatal Intensive Care Unit.

Both attachment and detachment are enacted creatively by parents with premature infants on a Danish NICU. Navne, Svendsen, and Gammeltoft (2018) conducted extensive fieldwork at a Level Three NICU[67] in urban Denmark. The authors observed a variety of strategies deployed by NICU staff to encourage parental attachment to their infants, regardless of their acuity or prognosis. However, for parents, a conscious detachment was used as a mode of parental attachment:

> "Refraining from touching, holding, and feeding their infants during critical periods, the parents enact detachment as integral to their practice of attachment…they navigate the broad continuum of forms of attachment and detachment" (Navne, Svendsen, and Gammeltoft 2018, 15).

The authors positioned parents as creative actors in shaping their early engagements with their infants. Much like the personhood of an extremely premature infant is unstable, the personhood of parents *as parents* was equally unstable and enmeshed with the infant personhood in that "bonding" between the two was culturally valued. While, like Navne and colleagues, I observed detachment as a mode of attachment on City NICU in the form of a physical and emotion separation, this enactment was highly nuanced to a New Zealand context – both in terms of the unique sociocultural climate, and in the great differences surrounding how New Zealand units are organised.[68]

I spoke to many mothers on City NICU about the daily activities they undertook on the unit which "made [them] feel like a mother". These activities were learned and the capability to do so was something accrued over a period of days, weeks, and months. Practices, such as feeding and clothing the infant, allowed the women to undertake a mothering role. Not only did these

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[67] A level three unit provides neonatal care to the most unwell and acute infants.

[68] While many NICUs across Scandinavia actively encourage parents to permanently reside alongside their infants in a private nursery, "rooming-in" (sleeping on unit with the baby) is only allowed in New Zealand NICUs as a test-run in the days preceding the infant's discharge.

practices aid in the management of precarious infant personhoods, feeding and clothing simultaneously reified a maternal personhood through the formation of relational bonds with the infant.

I spoke with Anna, a single parent of twin boys born premature, over coffee during her lunch break from a corporate job. She walked me through how she "learned to be a mum" during her boys' stay on City NICU. Integral to this process was doing "cares" (discussed previously). Doing cares, along with feeding and clothing her infants, fostered an intimacy with the babies which was challenged by their precarious medical position and physical separation through an incubator. For many parents, these practices were both a place of hope and excitement, but also one of fear and risk – something which needed to be learned and developed over time. For instance, for Abby, dressing Molly in clothes was a scary activity yet it fostered the maternal relationship, made Abby feel more like a mother, and helped mitigate Molly's unstable medical history:

> *I felt bad cause I wanted to do it [dress baby], I'd love to do it, but I also don't want to, you know, hurt her or wreck something that's going on in her body…But it was a big one [putting her in clothes]. I was like 'Yay'. Like 'You're a real baby now'." (Abby, mother of Molly, born at 26 weeks gestation)*

For Abby, the act of dressing Molly reinforced an attachment to the baby which was previously at risk due to the infant's precarious medical position. These practices promoted a sense of normalcy in an "alien" environment. Although different to infant care practices undertaken away from the NICU, these practices allowed parents to feel more secure in their role as *parents* to the babies and highlighted the increasing role of parental identity in personhood:

> *"I liked doing her cares, and Matt [husband] did too. It made us feel useful. More like actual parents. Like changing nappy and giving her a wee bath. I enjoyed it. One time my mother in law was late picking me up and I couldn't go in to do her cares, and I was just so upset. It's like the one thing you can do for your baby. It was so important for me. I didn't really feel like I was her mum for quite a long time until more and more of those things started happening, like getting [her] dressed, and then later, I learned to tube feed her, and by the time we got home, I had transitioned to being her mum by then. But at the start it was hard cause there really wasn't much I could do."*

> *(Jenn, mother to Aida, born at 30 weeks gestation)*

"Having some wee clothes of her own helped me just sort of feel like I was dressing her up and mothering her a bit

(Kirsty, mother of Eden, born at 33 weeks gestation)

For Jenn, it was the increased responsibility over Aida's care which really helped her to feel like a mother. This was a common theme in interviews with parents, specifically mothers, who had extended NICU stays. I observed both extreme excitement and trepidation when parents were first allowed to dress, wash, feed, or do "cares" for their infant. Increased responsibility and autonomy over infant care was key in the formation of both parental identity, and the culturally prioritised development of a nurturing relationship between parent and infant.

In an ethnographic study exploring human-object relations in an American NICU, Landzelius (2003) identified numerous structures which obscure infant personhood through impinging on the maternal ability to bond with the baby. The techno-medical collectives, such as incubators and drug support, act as substitutes for the maternal role, thus effectively making the mother physiologically "superfluous" in sustaining the life of her premature baby, while also restricting physical access to her child (Landzelius 2003, 2). An "epistemology of hygiene", the privileging of hygiene over human contact, also restricts the mother's access to her child for fear of exposing the baby to infection (Landzelius 2003, 1). In addition to these physical barriers, there also exist distinct cultural barriers between the baby and visiting family. Women may blame themselves for the traumatic circumstances surrounding the untimely birth of their infant. Maternal self-blame is an outcome which has been observed by Layne (1996) in her exploration of unfavourable birthing outcomes. Given the growing Western interest in practices which refocus birth as a natural expression of maternal physiology and female agency, such as home-birthing, unassisted-birthing, and the Bradley Method of birthing, women are more likely to blame themselves if their birth does not go as planned. The resulting trauma associated with the negative birth outcome may alienate the mother from her newly born baby through intense feelings of guilt and self-blame. This alienation may therefore act as a culturally mediated social barrier to the formation of a strong maternal-infant bond.

Medical scholarship supporting the need for adequate social bonding of the baby has resulted in a variety of strategies, or "new modes of attachment" (Landzelius 2003, 3) to be implemented in various NICU settings. Evidence suggests a myriad of immediate adverse health effects which arise from insufficient social bonding of the premature baby, including an inability to regulate body temperature and hormonal imbalances which result in pain (Kommers

et al. 2016). Longitudinal studies following the health of premature babies into adulthood has also suggested that inadequate social stimulation from birth increases the risk of neurological and psychological impairments, including low I.Q., attention deficit disorders, sensory disorders, anxiety, eating disorders, and depression – of which premature neonates are considered more "at risk" of developing later in life (Kommers et al. 2016; Johnson and Marlow 2014). However, various practices are attempting to combat these outcomes, such as supporting parents to partake in aspects of their infant's care. The practice of 'Kangaroo Cuddles' – skin to skin contact between parent and baby – is encouraged as it is understood to improve the health outcomes of premature infants, including stimulating the production of pain-relieving hormones such as oxytocin in the infant, while also fostering attachment between the baby and other individuals (Arnon et al., n.d.).

These practices speak to historically grounded social models of maternal-infant bonding, and a cultural privileging of this bonding whereby the practice of physical touch elicits a new dimension to the social relationship between infant and mother. This culture of bonding is also highly gendered. Eyer (1992) explored the ways in which elements of early maternal bonding and attachment are considered foundational to the social construction of motherhood. In bonding with her baby, a mother is understood to be fulfilling her own potential as a *gendered* person, while also allowing for the perceived benefits of maternal-infant bonding to come to fruition. For Hays (1998), Western ideals of mothering posit the social bond between infant and mother to be an all-encompassing aspect of the mother's personhood, and one which may in fact limit the mother's ability to fulfil other integral roles and identities. Further, if mothers are seen to deviate away from performing the culturally prescribed mother-infant bonding practices, the culturally assumed negative effects of a lack of normative social bonding may contribute to the categorisation of both the infant and the mother as undesirable members of society.

As parents expressed their fears of inadequacy fulling on-unit obligations such as a culturally prioritised parental bonding with the infant, many parents also expressed their exasperation in keeping up with their broader responsibilities *off* the unit. Their role as NICU parents was such that it often reduced and/or heavily shaped the manner that parents could exercise other facets of their identity. Furthermore, individuals each had their own responsibilities to maintain off unit, and these not only shaped their experiences of the NICU, but also staff social categorisation of particular parents, and by extension, their infants. Responsibilities off unit included caring for other children or family members, work commitments, and personal tasks

such as housework, mental health respite, and other heath related tasks. Many participants communicated unique constellations of external responsibilities and identities that were often strategically coordinated to better manage their additional identity as "NICU-parents".

Jaime, mother to Lily, born at 27 weeks gestation listed off her day to me as we talked over a tea and cake in the hospital cafeteria. She wakes at 5am, sometimes earlier, to the cries of her toddler in the next room. After feeding and changing the child, she pops him in the car and drives him to her mother's house 10 minutes away. She drops him off, still in her pyjamas, and drives home to shower, change, and eat something. By this point, Jaime told me, her body is starting to crave methadone.[69] But the chemist that dispenses "my daily medicine" doesn't open for another two hours. She usually uses this time to squeeze in a quick visit to Lily, and hopefully be in time for her "cares". With a mouthful of cake, Jaime explained how she usually heads out of the NICU just before 9am so she can receive her single dose of oral methadone from the chemist once it opens, and then drives straight to her work to begin a 6 hour shift at the garden centre. She mentioned that by the end of her shift, she's usually exhausted, but forces herself to do a quick clean of her flat before meeting her mum and son for dinner at her mum's house. She usually tries to fit in another visit to Lilly at the unit before she needs to head back to her mum's to pick up her son and put him into bed.

Jaime's day was different to Anna's, previously introduced. While her twin boys were on the unit, Anna's primary external responsibility was her cats:

> *"I was really lucky cause I had finished work so my responsibility there was done. I didn't have any other kids or anything, so the only other thing I needed to look after was my cats. I was [home] in the mornings and evenings, but when I was rooming in, my parents don't live too far away so they were just really good with removing all other worries I had, and making sure that I could focus solely on the boys."*

Family support was vital for many parents in juggling their other responsibilities. For Jaime, her mother provided the necessary childcare for her toddler, while Anna's parents fed her cats and brought meals for her freezer. The types of external responsibilities parents had, and/or the way in which they managed the external responsibilities was sometimes a source of conflict between parents and staff, and communicated clear ideas about what staff thought a good parent

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[69] Methadone is a type of opioid typically used to manage heroin addiction and chronic pain. Jaime received methadone to manage her addiction to heroin. She transitioned from heroin to methadone during her first trimester of pregnancy. Jaime chose not to talk extensively about her addiction, therefore, I have not written about this in more detail.

looked like, and showed how these ideas further shaped relational articulations of infant personhood based off the social categorisation of parents.

What is a Good Parent?

"We found out quickly that they were almost assessing us on what sort of parents we were. Are you going to be the attentive parents, or have you got 10 kids, or no time, so I think they figured we were going to be the try hard parents." (███████████)

'Good parenting' is common term in popular media as something for parents to achieve and undertake. WebMD, a well-known website used for health advice, lists 10 "commandments of good parenting" that reinforce the ideology of parenting as an active and intensive assemblage of practices, relationships, and ideas (Davis n.d.). For instance, the first commandment "What you do matters" emphasises the framing of parents as instrumental to raising productive citizens, persons, and family members.[70] Active parental involvement in daily activities is continuously referred to as best practice for parenting across popular media.

Both staff and parents communicated clear ideas about how a good NICU parent should act and what a good parent should look like. With the "emergent ideology" of intensive motherhood as a contemporary standard for good childcare, parenting more generally is an increasingly value laden activity (Faircloth 2013; 2014). In the Euro-American context, parents, in particular mothers, operate within a set of dynamic, often contradictory, norms which advise how individuals should parent their children in the best possible manner. Sociologist Sharon Hays (1998) tracked the steady emergence of "intensive mothering" as a gold standard parenting ideology which puts particular pressure on women to 'actively' parent their children. To do so is touted as a moral obligation both towards the child, to the parent themselves, and to wider society in producing a productive member of the community. The word 'parent' moves from a noun to verb in an increasingly complex and resource rich configuration of necessary behaviours, activities, and ideas which all are imperative to raising a 'good' child.

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[70] This is a problematic, socially classed, view of parenthood and situated heavily within neoliberal ideals of responsibility and independence. Ahoo Tabatabai (2019) explored how, for mothers of children with disability, these ideals are not always achievable or even desired. In touting self-sufficiency and independence as key characterises parents should instill in their children, the neoliberal paradigm overlooks the ideals of mothers who parent disabled children whereby, for many, interdependency is valued and necessary. Many others have also explored the relationships between neoliberal paradigms, parenting, and disability (such as Frederick 2017 and Fritsch 2017).

Such ideas are not only promoted through popular media and parenting guides, but are also embedded in wider political structures. In interviews with low income Canadian mothers, Romagnoli and Wall (2012) highlighted a fear of state intervention as key to why mothers sought government funded parenting classes. These parenting classes were "prescriptive and regulative" in parenting style and involved active surveillance of attendees. Parents claimed that heavy work commitments and financial strain made the expectations from the classes difficult and hard to maintain. Intensive parenting requires a degree of financial stability and employment flexibility which may be difficult to attain outside of the upper middle class.

For parents in the NICU, work commitments and the resultant financial strain meant that many were unable to spend as much time at the unit as they would otherwise. The ideal NICU parent was one who could afford to structure work commitments around their on-unit responsibilities. This type of job flexibility is characteristic of those found in the upper middle class. Various studies have highlighted how class shapes workers' abilities to structure their work schedule and location (Salmieri 2009; Gerstel and Clawson 2014; 2015). Many parents at City NICU were acutely required to go back to work, or to care for other children. Some were given very little flexibility over these work hours and scheduling, and expressed great stress over the prospect of returning to work. Extended parental absence from the unit was often met by nurses and other parents with disapproval:

> *"It's hard to understand why parents won't come and visit their babies. There are just babies who don't get visited. It's awful." (Anna, mother of Jackson, born at 24 weeks)*

In expressing her disapproval of parents who "won't come visit their babies", Anna employs a very class-based judgement both assuming that all parents have the capacity to visit, and highlights the degree to which bonding through visitation is culturally valued in this context. Parents who do not visit the NICU are reduced to their identity as ("bad") "NICU-parents". Other responsibilities and factors are ignored. This was also framed in terms of ethnicity. In a preliminary meeting with senior nurses, I was told that I should "look into why those young Māori mums never visit their babies." A lack of parental visits was again very much deemed a moral issue and one which served as an early maker of poor parenting though a lack of involvement in the NICU. Tied again to the cultural value given to bonding, a lack of visitation was equally linked to the development of undesirable persons.

Nevertheless, this relationship between time spent on the unit and attitudes towards certain parents was more complex than a negative correlation (less time correlated to bad parent). In

fact, parents who spent "too much time" on the unit were assessed as "too involved" by some staff. For instance, I observed a mother being told to go home and get some rest "so [she] can be a good and refreshed mum tomorrow". This woman had spent approximately 7 hours at the cotside, reading and talking to her infant before being told to go home. I was told later by the same nurse that sending her home was not only for the mother's benefit, but also for the other nurses in the room. "It allows us to really get our jobs done" the nurse told me, as having parents in the nursery is time consuming and as they can "get in the way". Toward the end of my own NICU stay, my parents were told to take a one week holiday by the neonatologist. I wonder whether this was because he wanted my parents to come back refreshed, or if he simply wanted them out of the way. Clearly, there was a set window for the appropriate amount of time a parent should spend on the unit: too little time, and parents were deemed uninvolved and irresponsible, while too much time, and parents were deemed burnt out and in the way. Limited attention was actually paid by staff to understand the specific reasons why parents were not coming to the unit, or coming too much.

The need for breastmilk was referred to as one manner in which parental attendance at the unit was understood to be beneficial. In addition, breastfeeding is often a way in which infant personhood is developed relationally. The exchange of fluids, including breastmilk, is equally an exchange of personhood between both the mother and infant, and the wider social group (Tomori 2015). In interviews with mothers, breastmilk production was cited as a metric of good mothering. Anthropologist Vanessa Maher (1992) highlighted the cultural importance of breastfeeding beyond simply a mode of feeding and bonding with an infant. Rather, breastfeeding is imbued with various dynamic socio-cultural ideologies, norms, and assumptions. Within the wider context of intensive mothering, Ellie Lee (2008) suggested breastfeeding as one manner in which mothers are morally judged as good or bad mothers. Women who breastfeed were framed as morally superior in making an active decision to feed their infant using their breast. Choice is foregrounded. By comparison, women who choose not to breastfeed, or who are unable to, were framed using a language of deficit. Breastfeeding advocacy groups further popularised the idea that formula feeding is 'risky' both to the mother and infant. This message was communicated through breastfeeding advocacy groups such as La Leche League, and although claimed on the basis of scientific evidence, were grounded in cultural ideas of how a good mother should behave. For the women interviewed by Lee, the practice of infant feeding was enmeshed with maternal identity, whereby formula feeding prompted a perceived loss of maternal identity. Feelings of loss, and the language of deficit,

were equally prominent features in my interviews with NICU mothers. However, due to the often medically unstable nature of the infants, many women expressed compounded pressure to provide adequate amounts of breastmilk while aware that this milk would usually be supplemented with formula.

In New Zealand, breastfeeding is heavily promoted by the Ministry of Health and associated health promotion agencies. Nestled between the maternity wards and the NICU at hospital, was a large Ministry of Health promotional banner that depicted a Pākehā woman breastfeeding her infant alongside the slogan "Breast is Best". Midwives specialising in breastfeeding, termed "lactation consultants", moved between both the NICU and the antenatal wards, teaching women how to breastfeed and troubleshooting any issues. In an edited collection, anthropologist Annette Beasley and colleagues (1998) observed that throughout the 1990s, following WHO recommendations, there was a marked increase in government health promotion initiatives set to increasing the rate of infant breastfeeding across the New Zealand population. In the same volume, Beasley and others observed that the amount of breastmilk produced, or future milk supply, was a source of anxiety for mothers in an urban maternity unit. Such anxieties were compounded by the popular messages in support of breastmilk as a sole source of nutrition for young infants and as important for future health in childhood. This anxiety was also heavily present in City NICU, over 20 years later.

For a premature infant, the provision of nutrition at City NICU was a fairly intensive and important process. A newly-born extremely premature infant almost always received TPN exclusively through a central line because their digestive systems were not mature enough to digest food.[71] Infants were slowly introduced to breastmilk and/or formula through a feeding tube. Infants were heavily monitored to ensure appropriate digestion and weight gain. Providing the appropriate nutrition and method of delivery was closely managed and measured by medical professionals. For TPN and formula, precise calculations were used to determine the necessary nutritional content. Even breastfeeding was medicalised. I observed mothers and nurses talking of "a good latch" versus a "bad latch from tongue tie" or "weird nipple anatomy". Speech language therapists and specialist midwives medically managed breastfeeding through minor procedures and tools directed at the infant. I observed the "quick snip" of a tongue tie procedure that aimed to producing a "better latch to the bottle and breast". For mothers of tube fed premature infants, staff placed clear pressure on women to produce enough milk for the

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[71] See footnotes 29 and 30 in chapter 2.

tube feeds. For Lisa, mother to Parker, at 26 weeks, the decision to stop expressing breastmilk arose from a near constant pressure from nurses to produce enough breastmilk for Parker's feeding:

> *"I decided to stop pumping after 100 days because I just couldn't do it anymore…The nurses would often just come in and say "there's not much milk left", and I was getting all stressed so I wasn't producing much in the end anyway. It would be the first thing they asked you, like they'd be "Did you bring more milk in?" or "Is your husband going to come in to bring more milk?" If you hadn't been in for a day, it was all about milk."*

The immense pressure placed on mothers to produce enough breastmilk further resulted in feelings of inadequacy and a loss of maternal personhood, similar to that previously discussed. Mothering was so closely intertwined with infant feeding by breastmilk that an inability to so resulted in sadness and loss:

> *"I found it hard to be rested enough to produce enough milk. Despite getting up a couple times a night, and expressing every four hours, I ran low on milk. I had a wonderful milk donor , but that journey made me feel very much inadequate. I felt like the least I could do was provide nutrition for my babies, and I couldn't even manage that." (Lisa, mother to twin boys, born at 30 weeks gestation)*
>
> *J: Because I was on lithium, I couldn't breastfeed.*
> *B: You got tired of them being like "breastmilk is like gold".*
> *J: Three different doctors asked me for breastmilk. And I said, you can't put her on that. I found it quite upsetting.*
> ██████████)

While most women to whom I spoke cited the pressure to express breastmilk as a primary dissatisfaction with their NICU experiences, I also observed nurses carefully and respectfully tell women that breastmilk "is not the be all and end all". I was told by a parent in City NICU that she was told by nurse that formula has the same, if not better, nutritional content to breastmilk, so she should not worry about producing too little milk. Formula "top ups"[72] were so frequent for some infants that the formula itself was framed as simply part of that infant's treatment routine – "nothing to get your knickers in a twist about" I was told by a giggling parent.

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[72] A "top up" refers to the supplementation of a breastfeed (or bottle feed with expressed breastmilk) with a bottle feed of infant formula.

Parents elsewhere have reframed supplemental feeding in a creative manner. In a Danish NICU, bovine colostrum was used to supplement the feeding of premature infants. An anthropological study conducted by Dam and colleagues (2017) explored the role of bovine colostrum supplementation for premature infants. The authors observed that parents explained this practice using a language of inter-species kinship to rethink the sharing of milk products between humans and animals. On City NICU, a similar supplementation was in its trial stages. I noticed that parents seemed much more resistant in giving consent to the bovine colostrum study compared to other pharmaceutical studies. This aspect is an interesting and necessary avenue for further study, which further reinforces the cultural role of breastmilk, and related milk products, in the neonatal sector. For women on City NICU, breastmilk was very much perceived as a quantifiable measure of good mothering whereby the amount of breastmilk produced was linked to how well a woman was performing in her role as a mother. The frequent use of scientific knowledge to justify the benefits of breastfeeding, to both the baby, and the maternal-infant bond, further illustrates the role of breastfeeding as a lens through which to examine how the actions of mothers were framed to shape the type of infant personhood developed.

Further, the ability to understand and use medical language – "speaking NICU" – externally signposted particular types of parents, according to one bedside nurse. "Speaking NICU" communicated that parents were and would be attentive to the unique medical needs of the infant. A good parent was one who could clearly and accurately communicate the pathologies and treatment of their infant, and was generally medically literate. While not only indicating a bias toward highly educated parents, the staff desire for parents to competently "speak NICU" also communicated clear raced and classed ideas about appropriate language use, such as particular vocabularies and grammars. However, medical literacy was very much a double-edged sword. On one hand, a staff-perceived lack of medical literacy meant that parents were framed using a language of deficit, generally understood to be less involved, and socially categorised as working class. Yet, those who exhibited high levels of medical literacy, although perceived as highly attentive and involved parents, were also thought of as simply irritating to staff and in the way. "These are the parents who ask all the questions" I was told by a bedside nurse. Much like parents who spend "too much" time on the unit, these highly medically literate parents took time with nurses, asking questions, and talking at length about their infants medical condition. Although there was some complexity in that they were often perceived as more irritating, medically literate parents were still more generally assessed as good parents,

and socially categorised as upper middle class Pākehā, in the language used by bedside nurses and as explained by other parents.

The politics of language fits into a much larger politicisation of certain parents and families on the NICU and in the biomedical sphere more generally.[73] At the time of writing (July 2019), this is a great source of national public debate. In June 2019, domestic media outlet Newsroom made public an investigation delving into the removal of Māori infants and children by the state ("New Zealand's Own 'Taken Generation'" 2019). The investigation was accompanied by the release of a video depicting the attempted "uplift" of a Māori baby by Oranga Tamariki (The Ministry for Children) due to a perceived unsafe home environment. The video showed a young Māori mum holding on to her newborn while social workers from Oranga Tamariki attempted to take the infant into state care. Later in the video, the mother's family were barred from entering the hospital to support the mother by police. In addition, the mother's midwife was also barred from entering the hospital. The journalist covering the investigation was met with institutional barriers in reporting by hospital administration.

Māori infants are disproportionately represented in state "uplift" statistics. Tina Ngata (2019) argued that this is as a result of the harmful legacy of colonialism in New Zealand which has extended far beyond the video depicted in the news article:

> "We live the reality of these intimidating tactics every day. Our health system has been identified as racist towards Māori from within its own ranks, and by the international Commission for the Elimination of Racism and Discrimination in Geneva. We have known for a long time that Māori children are many times more likely to be taken from their families than non-Māori." (Ngata 2019)

The Newsroom investigation highlights an example of wider discrimination against Māori by state agencies in New Zealand and the healthcare sector. Although the video depicted courageous hospital staff successfully protecting the mother and infant from "uplifters", both the video and other sources highlight the role of medical staff in reinforcing racist and discriminatory policies. This increased surveillance and politicisation of Māori families was present at City NICU, both in my own observations, and in those from parents and staff.

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[73] This is not unique to New Zealand. In her ethnographic work with Black mothers in an American NICU, Dana-Ain Davis (2019) argued that racialized treatment of Black birthing people and their babies is indicative of the "afterlife of slavery" in the United States. Davis's critical race approach decouples race from class in specifically focussing on the experiences of middle to upper class Black women to highlight some of the ways in which racism cuts across class.

Infants under state care were referred to as "uplift babies" or "CYFs babies" at City NICU. From interviews with parents and staff across New Zealand, I know that this terminology was also used in other NICUs and SCBUs at the time. During participant observation, the presence of a particular infant under state care resulted in hyper-surveillance of the entire unit and an increase in security. Locked main doors and/or the presence of a security guard alerted me to the presence of an infant under state care on the unit. The assumption was that "mum would try and come steal baby", according to one nurse, therefore prompting increased security measures across the unit. I cannot speak to how this increased surveillance shaped the movement of premature infants through the unit as these infants were not born premature. One nurse told me of an infant she cared for in the past who was to be taken into state care upon discharge. He was admitted to the NICU due to maternal opioid use:

"I'm just like, how could the mother have done this to him?" (Nurse Lexie)

Risky parental behaviours resulted in judgement and increased surveillance from staff. Some parents were watched more closely than others, and were spoken about differently by nurses when they finished visiting. I observed the use of racist language to refer to one Māori family in the study. The parents were 16 years of age, gang-affiliated, and from a low socio-economic background. These features were the source of much staff judgement and increased surveillance of the father when visiting his infant. I observed staff refer to this father as a "drongo"[74] and suspect him of stealing medications. Other parents in the nursery also expressed their dissatisfaction with sharing the nursery with this family. One mother told me in hushed, albeit apologetic tones, that she "keeps more of an eye on her stuff" when this family was present.

As identified in a report led by Leonie Pihama (2010), there exists a dearth of research exploring Māori experience of the NICU. From interviews, Pihama observed that restricted family accessibility to NICU was sometimes a cause of distress and conflict. Due to infection control and space restrictions, there exist limitations on how many family members are permitted to be by the incubator. At City NICU, I observed many family members be told to leave due to these rules.[75] This highlights a prioritisation of the nuclear family as standard in

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[74] In New Zealand English slang, a "drongo" refers to someone who is considered unintelligent.

[75] At City NICU, protocol dictates a maximum of two people (in addition to any staff) are allowed by a single incubator. One of the two people was required to be a parent of that infant. Non-parents (including siblings and grandparents needed a parental escort at all times). In unique situations and with senior management approval,

the NICU. Wider family were monitored closely in their presence on the NICU to make sure people were not crowding the incubator. Pihama emphasised a feeling of isolation and discomfort for Māori in the NICU. Simply on the basis of unit policy, the ideal family must be a nuclear one.

While practices were adjusted and perspectives varied, it was clear that certain parents and families were generally deemed better than others, and more capable of parenting a premature infant. Practices such as breastfeeding, using medical language, and visiting enough, all contributed to staff and parent views on the 'good parent'. In addition, factors such as ethnicity, socio-economic status, and family composition all shaped how certain families were engaged with by staff and other parents. The ideal parents were Pākehā, upper middle class with flexible jobs, and little responsibilities off unit. They would spend time on the unit, but not too much. They were involved and medically literature, but to the point where they got in the way. The women had smooth pregnancies, where they were a good weight, and did not engage in risky behaviours. The perceived judgement from staff and other parents heavily shaped parents' experiences of the NICU. These experiences of judgement were further reinforced in the use of possessive language by staff and conflicts over ownership.

"Our Babies"

Parenting experiences in the NICU were shaped by relationships with NICU staff, particularly bedside nurses. Most parents I spoke to experienced varying degrees of conflict with NICU staff regarding what they thought was best for their child while receiving care on the unit. Equally, many staff I spoke to also highlighted conflict with parents as a fairly frequent occurrence. Tension and conflict between staff and parents often centred on narratives of care and ownership. Parents expressed anger and discomfort at the language of power and ownership wielded by nurses in relation to the infants. Furthermore, conflict often arose from differences in opinion and in determining the right distribution of responsibility between parents and nurses.

Daily, I observed nurses use possessive language when referring to the infant's under their care: "*your* baby had an apnoea while you were on break" or "*my* one is being a real pain". Visible in the language used, nurses hold a sense of ownership towards the infants who have been assigned to their care. This is also a feature of NICU nursing observed by nurse Pat. After

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grandparents of the infant were afforded the status of 'parent' and allowed to visit unattended. I only observed this exception when an infant's mother was a teenager.

the completion of her night shift, we sat in the hospital café, and discussed some key issues faced in nurse-parent relationships. Pat explains that the language of ownership and possession is a key source of conflict, and something which she has actively tried to change:

> *"It is the biggest and most important thing. I always say to myself 'this is not my baby, this is [the parent's] baby. They need to tell me, to a point, what they want, and how they want me to do it. I will work with them every step of the way. I learnt that early on. It's not my baby, it's their baby."*

Pat pushed against the narratives of ownership so commonly deployed in NICU nursing. Beyond the language used by staff, parents spoke of certain staff actions as reducing their sense of ownership and responsibility towards their child and negatively affected their ability to bond. For many parents, the restriction of touch and kangaroo cuddles was one way in which their status as the infant's parent was perceived as challenged and their ability to bond was hindered. Being told when they were allowed to pick up their infant, or if they were allowed to touch their infant, all the while a nurse was handling their infant, was a source of conflict for parents. For some parents, the mark of a good nurse was one who made space in their work for parents to touch and cuddle the infant as much as was possible. These parental concerns also highlight the significant value placed on touch as instrumental to bonding.

> *"I found it frustrating for a start cause I just wanted to give [the boys] a cuddle, but a couple times I had the nurses say "sorry we can't give you a cuddle right now cause we're really busy" or "they've just had a feed". That was a little frustrating." (Anna)*

> *"If there were good supportive nurses, then I'd have kangaroo cuddles as soon as I could. But with others, it was annoying cause they'd say that he was much more settled [in his incubator] or that it really wears him out if he's on me. But I knew from what I was reading that it is quite the opposite. So some days it was really distressing because I just wanted to hold my baby"(Claire)*

As Claire observed, differences in information source and opinion were often present between parents and nurses. NICU staff often employed scientific and medical vocabularies to describe the validity of their practices in the face of parental disagreement or conflict. This speaks to the immense cultural capital attached to scientific knowledge as hierarchically superior to other forms of knowledge and evidence. Every instance of this knowledge deployment by staff that I observed went unchallenged by parents (at least in that moment of time). However, for "bolshie" parents, this information was very much challenged.

I spoke to both ▮ and Marie individually over Skype. Each told me of their frustrations surrounding how their infants were treated during their NICU admissions. For Marie, a nurse herself, the staff decision to prescribe her son milk fortifier derived from cow's milk was a great source of distress and conflict. Marie believed she was forced into accepting the administration of milk fortifier through moral shaming by NICU staff:

> *"[the neonatologist] said to me 'Well it's up to you if you want a baby at the back of the bus or the front' … so basically saying that if I didn't give it to him, I was then choosing to make him dumb. So I don't know…like little things, yeah like the…I found like a lot of what they told you was dumbed down, and for me, that was a big thing, cause you don't need to…like I'm not an idiot."*

Moral shaming by NICU staff over the use of milk fortifier was also experienced by ▮ during her son's NICU admission. She tells me how she felt disempowered by both nurses and doctors over their prescription of cow's milk fortifier despite not giving staff consent to administer this supplement. When she raised this issue during medical rounds, she was told to be quiet, and save her questions till the end. Upon being granted permission to speak, her request that her son be taken off milk fortifier was overridden by the doctor, and he continued to receive the fortifier. ▮ was dissatisfied with both the lack of concern for her wishes, and that she felt staff assumed they always knew what was best due to the scientific evidence they spoke of. Providing consent was an important principle for ▮, and when this was ignored, she felt demoralised. Similar to Landman's (1998) aforementioned discussion of parenting a medically complex child, many NICU parents felt "bulldozed" by medical authority. Many, like ▮ and Marie, felt the medical establishment attempted to subsume and override their knowledge as parents. When parents were able to "speak NICU", their wishes for the medical treatment of their infant were more appropriately granted by staff. A *good* NICU parent was one who subscribed to the medical authority. These norms continue well beyond discharge with the increased medical surveillance of ex-premature infants and children. During their time on the NICU, parents are socialised into certain ways of parenting, and *good* parenting.

Conclusions

Parenting a NICU baby was a unique experience compared to that of a healthy and/or full-term baby. Parents were expected to fulfil certain roles and responsibilities unique to the neonatal unit. These communicated clear expectations about how unit staff believed parents should look, and behave with Pākehā middle to upper middle class sensibilities. Both parents and staff

emphasised what they thought a 'good' parent should look like. In turn, this shaped how the NICU was set up to best accommodate for their model of parenthood as Pākehā, upper-middle class, educated, heterosexual, and nuclear. These values of good parenting in the NICU operated within the wider context of parenting norms in New Zealand that are both raced and classed. Parents and babies were socially categorised, and stratified, by staff and other parents in the negotiation of multiple personhoods.

Narratives of personhood multiple were articulated at points of tension which also often rested on how individuals were positioned socially. Specific NICU knowledges, such as clinical ideas of sex and parenting, were continually reframed, reified, and/or strategically hidden, in the social and cultural positioning of infants and their families. As I discuss next, the harmful effects of this categorisation shaped some of the tension and contradictions in how infants' personhoods were negotiated. For instance, a raced and classed framing of certain parents was one component that made up political and economic logics that shaped premature personhoods. Staff used political and economic justifications to articulate the types of care given to babies from backgrounds deemed undesirable and desirable, therefore constituting additional layers of personhood between babies.

6

Interlude: Coming Home

To supplement the reading of my medical notes, I watched the home videos my parents recorded during my NICU stay and after discharge. Until this point, tracking my neonatal story in the medical notes primarily constructed a picture of just *me*. My parents were mentioned occasionally, in social work notes and elsewhere. However, they were pretty much background noise as written into the notes. Yet in the home videos, I was better able to discern their position in events and processes I'd read about. One video shows my dad giving me my first bath, joking that he could submerge me fully underwater and I'd still be able to breathe thanks to the nasal cannula and oxygen steadily streaming up my nostrils. Another shows my mum cradling me in one arm, wrapped warmly in a colourful crochet quilt, while holding a syringe of formula in her other hand. She holds the syringe high, using gravity, to bolus the formula through my feeding tube. The video cuts to a clip taken 10 minutes later: a nurse helps mum to navigate the wires and tubes as she places me back into my open cot. These practices of feeding and bathing were delayed 'firsts', only done well after I was born, and therefore much anticipated. The videos show my young parents' beaming grins as they excitedly do these things for the first or second time.

The next clip was taken in a completely different setting, although there are some of the same characters and props from the last video. I have aged, to about 6 months, and am bouncing happily in a cream coloured bouncenette in the centre of the living room. I know this to be my very first home: a small one-bedroom apartment in Mount Victoria that I shared with my parents. Seated on plush brown couches, surrounding my bouncenette, are my Oma and Opa. I presume my dad is behind the camera, and my mum is crouched next to me. As the recording continues, I learn this clip is being filmed for my great-Oma back in Holland. My Oma, Opa, and mum switch freely between Dutch and English, speaking to the intended viewer on the other side of the globe.

The scene is littered with props, some typical of a Kiwi living room but others rather foreign. A small television faces the couches. Rattles rest around the bouncenette, and alongside a plastic baby bath. Nestled off to the side is a four-plug power board, connected to a surge protector and an extension cord which snakes off the screen. I can see that the power board provides electricity to an oxygen concentrator. The bulky concentrator is then connected to a nasal cannula taped to my face. Another plug supplies

power to a small black plastic box, with red numerical displays. Another cord runs from this box to an electrode taped to my foot. I recognise this as one of the portable heartrate and oxygen saturation monitors sometimes given to parents of oxygen dependent children. Off to the side, I can also see a portable oxygen tank, fitted into a type of two wheeled trolley with one long handle. For my parents, this scene would have been pretty normal. Given they'd spent 3 months with me on the NICU, this environment would have been much less technologized that they would otherwise be used to on the unit. Yet, although coming home meant I was no longer a NICU patient, it would be quite a while before I was no longer a NICU baby.

Chapter 8: Political and Economic Rationalisation of Personhood

"You must have been a very expensive baby" an old friend told me during my first year at university. "All that care and medicine must have cost the government an awful lot" she followed with a laugh. At the time, I was not quite sure how to respond to this. *Yes* I probably cost the government significantly more than a healthy full term infant. Even today, my cut of government expenditure in the health sector is likely higher than an average 24 year old woman from an upper middle class background, all due to the rather unfortunate yet mild sequalae of prematurity. I was also confronted with the fact that considerable time and effort was taken by others to get me healthy. Doctors, nurses, allied medical professionals, social workers, and the like. All these individuals require a steady stream of funding and wages to do their jobs well. In addition, each individual would have required various packages of specialised tools and resources, all of which cost the healthcare sector money. These funding streams not only finance policy and operational work on premature infants, but also provision wider work in child health and maternity services. The source of this funding is commonly represented as "the taxpayer" – a mythologised body of individuals who fund government actions.

I would be lying if I said I never felt particularly indebted to the taxpayers of 1995. As a teenager, I became increasingly aware of just how much NICU care costs. At the age of 13, I came across a CNN news article with the headline "Average preemie costs $49 000 [USD] in the first year" (Landau 2009). This worked out to over $72 000 NZD. That is a lot of money for one baby to 'use' over their first year in recovering from an early birth. The knowledge that I was an "expensive baby" put a fair amount of emotional weight on my shoulders: I should be a *good* citizen, get a *good* government job, pay my taxes, and my student loan. I feel the need to somehow *give back* to the collective of individuals who provided and funded the lifesaving treatment I required. In order to do so, I must somehow make a contribution to wider society that offsets all I have required as an infant. I know this is a futile and probably unnecessary task. However, I still feel the weight of these expectations, even as I write this thesis on a tax-exempt income. Quite possibly, these expectations are one of the many reasons I have chosen to actually write this thesis. It is probably the hope of most PhD candidates that their doctorates make a contribution beyond the academic. But how many write a thesis to pay off a theoretical life loan?

Beyond my own personal narrative, the 'cost' of premature birth is heavily discussed in public debate. In addition to many academic studies that have explored the financial cost of premature

birth (such as Petrou 2003; Rushing and Ment 2004; Clements et al. 2007), various not-for-profit organisations have engaged in this discussion, such as the March of Dimes organisation founded by Franklin D. Roosevelt.[76] With its primary goal being to lower rates of premature birth, the organisation produces publications on both the financial cost of premature birth, but also the "impact to society" of premature birth (March of Dimes 2015).[77] These discussions are framed within a wider cost-benefit analysis that attempt to measure cost of treatment, risk of long term complications, and likelihood of continued medical treatment. Such debates are value laden and communicate both the value placed on early life, as well as the desire for productive citizens. Furthermore, these equally highlight the use of various political and economic logics in rationalising premature personhood.

This chapter will explore the role of premature infants and those who care for them as political and economic subjects. I explore how economic narratives are used on the NICU to destabilise the personhood of some premature infants, and in terms of the associated labour, while reinforcing the legitimacy of treating others. The manner in which economic narratives are communicated and enacted in the NICU reflect wider political discussions of cost versus benefit but also illustrate cultural assumptions about quality of life, including questions of survival, managing uncertainty, and debating life-worth. In effect, the neonatal space is a highly political one where political and economic knowledge systems are used to negotiate and legitimise personhood(s). In addition, although the neonatal space was one of a wealth of technological advances which sustain unstable lives, economic precarity was equally visible. Yet, this also illuminated the boarders of biomedical intervention whereby the questions of survival, managing uncertainty, and debating quality of life were situated within a wider moral economy of care at City NICU.

A Costly Endeavour?

The provision of medical care to extremely premature infants is exceptionally resource and labour intensive. In City NICU, nurses were well aware of this financial cost, and mitigation strategies were put in place. Nurses spoke of their nuanced relationship with the cost of

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[76] Roosevelt initially established the organization specifically for infants and their families affected by infant polio in response to himself having the disease as an adult. Following the development of the polio vaccine, the organization diversified its focus to maternal and infant health more generally.

[77] This webpage provides a financial representation of the effects of prematurity in the United States, including cost of healthcare, special education, and cost of "lost work and pay" for adults who were born premature. This list of costs is given as an answer to the question: "How much does premature birth cost society?" (March of Dimes 2015).

providing intensive care. These economic narratives, although dynamic, all featured a discomfort over the cost of recourses and care, especially regarding infants born within the grey areas of viability. In some instances, these economic narratives were invoked to reference particular families and babies – "the precious IVF baby"[78] which implied the infant was already a costly endeavour prior to NICU admission. Further, material reminders of cost were peppered around the NICU, and served as reminders to staff that the healthcare budget was not unlimited. Finally, an ongoing staffing crisis, coupled with a nationwide dissatisfaction over nursing wages, added to the narratives of cost and financial precariousness on the NICU.

The financialisation of various national social services, including healthcare, is increasingly prevalent in New Zealand (Malva 2016; Copland 2017; Rowe-Williams 2018). I use the term financialisation broadly to refer to the ways in which the everyday is increasingly shaped by individual and institutional financial logics and structures. This approach goes beyond the focus of financialisation as primarily about government resource accumulation, in equally identifying the unique financial logics of citizens and wider institutions (van der Zwan 2014). Trundle (2017) highlighted how the financial reforms of the 1980s and 1990s have continued to shape the present financialised nature of the New Zealand healthcare system governed as a corporate structure. While City NICU is a part of the government system via the national public healthcare model,[79] individual actors exercise financial logics and processes in moving through the unit. Various clinical decisions were further shaped by individual subjective assessments of cost, benefit, and value. However, these individual logics of cost and benefit were still often articulated within narratives of (productive) citizenship and personhood.

Research bodies, government intuitions, and independent agencies affiliated with the healthcare sector in New Zealand are increasingly focussed on quantifying healthcare costs and using specific algorithms to do so. For instance, the University of Otago administers a package of research programs which aim to measure heath costs through a health costs calculator (University of Otago n.d.). The aim of this package of government funded programmes is to

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[78] This phrase was used to refer to an infant or foetus conceived using any reproductive technology, including in-vitro fertilization (IVF).

[79] The domestic health system is funded primarily by Vote Health, as well as the Accident Compensation Commission (ACC). Approximately 75 percent of Vote Health funding is then passed on to DHBs – this is based on individual contracts held between the Ministry of Health and the DHBs. This is calculated by The Population-Based Funding Formula which takes into account population numbers, and adjustment for specialist services.

increase cost-effectiveness in managing various cancers, immune disorders, and other diseases. The financialisation of the New Zealand healthcare system is equally visible in the use of cost-utility analysis (CUA) within the Pharmaceutical Management Agency (Pharmac). This crown entity regulates which medications are subsidised by the government. Pharmac uses CUAs as one method to determine whether a medication should be subsidized. In an ethnographic analysis of Pharmac in New Zealand, anthropologist Veronica Adams (2016) explores how the use of CUA is exemplary of a preoccupation with cost and value in the healthcare sector:

> "When making decisions about which pharmaceutical treatments should be funded the goal for Pharmac is not always about achieving health outcomes, but rather how favourable Pharmac's position is after negotiations with pharmaceutical companies. The Pharmac model for negotiating medicines prices is based on an ideology of investment… Within the New Zealand health care system Pharmac perpetuates neoliberal ideology of investment and cost effectiveness as a means to restrict pharmaceutical spending." (Adams 2016, 49)

A similar trend towards financialised decision making, on the basis of cost versus utility, was also visible at City NICU in the use of labour and resources to treat certain infants. Time and time again, "the taxpayer" was deployed as both a reminder for staff to use resources sustainably, but also as a point for debate and discussion over the legitimacy of treating some infants – particularly those with very poor prognoses. "The taxpayer" was used in general terms to reference the wider working population who paid taxes to the government. Nurses spoke of "taxpayers' money" as funding the work they do and the resources necessary to do so. This category of individual (taxpayer) was further deployed to denote a static and anonymous body of funding which, by virtue of "paying taxes" was designated a type of authority over decisions made. Yet due to the lack of individual identity attributed to "the taxpayer", the authority was executed by staff. Staff therefore acted on behalf of the faceless taxpayer, in their own capacities as taxpayers, and in their own judgement as medical or nursing professionals. The resulting diversity of different identities and authorities sometimes resulted in financial logics and practices that seemed at tension with various roles.

As far as I am aware, no academic studies have attempted to quantify the financial cost of NICU care, per infant treated, in New Zealand. However, some key financial figures were released by the Ministry of Health to a new media outlet for reporting:

> "The most complex cases, according to the ministry, clock in at $1160 a day; for an average 44-day stay, that's $51,000. And that doesn't include operations. Auckland District Health Board says once operations are included, its average per-day range comes in at $3000-$6000, bringing that 44-day stay to a top end of more than $250,000." (Barnett 2011)

Although the average length of stay (ALOS) for an infant was reported as 44 days, the ALOS for an *extremely* premature infant is much longer. Data released in 2015 by the Australian and New Zealand Neonatal Network (ANZNN) suggested that the median LOS for a surviving infant born below 24 weeks gestation is 137 days (Chow et al. 2019). In contrast, a surviving infant born at 28 weeks gestation had a median LOS of 69 days. Extrapolating from the ANZNN data, the average cost of a single NICU admission for an extremely premature infant may well exceed the averages suggested in the news media article. As an interesting point of comparison, many American studies have attempted to quantify the cost of a NICU admission for extremely premature infants. A study estimating the national cost of NICU care for premature and low-birthweight infants in the United States found infants born prior to 28 weeks and/or weighing below 1000 grams at birth received an average of $65 600 USD worth of care per admission (Russell et al. 2007). New Zealand operates under a publicly funded healthcare model whereby parents of NICU infants do not need to pay for the care given.

Scholars have also attempted to determine the cost effectiveness of NICU care based off survival rates. Lantos and Meadow (2006; 2011) argued that NICU care is highly cost effective compared to child and adult intensive care given that deaths on the NICU tend to occur soon after birth and that most resources are used to treat infants who ultimately survive. While this may also be the case at City NICU, economic narratives were primarily used in reference to infants who had very poor prognoses and/or those who would eventually die.

When I spoke to nurses about some of these babies, many expressed that the cost of care was something they thought deeply about. More in depth discussions with nurses about cost and resource use were more often in reference to infants born at 23 and 24-weeks gestation – those considered to accrue the highest of NICU cost, resources, and labour:

> *"Think of all the taxpayers' money used on some of these kids. And it won't end when they leave here. They'll need help for a long time"* (Nurse Katie)

> *"It's an awful thing to say, but the cost to the system of keeping these babies alive…like I don't even know exactly what it is…I imagine its thousands of dollars to have one on*

one nursing for a baby, for 24 hours a day, all the machinery, all the medications."
(Nurse Leah)

"It is something I struggle with a bit. Like how much money and time and effort we put into these babies who have a very low quality of life, but then it's not really our decision to make. And not being a parent myself, I think, makes quite a difference to that I don't know what I would do in that situation. It's an interesting ethical dilemma" (Nurse Rebecca)

Nurses highlight an acute cognisance of the time and resources used to provision intensive care. Further, the quote from Nurse Rebecca also illustrates a type of ethical bracketing used by nurses within their explanations of cost. In quantifying her discomfort over "time and effort", Rebecca adds that the decision is not one to be made by nurses. Rather, Rebecca positions responsibility with parents and medical staff. This ethical bracketing exemplifies both a professional tension previously discussed in chapter 5, as well as an explicit valuation of parental authority in such decision making. Simultaneously, nurses still made explicit judgement over these decisions, including the provision of care to infants where significant morbidity was predicted by medical staff. These judgements highlight clear cultural assumptions in the differentiation of value and quality of life in infant personhood(s).

Nevertheless, these discussions by nurses were clearly taboo. Statements expressing worry, concern, and/or discomfort about the cost of NICU care were communicated in hushed apologetic voices, accompanied by a grimace or nervous look-around. Parents were not to know some staff felt this way, although from interviews with parents, I know many parents felt the same. Yet for parents, the notion of cost was more of an amusing anecdote they used in telling their birth stories rather than something confessed in quite hushed tones: "My baby cost $50 000" and "I'm definitely getting my taxes paid back!" I suspect this difference is because parents were primarily concerned with the health of their infant while in the NICU rather than government expenditure, at that particular moment in time. These explicit narratives of cost and invocations of "the taxpayer" emphasise that, although the NICU was very much isolated, it was still heavily situated in the wider political economy. The wealth of online news articles and scholarly works seeking to reduce NICU cost and increase cost-effectiveness, further speaks to the increased focus on national health expenditure. At the local level, material objects were imbued with such narratives.

In the afternoon on a sunny Wednesday, I was seated on a tall metal stool facing two vacant high-acuity bedspaces. I had realised the night before, that I always set up my stool in the same position: to the right of the two high acuity incubators, facing outward. This position gave me the widest view. From my perch, I could see all bedspaces in nursery D, including two high-acuity bedspaces in the adjacent nursery. If I strained, I was also able to see out the nursery doors and toward the front desk. Crucial to this position was my ability to see the clock hanging from the ceiling in the centre of the room. I *needed* the clock. It was a signpost for heading my fieldnotes, and signalling when I should go for a walk around the hospital. If I sat on the hard stool for more than a few hours without moving, my legs tended to cramp. Yet as I usually didn't notice the hours slipping by during fieldwork, a quick glance at the clock was a good reminder to eat and move. However, on this day I moved my stool to a different vantage point. I was not able to see the clockface, only the edge. I could not see the adjacent nursery, nor all the bedspaces. And even if I strained, I definitely could not see the front desk. I found this unnerving. But as my eyes refocussed to their new landscape, I noticed something fascinating that I hadn't seen before.

Next to various handbooks and papers, resting on a beige bench which spanned the length of the wall, were two carboard boxes. The top flaps had been cut off, leaving each box with ragged edges exposing the corrugated cardboard interior. At first, I couldn't see the contents of these boxes, but labels constructed from white paper affixed to the boxes with cellotape gave me an indication of what these might contain: "single lumen" and "double lumen". Below these titles was the price of each individual product. A double lumen cost a few dollars more than single lumen. These were PICC lines (peripherally inserted venous catheters) a type of central line, often termed "longlines" by parents and staff. PICCs are used in City NICU to give medication and TPN. As a form of intravenous access, a PICC is hardier than a basic peripheral intravenous line. It is inserted into the arm or leg and threaded up the vein to a large vein close to the heart. These catheters last longer and can be used to give medications that would be damaging to smaller veins in the arms or legs. PICCs can have one, two or even three lumens. Each lumen can be used for the administration of separate fluids or medications. Most of the PICC lines I'd seen were double lumen, that is to say, two lines in one, with two injection or connection sites on the outside of the body. The more lumens, the more external ports for inputting medications and TPN at the same time. These lines were so commonplace at City NICU that I hadn't really thought deeper about their financial impact. *Sure,* they must cost the unit money. It also makes sense that a double lumen is more expensive than a single

I was interested as to why these boxes had prices on them. Did the price of a line influence the bedside medical treatment? Apparently so, I was told by the bedside nurse. The price labels remind staff to choose their products wisely: Does this baby really need a double lumen or would a single lumen suffice? This is a reminder that all these products, even those used frequently as part of routine care, still cost the unit money. So, the choice of lumen isn't just a clinical one, but a financial one as well. Responsibility over resources is distributed to bedside staff through the communication of price. Yet at the same time, the prescribing doctor would likely not see the cost label given it was the nurses who often fetched the PICC lines from the box. There was therefore a barrier between the commissioner of the PICC line and the awareness of price. This knowledge was then diffused through the action and associated emotional labour of nurses who were the individuals that frequently saw the cost signposting. However, this is not to say that doctors were not equally aware of the costs. On occasion, I saw the commissioning doctor fetch their own supplies from the cost labelled box.

Cost was also a factor in staff decisions to use other products. In the days after I moved the stool, I observed a debate between staff, doctors and nurses, over which type of TPN should be used for baby Isabella, whom I introduced in a prior chapter. The product choices were "early life TPN" and "regular TPN". As made obvious by the name, early life TPN is specially formulated for use in the first day or so of an infant's life. At this point, Isabella was almost 18 hours old. "Should we give her a few hours of early life, then switch out to regular?" one nurse asked. "Then we'd just be wasting the rest of the early life bag" a registrar answered. Ultimately, they decided to put Isabella straight on regular TPN given her 'advanced' age and the desire to avoid resource waste in a half-used bag of early life TPN. While infant wellbeing was at the helm of these discussions, financial implications were explicitly overlaid. The economic position of City NICU was very much visible in the day to day actions of staff who simultaneously endeavoured to provide the best care while operating within resource constraints, a desire to work sustainably, and in directing resources to those they deemed most acceptable and/or in need.

At the same time, the degree of economic precarity discussed above was equally countered by the consistent focus on neonatal research and technological developments explored in chapter 5. This feature was also observed by Anspach (1997) in an account of neonatal care in the United States. She identified a "paradox" in the state at once funnelling financial support to NICU research yet also restricting resources associated with post-NICU care and the sequalae of premature birth. Yet in contrast to Anspach, I identified both a restriction and augmentation

of resources *onsite*. This is quite possibly due to differences in healthcare funding between the United States and New Zealand. Nevertheless, at the local NICU level, staff operated within a context of both resource instability and abundance. Economic justifications featured in clinical decision making, as did assumptions on the "cost" and "value" of certain infants and the financial positions of their families.

Navne and Svendsen (2018) astutely observed the role of "origin stories" in a Danish NICU. As mentioned in chapter 5, the family history and social background of an infant – the origin stories – are sometimes brought into clinical decision making. Especially in the case of unstable infants, staff may look to family background as an aspect in determining the best course of action. For the authors, this attention paid to wider systems of care speaks to the value placed on the presence of family as constitutive of a "life worth living" in the context of the Danish welfare state. At City NICU, I also observed the role of "origin stories" in decision making. However, these were very much imbued with economic narratives of cost and value, specifically in regard to the mode of conception and parental social categories, such as use of assisted reproductive technologies and ethnicity.

Many nurses I worked with spoke of "precious babies". These were babies often conceived after many costly unsuccessful cycles of in-vitro fertilisation (IVF) and/or other types of assisted reproductive technologies (ARTs). Parents "desperately wanted" these babies, "spent so much money on" them, and "[were] their last chance at having a baby". As couples are waiting later to have children in New Zealand (Righarts et al. 2015), more are forced to use ARTs to become pregnant given fertility decreases with age. Furthermore, conception via IVF increases the risk of premature birth and resulting NICU admission (Wisborg, Ingerslev, and Henriksen 2010; Farhi et al. 2013). The incidence of twin and triplet birth is also correlated with use of ARTs – of which both multiples and IVF use increase risk for premature delivery and NICU admission (Barrington and Janvier 2013). There were quite a few of these "precious" and "expensive" babies at City NICU during my time there. A few of whom were some of the sickest onsite. The features of their conception, such as the use of ARTs, was used by some nurses to justify, sometimes cynically, the intensive care given to so-called "futile cases". As observed by Navne and Svendsen, this speaks to the role of family in shaping clinical care yet in a slightly different manner. The maintenance of "life itself" (Rose 2006) or "bare life" (Agamben 1998) was, in one way, justified by the infant being "precious", "costly", and coming from a particular socioeconomic background. These "precious babies" were valued to

the extent that they were rare and wanted. Yet they were also *uncertain* lives due to their potentially unstable clinical position and personhood.

Comparatively, the "origin story" of another infant may shape clinical decisions in a different way. Hypothetical infants were crafted by nurses as points for comparison when they explained the role of family background in care decisions. These hypotheticals sometimes relied on racist positionings of certain babies and families to justify prospective clinical decision making. One nurse explained to me a hypothetical situation where heroic care might not have been used, in comparison to a "precious IVF" baby:

> *"Imagine a baby, like Baby [X], same issues…same problems. But not like [X], this one was from a teen mum, 15 or 16 years old, maybe younger. Might have other kids, probably struggling financially. Māori or Pacific, maybe a refugee. Not in school anymore but trying to work, maybe in a low pay job or something…Something like that…Imagine the baby will have the same problems or disabilities, if it even survives. That is going to be really bloody hard for that mum. And baby probably won't get all the stuff he needs, support and stuff. In that case, we might not push the baby as hard as we are doing with Baby [X]." (Nurse McKenzie)[80]*

In this instance, a hypothetical infant was constructed by the nurse with a background deemed undesirable. Yet the background was simplified as a point of comparison for an active case where care might otherwise be classed as futile. Furthermore, parents who were older and/or undertook many cycles of fertility treatments were assumed to be in a better financial position to care for a medically complex or fragile infant upon discharge. While healthcare is publicly funded, those deemed "worse off" financially were considered unable to afford added extra therapies which might be necessary for the sequalae of extreme prematurity. Rayna Rapp's framework of (1990) "moral pioneers" is relevant here. The use of hypothetical situations as points of contrast was one way in which nurses exercised their moral agency over contentious clinical decisions and the subjective negotiations of personhood. However, the moral agency in determining legitimate personhood was nuanced by the moral bracketing discussed above. These existed a clear tension between judgements made and the desire to defer responsibility to others.

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[80] Pseudonym used at request of participant

This was further nuanced by ethnic judgements whereby "Māori or Pacific, maybe refugee" parents were understood to be less financially stable, and thus ethnicity as well as financial status would therefore feature in clinical decision making. The financial instabilities were also assumed as congruent with brown or black bodies. Wider racist assumptions, extending to the infant body, have also been made visible to the public. Outrage (Jones 2018; Smith 2018; Mclauchlan 2019) followed the release of the Annual Report of Perinatal and Maternal Mortality Review Committee (PMMRC 2018) which reported resuscitation rates of extremely premature infants by ethnicity. It highlighted a lower rate of resuscitation for Māori and Pasifika infants at birth compared to Pākehā infants born at the same gestation and with no congenital abnormalities. This difference was attributed to an implicit racial bias in hospitals. In conjunction with the role of specific narratives of cost and value, this highlights the role of institutional racism and structural violence in the healthcare sector. Equally, these racist assumptions were one factor in a wider constellation of features in negotiating infant personhood(s) deemed acceptable, valued, and worthy of resource -rich intensive care.

Beyond the resource laden nature of NICU care, chronic understaffing was also a primary staff concern which equally speaks to the wider resource precarity in the public healthcare sector. Understaffing in the public healthcare system has been a significant point of public debate across the country. This understaffing goes beyond the walls of City NICU. A Public Services Association survey of New Zealand public healthcare workers reported that short-staffing was a major concern for staff whereby a lack of nurses, medical staff, and allied health professionals is understood to heavily shape patient care and work satisfaction (RNZ 2018). Bedside nurses in the NICU spoke of their job dissatisfaction as primarily attributed to understaffing and bullying from senior nursing staff. I was told by nurses how their work environment was "stressful", "crap", "like the movie Mean Girls" and "just a bit shit". Further, the intense pressure associated with working in an understaffed yet high acuity space was cited as cause of job dissatisfaction. While nurses stated immediate care was never compromised due to chronic understaffing, they said it still shaped patient and family care. For instance, an infant might not be able to receive kangaroo cuddles one day due to busy nursing staff. This was a feature which caused much concern for some parents who found it upsetting that there weren't enough nursing staff, or that the nurses were too busy, to allow kangaroo cuddles. Simultaneously, nurses expressed their frustration when unable to make parents as comfortable as possible due to time and resource constraints.

As mentioned previously, the lay-z-boy recliners were a sought after commodity at City NICU. These were primarily used for kangaroo cuddles. However, there were a limited number onsite which sometimes restricted availability for parental usage. The prized chairs were bought from donated funds thus were dependent on the altruism of community members. "In a perfect world," one nurse told me "there would be one of these chairs in every nursery…two if we had the space or money. I'm not sure if we could actually fit those nice big ones in every nursery". These financial narratives were used within a wider context of economic and political justifications in neonatal care more generally. Especially for infants born within the grey areas of viability, questions of survival, states of uncertainty, and quality of life debates shaped how the infants and their families are talked about in wider political and academic discourse. Further, such narratives justified the personhood of some infants, while destabilising that of others.

The Politics of Prematurity

Rates of survival to discharge for premature infants have steadily improved with the development of neonatal technologies. Even for those born at the so-called edge of viability (between 22 and 24 weeks gestation), the rate of survival is significant. A study at an urban NICU in New Zealand reported survival rates at two years post discharge as 58 percent for infants born at 23 weeks gestation and 60 percent for infants born at 24 weeks gestation (Berry et al. 2017). This does not take into account the sequalae of prematurity experienced by survivors. In addition, the authors acknowledge the high degree of technology and expertise catered to treating extremely premature infants at their particular centre. While over half of the "periviable"[81] infants survived to two years of age, this may not be reflected in other centres across New Zealand. I was also told by many staff at City NICU that New Zealand is unique in their comparatively aggressive treatment of those at the edges of gestational viability. Many nurses expressed the perception that NICUs across New Zealand are more aggressive in treating extremely premature infants than many other countries, such as those in Europe. This positioning of national neonatal care was also reflected by some members of the neonatal charity sector.

Neil, director of The Neonatal Trust, a charitable organisation which funds, produces educational material, and raises awareness for parents and families with an infant or infants in NICUs and SCBUs across the country, spoke of some nuances in the New Zealand context. He

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[81] This typically refers to infants at the grey areas of viability (between 22 and 24 weeks gestation).

used a parent support booklet, depicting a tiny foot encircled in a wedding ring on the cover, to reference his statements:

> *"One of our hero images is wee Charlotte's foot. [points to image] So that's a finger, next to wee Charlotte's foot. She was born at 23 weeks and 3 days, 12 years ago. If she was born in pretty much any other country in the world, they would not have been able to save her. Wellington, New Zealand is an absolute world leader. We produce the booklet with that picture, and a few years ago, a NICU refused to hand out the booklet because it said 23 weeks and 3 days on the inside cover, refencing the photo, because their official policy was…24 weeks [gestation] was the cut-off [for resuscitation]. (Neil)*

In addition to highlighting the controversy surrounding gestational cut-offs, this quote also illustrates the value of hope and possibility given to images of the NICU by those operating within the neonatal sector. The "hero image" of Charlotte was both a marker of hope, and indicative of the reach of medical possibility. Furthermore, despite the (perceived) aggressive and primarily successful treatment of this particular infant to discharge, questions of more general infant survival were palpable during my time at City NICU. Parents and staff expressed their continued fear over the uncertainty of both survival and outcomes. These narratives of fear and uncertainty were very much focussed on specific infants where both immediate survival and long term quality of life was in question:

> *"If you have a healthy baby come out at the end of it, then that's awesome. But if you have a baby come out [of NICU] who has all these issues, and who is going to constantly be in the system, and the parents are going to be at home looking after this baby all the time for most of its life…and I don't know…I always think…what's the quality of life for the baby, and the parents then?" (Nurse Leah)*

> *"Sometimes we find ourselves in a situation with a baby who really would not survive unless it was in the newborn intensive care unit, receiving intensive care treatment, and we have a family who want everything done for their child. From a nursing point of view, when you know that you are inflicting pain on the baby, like suctioning and blood tests, for an outcome you cannot see for that baby, I think that is an area where we need more discussion (NNP Deb)*

Nurse Leah's use of "the system" to denote the wider welfare and healthcare sectors highlights how wider political debates shape the attitudes of staff on the NICU. This quote also highlights the cultural (de)valuation ascribed to different type of dependency. Parents who do not work

or pay tax were equally categorised, along with the baby, as dependent on "the system". Further, this positioning of dependency designates those who fall within the category as undesirable. In this manner, not only did the nurses communicate clear assumptions about which babies they understood as persons worth living, but also which parents could fulfil the role of an accepted person and citizen. The personhood of the infant was closely co-constructed by political and economic positionings of parents and staff. The nurses expressed their moral authority over determining what they believed to be a life worth living and the potentiality of citizenship. These quotes reveal the assumption that a life with disability is synonymous with a lessened quality of life and suffering. In addition, this suffering is believed to extend beyond the infant, and be of detriment to the wider family and "the system". Beyond the NICU, these narratives are heavily present in medical literature and political rhetoric.

As an early PhD candidate in the field of medical anthropology, my perusal of various library shelves was not isolated to the sections on the social sciences. In fact, I still often find myself surrounded by shelves of medical textbooks, specifically those concerning paediatrics and neonatology, rather than simply anthropological monographs. From time spent flicking through such books, I have become increasingly familiar with what seems to be a fairly typical layout used to structure these textbooks: one chapter for respiratory pathologies and treatment; one for gastrointestinal; one for neurological, and so on. However, beyond system-based discussions, there are also additional chapters concerning 'social' and 'cultural' topics, such as ethics and law. I found these tended to be toward the end of the textbooks, following sections on cultural competency and the like. In Buonocore at al. (2012), extensive focus was given to neonatal ethics (Linderkamp 2012) and legal issues (Fineschi and Turillazzi 2012), in addition to chapters on pathology and treatment for newborns receiving intensive care. Questions raised in these chapters resemble those I observed at City NICU – with a focus on determining survival while grappling with clinical uncertainty. However, it is to be expected that these textbook discussions were much more generalised and high-level than those taking place onsite. While the textbook speaks of ethical issues in general terms, those discussions at City NICU were often situated within specific cases, using (sometimes hypothetical) infants as explanatory points of refence and comparison.

In Buonocore at al. (2012), Linderkamp instructed medical staff to exude a "positive attitude" in the treatment of extremely premature infants as "this is an important determinant of [infant] prognosis" (Linderkamp 2012, 191). The author encouraged education as the answer to "irrational negative associations" held by staff regarding predication of infant outcomes and

survival rates. These statements are indicative of the moral value afforded to treating premature infants by the neonatologists. It was assumed that the prediction of "irrational" poor prognoses directly results in different treatment practices. Nevertheless, while I observed this "positive attitude" more so in the medical staff, it seemed less frequent in the nursing staff. Yet given professional constraints, nurses communicated that their prediction of a poor outcome "didn't really mean much" as they were not in a position to change the treatment trajectory. Again, this speaks to how survival and quality of life debates were spoken of differently between professional groups whereby medical staff "push the babies because they can" while nurses "see the day to day suffering of babies and their families'. Linderkamp also highlighted economic cost as one feature of importance in wider discussions of treatment for infants with a poor prognosis. Simultaneously, Linderkamp is at once emphasising a positive outlook in the face of "negative assumptions" regarding treating extremely premature infants – and therefore designating moral value to the treatment – while also calling for a cognisance of the financial cost. The infants hold moral value (indicative of a type of personhood), some more than others, and this is closely tied to the perceived moral value of the family they enter into. Yet, does this value offset perceived potential economic, social, and political burdens? This is, in effect, a question posed by Linderkamp, and one which I observed *in action* in City NICU. Further, this question structures much of the wider political rhetoric both in New Zealand and beyond, regarding the treatment of those born at the limits of viability, further placing these infants in a position of contested personhood.

In 2011, the Listener, a national current affairs magazine, published an article exploring the state of premature birth in New Zealand while also telling the story of the author's own infant born premature due to uterine abnormality (Barnett 2011). The article seems to ask similar questions to those posed above:

> "New Zealand's rising number of premature babies cost millions in care for uncertain outcomes…the pressure on the neonatal units is immense, with an unpredictable and increasing patient load. And the question must be asked: just how much effort should be made to save very premature babies, when many suffer ongoing health problems?" (Barnett 2011)

The authors effectively questioned whether the degree of care, economic burden, and perceived likelihood for poor infant outcomes offsets the possibility for a good outcome in those born at 23 or 24 weeks gestation. Yet although Barnett wrote of extremely premature infants in her capacity as the mother of an infant born premature, her child was born at 31 weeks gestation –

far from those born at the point of viability she references as the most contentious. The author spoke of the premature babies affectionately while also explaining the immense cost to the Ministry of Health in maintaining their survival. Cost to the government, and the perceived likelihood of continued cost and poor quality of life, were cited as barriers to lowering the gestation at which infants should be resuscitated below 24 or 23 weeks gestation. More recently, the public image of premature babies in the media has followed a similar trend: these are New Zealand's "littlest patients", "saving [their] lives" is written of in a glorified manner (Duncan 2017), and a prominent neonatologist speaks frequently to the media advocating for intensive care of those born at 23 and 24 weeks (Duncan 2017; Flahive 2018).Yet, in the face of a working group proposing setting a national standard for resuscitation at 23 weeks gestation, media representation also emphasises the significant cost to already limited resources which may rise if a lowered gestational approach is standardised across neonatal units (Duckor-Jones 2018). Although neonatal care is also frequently touted in the media as "saving lives" (and saving persons), attention is also paid to an increasing economic precarity surrounding the care given. Public outrage followed the release of various news investigations detailing the degree of overcrowding, understaffing, and limited resources at various units. This state of resource precarity extends beyond the NICU, and into the wider maternity sector in New Zealand (Duff 2018; Meier 2018; Broughton 2019). The media presents a contradictory picture of premature birth in New Zealand, where at once, the public image of infants as valued and precious, whom we have moral imperative to 'save', is muddied by a perceived economic and social burden which accompanies them. There is a tension between the portrayals of premature infants as valuable and possessing an immutable and innate type of personhood, yet equally contentious in worth and value.

In the United States, this public portrayal of the premature infant has resulted in the development of various health activism movements. Landzelius (2006) observed that the premature baby and its mother have been given a "makeover" in the American media portrayal of premature infants. The premature infant has moved from its early alignment with the costly "cocaine babies" of "welfare mothers", to the affluent IVF-conceived "whitewashed" heroic duo of a "self-sacrificing mother" and her infant, as an embodiment of technoscientific cultural capital. This was a transition from an unproductive and undesired type of personhood, to one which is valued and desired by virtue of social and cultural categorisation. At the time of this ideological shift, a multitude of parent activist groups gained traction and visibility in

advocating for the rights and representation of premature babies in both the public and biomedical spheres.

Beyond the upper middle-class activism of American "preemie parents", Abadia-Barrero (2018) observed a similar politicisation of neonatal care in Colombia. The author tracked the development of Kangaroo Mother Care (KMC) programmes across Colombia as subaltern resistance to hegemonic powers of for-profit medical care in the country. Abadia-Barrero critiqued the labelling of KMC in Columbia as "reverse innovation" due to the resultant commodification and co-option of this label and programme by the private health sector. I observed a similar political framing of KMC by some mothers at City NICU. Although KMC was spoken of as clinically encouraged by staff, for some mothers, their desire to practice KMC was not supported enough. For Lydia, the practice of KMC was not only a way she could care and bond for her infant, but also a way to show her power and authority in the face of NICU policies she did not agree with, but felt she could not fight directly. Beyond some neonatal charities and individual practices onsite, I have observed very limited overtly activist sentiments in the New Zealand NICU sector. However, it is also worth noting that there exists a dearth of legislation that explicitly references premature babies or premature birth.

The United States' legislation contains an entire act expressing a federal commitment to support those affected by premature birth *and* setting a legislative imperative funding further research into reducing the rate and effects of early birth ("PREEMIE Act 2018" 2018). In New Zealand, the only such legislative mention of premature birth concerns the paid parental leave amendments within the Parental Leave and Employment Protection Act 1987 (the Act). In 2016, an amendment (the Amendment) was added to the Act allowing for extended paid parental leave for those caring for a premature baby and who would otherwise receive paid parental leave. The Amendment provides extra paid parental leave in addition to that usually provisioned in previous legislature. In addition to regular paid parental leave, parents of premature infants may receive special payments each week from the infant's birth, till when the infant would have reached 36 weeks gestation.[82] These payments are to account for the extra time parents may require off work when caring for a premature infant, which regular paid parental leave would otherwise not account for. A cabinet paper proactively released by the Ministry of Business, Innovation, and Employment, highlighted the cost of the Amendment to

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[82] For instance, if an infant was born at 29 weeks gestation, the parent would receive seven weeks of paid parent leave payments, in addition to the paid parents leave payments they would have received if the infant had been born to term.

the government. When the Amendment was presented to Cabinet, it was predicted that the cost of administering and provisioning the new payments would exceed $3 million NZD per annum (Office of the Minister for Workplace Relations and Safety 2015). The Amendment somewhat represents the enactment of a political assumption that the premature infant and their family is entitled to state support. However, this exists alongside the onsite categorisation of some parents as dependents, and some babies as "drains on the system."

Nevertheless, the premature person is becoming an increasingly visible locus of biopolitical authority and debate. In New Zealand, this politicisation is occurring via a variety of aforementioned processes: propositions to protocolise gestational viability vis a vis resuscitation (from government supported working groups); an on-unit cognisance of resource precarity; narratives of cost and benefit; financialised logics of care and infant background; and an increasing media presence. Rates of prematurity have also become a measure of political success which implies an acute political awareness of such power dynamics.

Conclusions

The care of extremely premature infants, and the clinical decisions involved, *are* implicitly political and economic: determining who to resuscitate is not only a decision based on predicating best outcomes, it is inherently a decision involving the negotiation of personhood whereby economic and political narratives (de)legitimise different types of persons, citizens, parents, and babies. Yet, as observed by Marsland and Prince (2012), the reach of contemporary biopolitics is not absolute. Operating within this healthcare political economy are persons – doctors, nurses, and parents – whereby deeply personal notions of care, emotion, and value further shape their actions and narratives, such as in the construction of highly emotive infant backgrounds to explain resource use within the context of care. Working within a context of economic and political regulation simultaneously restricted *and enabled* a moral economy of care at City NICU where moral bracketing of justifications and cultural assumptions exist alongside each other. The sociality in conferring or denying personhood (Kaufman and Morgan 2005) was equally individualised, yet multiple, in the emotive justifications used to negotiate personhood for particular infants. Further, in operating within resource constraints, such reflections about 'life quality', uncertainty, infant survival, and the reaches of medical technologies were presented as all the more acute. Both within and between infants, certain inequalities shaped how multiple personhoods were enacted, but also made contradictions within the broader economic and political rationalisations.

Interlude: 24 Years Later

If I wasn't doing my thesis on this topic, I'd probably think about my own prematurity much less. Perhaps, only when struggling to see or breathe would I be reminded that I was a NICU baby. However, I *did* do my PhD research on prematurity, and therefore it is rather impossible to ignore my positionality in this research and thesis, which have made up much of what I do, day to day, these past 3 years.

In the years following my discharge, my prematurity remained a feature in how I grew up. Paediatrician visits and hospital admissions were somewhat regular; I required occupational and physical therapy; and common colds prompted more cause for concern. However, these features equally extended beyond my health status. I was probably parented a little more closely than I otherwise would, due to my precarious early days, weeks, and months. Special care was taken by my family and wider network to ensure I'd have all the same opportunities I would if I was born at full term. It is for this reason, among others, that I believe I was able to write this thesis.

When I was doing fieldwork on City NICU, many staff and parents were shocked and surprised to hear I was born at 26 weeks. While one nurse laughed, "You don't look prem!", other nurses recognised my prematurity in my small stature, recurrent wheeze, and the white dot of a cataract in my right eye. Others asked if I still have scars from chest tubes (I do) or PICC lines (I also do). Some wanted to feel the shape of my head and see if I have sensitive feet. One thought that maybe I am left handed due to the brain bleed I suffered in NICU. Others nodded approvingly when I admitted I struggled walking up stairs, while others were surprised to hear I skipped a year in school. One asked if I'd participate in a research study of her own. "Quid pro quo" I replied.

Concluding Remarks: From Future Research to Structural Change

The Health Standards working group has yet to reach a decision on whether to set a national standard for the resuscitation of extremely premature infants. The provision of a national standard would mean infants born prior to a predetermined cut-off gestation would not be given the intensive care necessary to survive. At the same time, infants born after a particular cut-off may be indiscriminately resuscitated on the basis of a bureaucratic protocol. Conversely, if the working group concludes that the status quo should be retained, NICU staff will continue to operate in a space of regulatory and ethical ambiguity. While hospital based protocol offer guidelines for staff, ultimately authority and power of decision making rests with the medical staff onsite. Not only do these possible outcomes shape the possible futures of soon-to-be born preterm infants at the borders of viability, both the potential outcomes and justifications make inherent claims about the personhood of the foetuses and infants in question. Furthermore, the potential for a regulatory imperative that prohibits the resuscitation or use of intensive care for any infant born prior to 23 weeks, for instance, may politically subvert cultural attitudes towards the attribution or designation of infant personhood. Equally, the same regulatory imperative implicitly infers a certain type of personhood to those born after the designated gestational cut-off. The requirement to resuscitate repositions the infant in question along a continuum of legitimacy, life-worth, and regulatory moral capital. Yet the possible regulations would not reduce or erase ambiguities. Rather, regulation would create a new set of tensions and ambiguities for staff and parents to negotiate and traverse.

As I ponder these possibilities, a discussion I had with baby Alice's mother Jennifer is at the forefront of my thinking. Alice's short life may well have been altered by the potential introduction of regulations prior to her birth. Jennifer and I spoke in a quiet moment seated on tattered chairs in City NICU's family room. As I mentioned earlier in the thesis, Alice was 'officially' born at 23+2 weeks. This date placed her just within the boundaries of what was considered viable and a legitimate subject of NICU care. However, as Jennifer revealed, "we might have gotten the dates wrong", indicating her gestation at birth may have actually been approximately 22 weeks. While this type of ambiguity did little to shape the eventual outcome – Alice died – , in retrospect, regulation may considerably trouble ambiguity such as this and create new ambiguities for parents and staff to traverse. I wonder if Alice was in fact officially registered as born at 22 weeks gestation, would the introduction of gestational regulations

preclude her from intensive care? Furthermore, would this preclusion subvert her assumed personhood, which was very much enacted during her short life? What would this mean for the experiences and identities of her family members? This regulatory shift would prompt new complexities in the negotiations and enactments of infant personhood in different spaces of ambiguity.

Yet I am reminded that concerns posed by potential regulation and the associated assumptions that couple gestation to personhood, exemplify just one lens through which the complexities of premature personhood are negotiated and articulated. As made visible through extensive ethnographic fieldwork, negotiations of personhood extended far beyond the corporeal and clinical bounds of the infant – existing as multiplicities of personhood. Not only was gestation used as a means through which personhood was debated, but equally, spaces, things, and ideas were imbued with multiple narratives of personhood, not just subject to the infant, but to those around them. In this manner, personhood was bilaterally and mutually enacted in ways that were sometimes contradictory. This is co-constituted by a network of individuals, objects, and ideologies which interacted to shape how personhood was negotiated differently across, and through, individuals.

New Directions, Implications, and Limitations

The overarching goal of this research was to initiate a conversation between academics in the field, such as myself, policy makers, and NICU staff, with the hope of effecting tangible change in the neonatal sector. An examination of personhood in the NICU made visible some key areas where changes could be made to improve the experiences of both parents and staff who care for extremely preterm infants. These range from smaller changes in language and actions, to wider structural shifts and policy development.

Staff and parent negotiated their own, each others' and infant personhoods, in multiple and sometimes contradictory ways based on their possible futures. These negotiations sometimes relied on ableist, classist, sexist, and racist assumptions which (de)legitimised particular types of care work. Such assumptions not only shaped the care of infants, but also shaped how certain parents and families were approached in the NICU setting. This study revealed some of the harms experienced by parents in this environment, primarily as a result of how the space was organised and disciplined by staff onsite and from wider bureaucratic powers. While some of these harms were justified by staff as necessary for infant care (such as the restriction of some family members allowed around an incubator), other harmful practices served no overt

purpose, such as the use of racist and classist language in reference to some parents. Further, cultural competency was a primary area that I saw as needing improvement. The on unit improvements also require broader structural changes in order for the environment to become safer for families. For instance, an actively anti-racist restructure of hospital policy is necessary to effect change and to combat the legacy of colonialism within public services. Such changes are also needed at the legislative level to enhance (and fund) better NICU care for babies and families across New Zealand. As discussed in the previous chapter, there exists a dearth of Acts concerning premature infants and their families in legislation. While the specialised parental leave payments are an important feature in the legislative body, I thoroughly believe more policy development is needed in supporting on-unit action against the racist, ableist, classist, and sexist assumptions that shape the care of infants and families.

Importantly, I level my critique at deep societal structures of racism, rather than at the actions of a specific NICU and/or groups of individuals. The legacy of colonialism which I observed at City NICU is a symptom of a much wider problem across healthcare services in New Zealand. Addressing this wider problem is necessary for real on-unit change to take place. As numerous scholars have revealed, the healthcare system in New Zealand is racist and in need of radical restructure (see Boulton, Tamehana, & Brannely 2013; Bryers-Brown 2015; Durie 2001). Integral to these structural changes are the voices of Māori in directing the shifts necessary to make the wider healthcare system, including the NICU, a safer space for all.

As both the clinical and bureaucratic environments that shape neonatal care continue to shift, anthropological research should equally examine these shifts. Further, this thesis posed many questions and openings for future anthropological research into the position of premature infants in New Zealand and beyond. This thesis primarily focussed on one urban NICU (although participants spanned the length of the country). More diverse geographic foci would offer a more nuanced understanding of the NICU environment, such as a focus on smaller rural NICUs or SCBUs that provision care to different social and cultural groups. The focus on a single NICU is both a limitation of the thesis, and simultaneously an important feature. The single locus for extensive participation was one component of a much more complex national system. Nevertheless, the single primary fieldsite allowed for meaningful and sustained engagement with a core place and group of individuals. Further, I enhanced this singular focus through interviews with participants from across the country. A future direction for this research could then focus on a different NICU serving a different community.

I also understand that further anthropological focus on the NICU should decentre prematurity as epitomising the neonatal experience. I spoke with some families of infants born to term with complex medical conditions who were frustrated with a perceived public and academic preoccupation with premature infants in the NICU, leaving others without such rigorous attention. While the NICU is probably most known as a space for premature infants, these units also provide life-saving care for newborns with a wide range of medical concerns. Therefore, an interesting and necessary avenue for future research in the NICU is one that explores the lifeworlds of infants who required NICU admission for an issue other than prematurity. This would also allow for an examination of personhood in the NICU through a vastly different lens. Very unwell infants born to term may not embody metaphors of the foetus in the same manner as an extremely preterm infant, yet they still occupy a highly unstable position.

I have proposed moving somewhat beyond the individual-relational dialectic, in effect, melding the two categories in reference to personhood. This move beyond the individual and relational is now fairly standard in anthropological discourse. However, I question what the theoretical landscape would look like if the categories were abandoned altogether. In this thesis, it has been useful to articulate the multiplicities of personhood and tensions using the analytic categories of relational and individual as simple yet malleable bases for analysis. Therefore, while Kaufman and Morgan's (2005, 330) brief mention of personhood as "intersubjective" may be one approach taken to understand personhood beyond the traditional dialectic, I question if a shift to this intersubjective approach might not allow particular gradations and tensions to be visible in the same way as personhood multiple.

I have levelled my theoretical contribution of personhood multiple (and as a multiplicity) as a nuancing of the existing anthropological theoretical contributions discussed throughout the thesis. Within interrelating discussions of gestation, time, space, work, social categories, agency and the politico-economic landscape, I have developed personhood as multiple. This is as an extension of personhood as social and intersubjective, dividual, relational and individual, situational, and potential. Personhood as multiple adds specific value to the theoretical framings of personhood as temporal, discussed throughout the thesis, such as that of Bird-David and Israeli (2010) with personhood positioned as situational, and Lupton (2013a; 2013b) where personhood is negotiated through potentials. I found these authors' foregrounding of temporalities useful in the development of personhood multiple, across time, space, things, and people. However, during fieldwork, I observed saw such a strong resistance away from time-

based ways of being in the NICU (as discussed in chapter 4), that I understand personhood as multiple to account for this nuance clearer.

In contributing to the theoretical landscape by positioning personhood as multiple, as a multiplicity, I do so to make visible certain tensions and contradictions between the diverse a negotiations – a framing of personhood as co-constituted, both enabling and restricting individualities but through complex and often hidden relationalities. In this way, I have found theoretical value in using analytical categories of relational and individual, but situate this in a much broader framework of the multiple, which makes space for particular gradations and tensions to visible, without an aforementioned temporal constraint.

A theoretical critique of personhood multiple could be levelled on the back of critiques positioned at the Latourian language of the multiple and multiplicity, particularly concerning questions of agency (discussed in chapter 6) – a common critique being that this type of language flattens the political landscape. Yet in this thesis, personhood as multiple is inherently political. As I have discussed, orientations towards the future highlighted how multiple futures are effectively ranked and stratified on the basis of cultural ideas about the body, health, and disability. A politics of personhood multiple was also clear at the intersections between modes of conception, ethnicity, and predicted rates of survival. These features extended much beyond framings of infant personhood, into ideas of parental personhood and how it was mobilised by staff in discussion of infant personhood.

At City NICU, narratives of an individualised personhood (denoting innate and corporeal features of personhood as well as emotional and deeply personal negotiations) existed within much broader social configurations of people, things, ideas, and structures. The multiple articulations of infant personhood that I have charted here highlight how persons are culturally produced and diverse on a cross-cutting set of cultural practices and concerns. Various social categories and manners of rationalisation mean that some infants are framed as more legitimate, and less contentious, than others based on socially mediated characteristics deemed innate to that infant. I have argued that personhood in this setting is multiple across both individualised and relational dynamics. Further, these dynamics were in constant and shifting states of tension and contradiction. These abstractions are complicated, but this reflects the overall complexity of the space itself: as a nursery-ICU hybrid, a place of living and dying, of foetuses and infants, and the space where my birth and my research coincided, separated by 24 years.

8

Postscript

I've been writing these interludes at various points of my PhD candidature. Early on, I knew I wanted to write these as a way to break up my thesis, and as points of reflection. I initially intended these points of reflection to based off a reading of my medical notes. While this has been a facet of the interludes, it soon became clear in writing that I simply wasn't able to disconnect the writing of my own neonatal journey, with the one I was concurrently undertaking at City NICU. Writing of my early birth constantly made me think of the tiny babies I hung out with during my fieldwork. When I wrote of my Golden Hours, I thought back to when I first met Jessie and Georgia, brand new, not even an hour old. Before the girls arrived, a lovely nurse in the nursery checked in with me, to make sure I'd be okay. These girls were born at the same gestation I was. One even weighed the same as I did. I think this nurse was worried I would freak out or be upset at seeing a newborn preemie who looked so similar to the pictures of me I'd grown up seeing. To be honest, I didn't see myself in Jessie or Georgia. They were, to be fair, completely different humans. Different people. However, it was strange, almost surreal, to see what 900 grams looked like in practice – I'd only ever seen infants of that weight in photos, mainly of me.

So as I wrote of various bits of my own story, my mind often wandered to those of others. I'd think about the parents, what they were doing now, how their other kids were faring. I'd think about City NICU and what was happening there. I never really went back to visit much after Alice died. Reading over my own medical notes and thinking about my story now makes me think of Alice's. While she lived for only 5 weeks, I think her story is an integral reminder that the length of time spent alive does not correlate with the strength and potency of bonds built. Even as a researcher, my experience of City NICU was shaped by Alice's life and her death. I followed the peaks and valleys of her clinical trajectory, expressed joy at her milestones, and sadness at her declines. I laughed when she winked at us, and cried when she died. Although I was never involved in the development of a new medicine, technology, or public health initiatives, I've had the opportunity to view life at a raw and powerful level. In doing so, I've been given the privilege to share the stories of tiny lives, including those whose stories ended far before they should have.

And, for that, I am beyond thankful.

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Appendix 1: VUW Human Ethics Approval Memo

TE WHARE WĀNANGA O TE ŪPOKO O TE IKA A MĀUI

VICTORIA
UNIVERSITY OF WELLINGTON

Phone   0-4-463 5205
Email   Averil.coxhead@vuw.ac.nz

MEMORANDUM

TO	Zoe Poppelwell
COPY TO	Catherine Trundle
FROM	Dr Averil Coxhead, Acting Convener, Human Ethics Committee

DATE	22 May 2017
PAGES	1

SUBJECT	**Ethics Approval: 24359** Talking About Preterm Neonates in the NICU

Thank you for your application for ethical approval, which has now been considered by the Standing Committee of the Human Ethics Committee.

Your application has been approved from the above date and this approval continues until 1 February 2020. If your data collection is not completed by this date you should apply to the Human Ethics Committee for an extension to this approval.

Best wishes with the research.

Averil Coxhead,
Acting Convener, Victoria University Human Ethics Committee

Appendix 2: Demographic Overview of Core Participants (Parents and Staff)[83]

Gender		
Characteristic	**Frequency**	**Percent (%)**
Male	8	16
Female	43	84
Ethnicity		
Characteristic	**Frequency**	**Percent (%)**
Pākeha (NZ European)	38	75
Māori	9	18
Other	4	7
Age		
Characteristic	**Frequency**	**Percent (%)**
0-19	7	14
20-39	24	47
40-59	10	19
60+	2	4
Did not answer	8	16
Type of Participant		
Characteristic	**Frequency**	**Percent (%)**
Hospital Staff	15	30
Parents	36	70

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[83] This demographic information (reported by participants) was collected as a part of follow up contact with key individuals. Some participants were lost to follow up, and others requested that some demographic information be omitted. Therefore, this table does not contain information from all participants that I worked with. Rather, this table contains the demographic information from 51 participants (a large proportion of total participants).

Appendix 3: Information Sheet and Consent Form

Experiences of Parents and Staff Caring for Premature Babies in the NICU

Interview Information Sheet

Thank you for your interest in this project. Please read this information before deciding whether or not to take part. If you decide to participate, thank you. If you decide not to take part, thank you for considering my request.

Who am I?

My name is Zoe Poppelwell and I am a Doctoral student in Cultural Anthropology at Victoria University of Wellington. This research project is work towards my PhD dissertation.

What is the aim of the project?

This project explores how medical professionals and families talk to, and about, premature babies in New Zealand NICUs. I am interested in how these attitudes take shape cot-side, and whether these attitudes change from birth to discharge. From this research, I hope to raise awareness of the social and cultural elements visible in the care of premature babies in New Zealand NICUs. This research has been approved by the Victoria University of Wellington Human Ethics Committee (Ethics Approval: 24359).

How can you help?

If you agree to take part, I will interview you at a location and time of your choosing. I will ask you questions about your experiences of having a premature baby in this NICU. The interview will take no longer than 90 minutes. After the first interview, I might interview you up to 2 more times, depending on your willingness and availability for more interviews. I will audio record the interview and write it up later. You can stop the interview at any time, without giving a reason. You can withdraw from the study by contacting me at any point up to three months after final the interview. If you withdraw, the information provided in the interviews will be destroyed or returned to you.

What will happen to the information you give?

This research is confidential. This means that the researchers named below will be aware of your identity but the research data will be aggregated and your identity will not be disclosed in any reports, presentations, or public documentation. However, you should be aware that in small projects your identity might be obvious to others in your community. Only my supervisors and I will read the notes or transcript of the interview. The interview transcripts, summaries and any recordings will be kept securely and destroyed 5 years after the research ends.

What will the project produce?

The information from my research will be used in my PhD dissertation, and may be used for other academic publications and conference presentations.

If you accept this invitation, what are your rights as a research participant?

You do not have to accept this invitation if you don't want to. If you do decide to participate, you have the right to:

- choose not to answer any question;
- ask for the audio recorder to be turned off at any time during the interview;
- withdraw from the study up to three months after the last interview;
- ask any questions about the study at any time;
- receive a copy of your interview transcript;
- agree on another name for me to use rather than your real name, in my final report;
- request an electronic copy of my final report.

If you have any questions or problems, who can you contact?

If you have any questions, either now or in the future, please feel free to contact either:

███████

Human Ethics Committee information

If you have any concerns about the ethical conduct of the research you may contact the Victoria University HEC Convener: ██████

VICTORIA
UNIVERSITY OF WELLINGTON

Experiences of Parents and Staff Caring for Premature Babies in the NICU

Consent to Interview

This consent form will be held for 5 years

Researcher: Zoe Poppelwell, School of Social and Cultural Studies, Victoria University of Wellington.

- I have read the Information Sheet and the project has been explained to me. My questions have been answered to my satisfaction. I understand that I can ask further questions at any time.

- I agree to take part in an audio recorded interview on my experiences of having a premature baby in the NICU.

I understand that:

- I may be interviewed up to 2 more times, if I am willing and available;

- I may withdraw from this study at any point up to three months after the final interview, without giving any reason. Any information that I have provided will be returned to me or destroyed;

- I may choose not to answer any question;

- I may ask for the audio recorder to be turned off at any time during the interview;

- I may ask any questions about the study at any time;

- The information I have provided will be destroyed 5 years after the research is finished;

- Any information I provide will be kept confidential to the researcher and the supervisor. I understand that the results will be used for an PhD dissertation and a summary of the results may be used in academic reports and/or presented at conferences.

- I consent to information or opinions which I have given being attributed to me in any reports on this research:　　Yes ☐　No ☐

- I would like another name of my choosing, rather than my real name, to be used the final report:　　Yes ☐　No ☐

- I would like a copy of the transcript of my interview: Yes ☐ No ☐

- I would like to receive a copy of the final report and have added my email address below: Yes ☐ No ☐

Signature of Participant:

_____

Name of Participant:

_____

Date:

_____

Contact Details:

_____

Experiences of Parents and Staff Caring for Premature Babies in the NICU

Observation Information Sheet for Parents

Thank you for your interest in this project. Please read this information before deciding whether or not to take part. If you decide to participate, thank you. If you decide not to take part, thank you for considering my request.

Who am I?

My name is Zoe Poppelwell and I am a Doctoral student in Cultural Anthropology at Victoria University of Wellington. This research project is work towards my PhD dissertation.

What is the aim of the project?

This project explores how medical professionals and families talk to, and about, premature babies in New Zealand NICUs. I am interested in how these attitudes take shape cot-side, and whether these attitudes change from birth to discharge. From this research, I hope to raise awareness of the social and cultural elements visible in the care of premature babies in New Zealand NICUs. This research has been approved by the Victoria University of Wellington Human Ethics Committee (Ethics Approval: 24359).

How can you help?

This research will involve my quiet observation on the Unit. If you agree to participate, I will be observing and taking written notes of the day-to-day activities of parents on the Unit who have consented to the study. Attached to this information sheet is an *Observation Protocol* which I would follow when observing Unit life. You would be able to withdraw involvement or send me away at any time during the study. You can withdraw from the study entirely by contacting me at any point up to three months after the study ends. If you withdraw, the information provided from my observation will be destroyed or returned to you.

What will happen to the information you give?

This research is confidential. This means that the researchers named below will be aware of your identity but the research data will be aggregated and your identity will not be disclosed in any reports, presentations, or public documentation. However, you should be aware that in small projects your identity might be obvious to others in your community. Only my supervisors and I will read the notes from observation. The observation notes will be kept securely and destroyed 5 years after the research ends.

What will the project produce?

The information from my research will be used in my PhD dissertation, and may be used for other academic publications and conference presentations.

If you accept this invitation, what are your rights as a research participant?

You do not have to accept this invitation if you don't want to. If you do decide to participate, you have the right to:

- ask that I leave the room at any moment in time without giving a reason;
- withdraw from the study up to three months after the study ends;
- ask any questions about the study at any time;
- agree on another name for me to use rather than your real name, in my final report;
- request an electronic copy of my final report.

If you have any questions or problems, who can you contact?

If you have any questions, either now or in the future, please feel free to contact either:

███████

Human Ethics Committee information

If you have any concerns about the ethical conduct of the research you may contact the Victoria University HEC Convener: Associate Professor. ███████

Experiences of Parents and Staff Caring for Premature Babies in the NICU

Consent to Observe on the NICU (Parents)

This consent form will be held for 5 years

Researcher: Zoe Poppelwell, School of Social and Cultural Studies, Victoria University of Wellington.

- I have read the Information Sheet and the Observation Protocol, and the project has been explained to me. My questions have been answered to my satisfaction. I understand that I can ask further questions at any time.

I understand that:

- the researcher will be observing and taking written notes of the day-to-day activities of parents and medical staff on the Unit who have consented to the study;

- the researcher will be following the 'Observation Protocol';

- I can send the researcher away at any time during the study.

- I may withdraw from this study at any point up to three months after the study ends. If I withdraw, information provided from the researcher's observation will be destroyed or returned to me;

- I may ask any questions about the study at any time;

- The information from observation will be destroyed 5 years after the research is finished;

- Any information I provide will be kept confidential to the researcher and the supervisor. I understand that the results will be used for an PhD dissertation and a summary of the results may be used in academic reports and/or presented at conferences.

- I consent to the researcher's presence on the NICU as an observer: Yes ☐ No ☐

- I consent to information or opinions which I have given being attributed to me in any reports on this research: Yes ☐ No ☐

- I would like another name of my choosing, rather than my real name, to be used the final report: Yes ☐ No ☐

Signature of Participant:

_____

Name of Participant:

_____

Date:

_____

Contact Details:

_____

Experiences of Parents and Staff Caring for Premature Babies in the NICU
Observation Protocol for Researcher

Researcher: Zoe Poppelwell

1. The researcher will be placed in an agreed upon NICU room by NICU staff.
2. Nurses will first consult with new NICU parents to ask if they would be comfortable being included in the research. The researcher will be introduced, by nurses, to willing parents to begin the process of gaining consent.
3. Upon receiving initial consent from parents, the researcher will ask if there are moments they know they would not like to be observed, such as during prayer or specific medical interventions.
4. The researcher will only observe in a room of the NICU where all parents and medical professionals have given consent to observation.
5. If one family member in the room does not give consent, the researcher will not observe in that particular room during the duration of their stay.
6. The researcher will be taking written notes of her observations.
7. If a participant were to withdraw from the study, the researcher would destroy the written notes pertaining to that individual, and would not use knowledge gained from observing that individual in her final report.
8. The researcher may use pseudonyms to refer to participants (if they desire).
9. The researcher will be clear about her status as a non-clinical researcher, on the Unit.
10. Under no circumstances will the researcher be involved in the medical treatment of any infants on the Unit.
11. The researcher will leave the room swiftly when asked.
12. The researcher will be quiet, and not touch anything (unless told to do otherwise).
13. The researcher will adhere strictly to the guidelines given by NICU staff – including, but not limited to:
    a. The researcher will not conduct observation on the Unit when sick.
    b. The researcher will adhere to a predetermined dress-code – to be discussed with staff.
    c. The researcher will scrub as required by NICU protocol.
14. Any additional protocol, specific to a participant, will be recorded on a participant-specific protocol sheet for the duration of the study period.