# Babies and Babble: Parents' Experiences of the Neonatal Unit and the Role of the Babble App

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Charlotte Gibson BA(Hons)

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# Abstract

Neonatal unit admission is commonly a highly distressing and difficult time for new parents, impacting their confidence in their parenting abilities and predisposing them to significant mental health difficulties (Ballantyne et al., 2017; Holditch-Davis & Miles, 2000). In response to admission, parents commonly report a need for clear, concise information and inclusion in neonatal care (Cleveland, 2008). Alongside the rise of technology and the prevalence of smartphones across the world, mobile health applications have been theorised as an effective method of delivering rapid, consistent and accessible information to health consumer populations. Within the neonatal sphere, such approaches have been growing in popularity, however, little research has focused on the development and efficacy of mobile health applications dedicated to needs of parents with an infant admitted to a neonatal unit. In response, MidCentral District Health Board has developed an informational mobile health application, Babble, for use in conjunction with traditional care formats and with the hopes of providing greater support to parents in neonatal units (Spargo & de Vries, 2018). Although utilised by parents, the Babble app is yet to be empirically evaluated and the impacts of its use are not well understood.

In this thesis, an exploration as to parents' experiences of the neonatal unit and the role of the Babble app is conducted in two parts. Study One explores the experiences of 449 parents with an infant admitted to a neonatal unit in New Zealand, across measures of distress, self-efficacy, how informed they felt during their infant's admission, and their Babble app use. Study Two involved in-depth qualitative interviews with eight mothers from the Palmerston North neonatal unit, (where the Babble app originated), exploring their perspectives of their infant's hospitalisation, and the Babble app itself.

Study One showed that parents experienced moderate distress, felt reasonably informed and considered themselves to be somewhat confident in their parental role during their infant’s neonatal admission. The Babble app did not demonstrate any significant effect on any of the variables of interest. However, results indicated that the more informed parents felt, the less distress they experienced. This relationship was partially mediated by enhanced self-efficacy, suggesting the importance of information in supporting parental self-efficacy and reducing distress.

Study Two expanded on these findings, identifying several key themes present in the experiences of mothers with infants admitted to a Level II+ neonatal unit. Firstly, findings indicated there were various ways in which mothers struggled with their parental role within a neonatal context, experiencing challenges related to managing their own expectations of the experience and asserting their role within the unit. Consistent and supportive relationships with staff, family, friends, and their partners, were seen as influential in the maternal experience. Most significantly, good communication and strong relationships with staff were seen to improve maternal confidence. Information was highly valued by mothers, with some variation in their interactions with information, depending on individual needs and styles. The Babble app was considered a useful adjunct to traditional care formats by mothers who identified that they were able to adapt and integrate its use in alignment with their individual preferences and needs.

Taken together, these findings suggest that for families, neonatal admission is a challenging and diverse experience. Staff are essential, not only as sources of information, but as part of a supportive relationship with families. The importance of informational support cannot be understated and its value in building parental self-efficacy and reducing parental distress was evidenced across both studies.  Ultimately, the findings presented here suggest that informational resources, such as Babble, can act supportively for parents and therefore, are worthy of further development and exploration.

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# Preface

This thesis takes the form of a partial thesis-with-publications format. The first three chapters consist of a general introduction to neonatal care provision, the parental experience of neonatal admission, and eTechnology. Study One is then included, followed by Study Two, in the format in which they have been submitted to their respective journals. The thesis closes with a general discussion, pulling together the findings from both journal articles and considering the overall outcomes and practical implications of the thesis as a whole. An additional conference presentation delivered in November 2019 at the Paediatric Society of New Zealand Conference is included in Appendix E.

The information provided in this thesis is my own, in keeping with the requirements of doctoral study. With guidance from my supervisors, I designed, implemented and performed all phases of the study. My supervisors provided input and feedback on my work at all stages. Dr Nathalie de Vries provided clinical advice and completed reviews on the journal articles prior to submission, and thus, is listed as an author as appropriate.

Ethical approval for the two studies reported in this thesis was obtained from the Massey University Human Ethics Committee, Southern A Application 18/64.

Charlotte Gibson

Doctoral Candidate

Massey University

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# 1. Introduction to Neonatal Care

## 1.1 Neonatal Units

For centuries, the care and protection of the most vulnerable has been prioritised by society, be that through law changes, development of services or investment in medical advances. Infants have often been placed in that category, with particular attention paid to arguably the most vulnerable of this group; those born small, sick or early. Beginning in 1880 with small chicken incubators, the care of preterm or sick infants has gradually developed alongside technological advances (Vandenberg & Hanson, 2013). By the 1990s, infants four to five weeks premature were supported by areas of the hospital specifically targeted to their needs (e.g., neonatal units), namely to feed, regulate infant temperature and avoid infection; however, strict rules prevented parental involvement throughout the infants' stay (Vandenberg & Hanson, 2013). With the advent of neonatology as a discipline of medicine, improving technology and antenatal care improvements at identifying those 'at risk', there has been an increase in infant survival and admission to these units (Ministry of Health, 2007). The number of admissions to neonatal units worldwide has been steadily increasing since 1996 and survival rates of around 90% of infants admitted to neonatal units are the norm for many developed countries, indicative of the medical community's increased ability to care for infants who require additional support (Vandenberg & Hanson, 2013).

In New Zealand, over 5,000 babies are admitted to a neonatal unit each year (The Neonatal Trust, 2012). Specific reasons for neonatal admission vary, as does length of stay, dependent on the severity and level of care required. New Zealand has 23 neonatal units located across the country servicing specific regions, at three different levels of care (Neonatal Nurses College Aotearoa, 2018). To better understand the care provided, it is important to first outline the New Zealand healthcare system in general.

## 1.2 New Zealand Healthcare

New Zealand's healthcare system is uniquely structured and has received international praise for its accessibility and affordability (Davis et al., 2014; de Onis & Habicht, 1996; Health Quality & Safety Commission New Zealand, 2015; Schlaudecker et al., 2017). The structure of New Zealand's healthcare is overseen and funded by the Ministry of Health, a core component of Central Government. Twenty District Health Boards (DHBs) cover different geographical catchments of New Zealand, providing common healthcare services to those within the area (see Figure 1; Ministry of Health, 2017).

**Figure 1**

*DHB Catchment Areas. Sourced from Ministry of Health (2017).*

Each DHB faces unique needs related to the provision of healthcare due to New Zealand's geographical dispersity and ethnic diversity. With a population of around five million spread across 268,676 square metres, the population is widely dispersed between urban and rural communities (Statistics New Zealand, 2017). New Zealand operates a system of regionalised care, whereby the main resources are centred in the major population areas, e.g., Auckland, Wellington and Christchurch (Donoghue et al., 2013). People who are located at a distance from a major centre or in a smaller city may be only able to receive certain types of specialist care away from their home or community. As a result, a significant amount of communication and cooperation is needed between DHBs to ensure people are receiving the necessary care and support.

In New Zealand, the dispersion of neonatal care facilities reflects that of other healthcare services provided, whereby the more severe, intensive care units are focused in highly populated areas. Some DHBs do not have the necessary facilities to care for infants who require neonatal care and so transfers between units and DHBs are common. Each unit is a highly sterile environment with significant amounts of specialised medical equipment and strict policies in place to protect the admitted infants.

The cultural diversity within New Zealand is exemplified in the results of the 2013 New Zealand Census with 74% of the population identifying as New Zealand European/Pākehā, 15% identifying as Māori, 12% identifying as Asian, and 7% identifying as Pacific peoples (Statistics New Zealand, 2015). 1% of the population surveyed identified as Middle Eastern, Latin American or African (Statistics New Zealand, 2015). An audit of New Zealand neonatal units performed in 2015 indicated that 52.6% of infants admitted identified as New Zealand European/Pākehā, 18.8% Māori, 13.5% Pacific peoples and 12.9% Asian (Chow et al., 2015). Given the over-representation of Māori and Pacific peoples within a neonatal unit context, it is necessary for neonatal units, (and DHBs in general), to consider and accommodate the unique requirements of these populations, with care reflecting the diverse cultural needs of New Zealand.

### *1.2.1 New Zealand Neonatal Care*

Worldwide, neonatal care provision is typically divided into three to four levels related to the prematurity of the infant and the degree of severity with regard to medical needs (Committee on Fetus and Newborn, 2012; Ministry of Health, 2007). The following section will overview the four levels of care prominent within a New Zealand context (see Table 1; Malatest International, 2019; Ministry of Health, 2007).

**Table 1**

*Overview of New Zealand Neonatal Units, DHB and Level of Care.*

| DHB | Name and Level of Unit |
|---|---|
| Northland | Whangarei Hospital: Special Care Baby Unit (Level II) |
| Waitematā | North Shore Hospital: Newborn Special Care Baby Unit (Level II) |
| | Waitakere Hospital: Special Care Baby Unit (Level II) |
| Auckland | Auckland Hospital: Newborn Intensive Care Unit (Level II & III) |
| Counties Manukau | Middlemore Hospital: Kidz First Neonatal Care (Level II & III) |
| Bay of Plenty | Tauranga Hospital: Special Care Baby Unit (Level II) |
| | Whakatane Hospital: Special Care Baby Unit (Level II) |
| Waikato | Waikato Hospital: Waikids Newborn Intensive Care Unit (Level I, II & III) |
| Tairawhiti | Gisborne Hospital: Neonatal Unit (Level II) |
| Lakes | Rotorua Hospital: Special Care Baby Unit (Level II) |
| Taranaki | Taranaki Base Hospital: Neonatal Unit (Level II+) |
| Wanganui | Wanganui Base Hospital: Special Care Baby Unit (Level II) |
| Hawke’s Bay | Hawke’s Bay Hospital: Special Care Baby Unit (Level II+) |
| MidCentral | Palmerston North Hospital: Neonatal Unit (Level II+) |
| Hutt | Hutt Valley Health: Special Care Baby Unit (Level II) |
| Wairarapa | Wairarapa Hospital: Special Care Baby Unit (Level II) |
| Capital and Coast | Wellington Hospital: Neonatal Intensive Care Unit (Level III) |
| Nelson Marlborough | Nelson Hospital: Special Care Baby Unit (Level II) |
| West Coast | Grey Base Hospital: McBrearty Ward (Level I) |
| Canterbury | Christchurch Women’s Hospital: Neonatal Intensive Care Unit (Level I, II & III) |
| South Canterbury | Timaru Hospital: Special Care Baby Unit (Level I) |
| Southern | Dunedin Hospital: Neonatal Intensive Care Unit (Level III) |
| | Timaru Hospital: Neonatal Unit (Level II) |
| | Southland Hospital: Neonatal Unit (Level II) |

**1.2.1.1 Level III Neonatal Intensive Care Unit.** Level III Neonatal Intensive Care Units (NICUs) provide the most intensive level of care to the most medically-fragile infants. Infants in these units are typically those born at less than 32 weeks gestation[1], those requiring significant respiratory support (e.g., mechanical ventilation[2]) or those under two kilograms (Malatest International, 2019; Ministry of Health, 2007). Infant palliative care may also take place in these units. Average length of stay in a NICU is around 40 days, indicative of the higher level of care necessary for these infants (Ministry of Health, 2007). Infants may require care consisting of invasive interventions and procedures, and are often surrounded by machinery, tubes and radiant warmers with the purpose of supporting survival. For those in a Level III unit across Australia and New Zealand, infant survival rates are around 92%, lower than the rates of other units at lower levels of care, reflecting the severity of the medical needs infants admitted to this unit experience (Donoghue, 2004).

**1.2.1.2 Level II and II+ Neonatal Unit/Special Care Baby Unit.** Level II neonatal units (also known as special care baby units) typically care for infants above 32 weeks gestation, as well as babies who have been transferred from a NICU once clinically stable (Ministry of Health, 2007). In most Level II units, admitted infants are required to be able to breathe on their own as there are no ventilation facilities (with the exception of emergencies, and in these cases, a less invasive form is commonly used; Ministry of Health, 2007). At times, Level II units are used to stabilise infants who require Level III care, until transfer to such care is possible, indicative of the dispersed and limited resources across New Zealand for high level neonatal care (Ministry of Health, 2007).

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[1] The average length of a human gestation period varies from 38 to 42 weeks long (Montvilo & Kalumuck, 2017). Babies born between 38-42 weeks are considered full-term.

[2] Use of medical equipment (e.g. high frequency oscillatory ventilation (HFOV), continuous positive airway pressure (CPAP) to assist or replace the infant's breathing (ADHB, 2011).

Level II+ neonatal units are considered to provide intermediate support, as these units are able to admit and care for infants over 28 weeks gestation (Ministry of Health, 2007). Reasons for admission typically include prematurity (< 37 weeks) and infants who may have respiratory difficulties, difficulties with temperature regulation, feeding difficulties and/or any medical needs. Average length of stay in these units is 7.5 days, slightly more than the typical week for Level II units (Ministry of Health, 2007). With increasing demand on Level III units, there have been higher numbers of infants who would typically require Level III care, being admitted to Level II+ units (Ministry of Health, 2007). For Level II/II+ units across Australia and New Zealand, infant survival rates are around 97% (Donoghue, 2004).

**1.2.1.3 Level 1 Neonatal Unit.** Level I neonatal units are less common in New Zealand, with beds at this level only located in three hospitals (Neonatal Nurses College Aotearoa, 2018). These units provide care to infants born at full-term with health complications, infants born after 32 weeks who are unwell or require some additional support, and infants awaiting transfers to higher level units (Committee on Fetus and Newborn, 2012).

## 1.3 Reasons for Admission

Although specific reasons for admission vary, infants requiring neonatal admission are often premature, small for gestational age, or critically ill (Ministry of Health, 2007). Typically, families are only aware of the need for neonatal admission subsequent to the birth; however, in some cases, mothers may be identified as ‘at risk’ during pregnancy (Chow et al., 2015). The inability to predict which infants may experience admission and thus, inability to warn parents, can drastically affect a parent’s ability to practically and emotionally prepare. Regardless of the specific reason for admission, hospitalisation is intended to help support the infant’s development and remedy any immediate health concerns, a process which can have significant and widespread impacts on the family as a whole.

Preterm or premature infants are defined as those born at 37 weeks gestation or younger (Ministry of Health, 2017). In New Zealand, around 7.3% of infants born annually fall into this category (Ministry of Health, 2017). Prematurity is one of the most common reasons for admission to a neonatal unit and rates of preterm birth have been steadily increasing over the last few decades (Kramer, 2009; Ministry of Health, 2007). Such an increase is possibly attributable to the enhanced ability for obstetric intervention, delayed childbearing, and assisted reproductive technologies resulting in multiple births, the latter two having been identified as risk factors for premature birth (Kramer, 2009). Premature infants commonly experience lower birthweight than those born full-term, with 95% of those born under 32 weeks (and around half of those born 32-36 weeks) recording low birthweight (Ministry of Health, 2017). Prematurity is the leading cause of neonatal death worldwide, but survival rates for premature infants have been steadily improving alongside advances in technology (Simmons et al., 2010). Currently, in New Zealand nearly 60% of infants born between 23 to 24 weeks survive, often without moderate or severe disability when optimal perinatal care is provided (Berry et al., 2017). When compared with full-term infants, premature infants often record higher rates of temperature instability, respiratory distress, infection, apnoea, low blood sugar, jaundice and feeding difficulties (Bracht et al., 2013; Dalton et al., 2018; Danbjørg et al., 2015; Gangi et al., 2013; Garfield et al., 2016; Melnyk et al., 2006; Razurel et al., 2017; Russell et al., 2018).

Small for gestational age infants are also commonly admitted to neonatal units. Small for gestational age infants are those born at a weight below the 10th percentile (de Onis & Habicht, 1996; Schlaudecker et al., 2017). They are often also born premature or their lowered birth weight typically co-occurs alongside another health condition, e.g., seizures and congenital abnormalities (Ewing et al., 2017; Katz et al., 2015). Small for gestational age infants are typically admitted to a neonatal unit for support with breathing, additional health complications associated with their size (e.g., an inability to regulate temperature), and to assist their general growth and development.

Aside from prematurity and small for gestational age, Darlow and colleagues (2009) identified that primary health diagnoses of infants admitted to neonatal units varied across gestational age but mainly included: respiratory diseases (pneumonia, hyaline membrane disease, transient tachypnoea of the newborn, meconium aspiration syndrome); congenital abnormalities; infections; neurological difficulties; neonatal abstinence syndrome; and surgical needs. Infants may also be admitted due to being large for gestational age (those born above the 90th percentile or greater than 4000 grams), and due to the associated health issues that occur alongside this, such as, hypoglycaemia, respiratory problems and jaundice (Sjaarda et al., 2014; Ribeiro et al., 2017). Full-term infants are admitted to neonatal units for a variety of difficulties, most commonly including breathing issues, sickness or infection, low blood sugar, lack of oxygen, difficulty with temperature regulation, jaundice, poor feeding and/or weight loss, and effects of maternal drug use (Donoghue, 2004).

# 2. The Neonatal Experience

The following chapter aims to provide a review of literature pertaining to the experience of parents with an infant admitted to a neonatal unit within both a New Zealand and international context. The implications of neonatal admission are complex and wide-ranging, including medical implications for the infant and emotional implications for the whole family. By exploring the neonatal care experience for parents, this chapter aims to identify the gaps in our contemporary understanding of these experiences and orient the reader to the context from which the Babble app originated.

## 2.1 Parental Mental Health and Neonatal Hospitalisation

Having an infant who requires hospitalisation can be destabilising and challenging for parents, often inciting an emotional crisis as they are thrust into the unfamiliar and unknown world of neonatal care (Turrill, 1999). Neonatal unit admission has been described as an ‘emotional rollercoaster’, a catastrophic event resulting in many feelings of anxiety, depression, grief, stress, and joy (Ballantyne et al., 2017). For the majority of families, the birth of an infant requiring admission is unexpected, leaving parents in shock and unprepared for the journey that unfolds (Affleck et al., 1991). Parents are thrown into a physical and psychological disequilibrium, so far removed from their own experience that typical and habitual coping mechanisms and resources are rendered ineffective (Affleck et al., 1991). As a result, many parents of neonates experience a range of negative emotions such as despair, anxiety, grief, disappointment, and guilt (Nyström & Axelsson, 2002).

Consequently, neonatal admission has been found to be associated with a higher prevalence of mental health difficulties for parents (Holditch-Davis & Miles, 2000). Immediately following the birth of their preterm infant, mothers were three times more likely to feel distressed compared to mothers of full-term infants (Meyer et al., 1995). Specifically, mothers of preterm infants have been evidenced to experience clinically significant psychological distress with greater levels of inter-correlated depressive, anxiety, stress, post-traumatic stress symptomology, and relationship difficulties (Carter et al., 2007). Various NICU-specific concerns (inclusive of: long-term health worries; feeling out of control; infant survival; separation from the infant; different parental experience; limitations in care; and helplessness) impact parents psychologically and may increase distress for this population (Davis et al., 2003; Joseph et al., 2007).

Mothers of infants in NICUs within the United States of America (USA) have been found more likely to experience postnatal depression with extreme symptomology when compared to mothers of healthy infants (Tahirkheli et al., 2014). New Zealand-based research by Carter and colleagues (2005) determined that parents of an infant admitted to a NICU experienced higher incidences of anxiety compared to controls. These differences were modest overall however, indicating that these experiences of anxiety may not be clinically significant. They also identified that there was no significant difference in depressive symptomology between 100 controls and 242 neonatal parents. It is possible that as New Zealand's healthcare system is governmentally funded, greater financial and practical support is provided to these families. The lack of this support in the United States of America (where healthcare is not funded) may lead to greater incidence of depression and anxiety for American parents. Other research within New Zealand has suggested that greater rates of family and financial stress exist for neonatal parents compared to controls, possibly contradicting this theory (Carter et al., 2007). However, it is more likely that if compared directly, these experiences of financial stress for New Zealand parents would be lower than that of their American counterparts, but higher than New Zealand-based controls.

In general, fathers of neonates have been found to experience elevated distress and depressive symptomology within multiple international studies (Carter et al., 2007; Cyr-Alves et al., 2018; Joseph et al., 2007). One recent study performed in the United States of America found that at admission to the NICU, 41% of fathers reported distress as measured by the Parental Stressor Scale (PSS; Berry & Jones, 1995) and/or minor symptoms of depression (Cyr-Alves et al., 2018). 16% reported symptoms consistent with major depression (Cyr-Alves et al., 2018). For some of these fathers, experiences of depression and distress were seen to persist for up to two months post-discharge (Cyr-Alves et al., 2018). Within a New Zealand sample, fathers were seen to record higher depression and anxiety as measured by the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) and the Edinburgh Postnatal Depression Scale (EPDS; Cox et al., 1987) when compared to controls (Carter et al., 2005). Interestingly, fathers' experiences of depression are seen to increase if their partner also experiences distress or depressive symptomology (Roque et al., 2017).

Parents of neonates have also been evidenced as at greater risk of developing stress-related disorders, such as acute stress disorder and post-traumatic stress disorder (Gangi et al., 2013; Roque et al., 2017). Parents may experience feelings of detachment or numbness, symptomatic of shock with strong feelings of unreality due to the significant crisis of neonatal admission (Heinemann et al., 2013). When admitted to a neonatal unit, infants are often removed suddenly from the mother's care immediately after birth, commonly with little explanation due to the need for urgent medical attention, which may be experienced by some parents as a trauma (DeMier et al., 1996; Holditch-Davis & Miles, 2000). Previous literature has identified premature birth as a significant source of stress for parents; when combined with hospitalisation and the neonatal unit environment, the stress of these events may compound and result in the development of an acute stress disorder (Gangi et al., 2013). Furthermore, the lack of ability to physically and emotionally prepare for the neonatal admission (and the overwhelming anxiety parents feel for the comfort, safety and life of their newborn) is seen to influence the prevalence of acute stress disorder and post-traumatic stress disorder (Bernard et al., 2011; Lefkowitz et al., 2010).

## 2.2 Neonatal Intensive Care Unit Stress Model

Miles and Carter (1983) developed the Parental Sources of Stress Model following identification of parental stress in response to children's hospitalisation in Paediatric Intensive Care Units (PICUs) and NICUs in the 1980s. Based on Magnusson's (1982) stress theory and theories around parental stress in a PICU, the model suggests that parents evaluation of various situational, environmental and individual stressors leads to a stress response (Dudek-Shriber, 2004). Wereszczak, Miles, and Holditch-Davis, (1997) then adapted this model to more accurately reflect the experiences of neonatal parents, with the intention of the model being used as a helpful framework through which to consider parental stress responses. The model, originally utilised to describe neonatal intensive care units specifically, has since been extrapolated to better understand the stress response experienced in any neonatal unit at any level of care.

The model considers personal characteristics that parents bring with them to the experience (e.g., personality, formative experiences, values), situational factors (e.g., NICU admission), the birth experience, and environmental stressors (e.g., equipment in the unit and infant behaviour). Appraisal of the environmental stressors is considered to be dependent on individual characteristics such as previous experiences of pregnancy, birth and parenthood as well as concurrent life events (Hagen et al., 2016). Each individual's experience of stress is considered to increase or decrease dependent on additional factors such as parents' personal resources, environmental support, family support or staff. Additionally, parents then utilise a combination of their own inherent coping strategies and newly created coping strategies (which develop in response to the situation) to influence the stress response experienced. Spear, Leef, Epps, and Locke, (2002) identified through their research that parents' own internal psychology and experiences were more influential in the level and degree of stress manifested than the infant's health and wellbeing. As per this model, parental responses to the stress of NICU hospitalisation are considered to vary between adaptive and maladaptive, as a result of the variables afore mentioned (Dudek-Shriber, 2004).

## 2.3 Parental Experiences of the Neonatal Unit

As the previous section has identified, parents often experience significant stress upon their infant's hospitalisation. Research suggests that parents typically experience stress in response to three key components of the neonatal experience: the neonatal environment, infant-related factors (e.g., health, appearance), and parental role adoption (Affleck et al., 1991; Barr, 2015; Miles et al., 1992; Miles et al., 1993). Literature pertaining to the parental experiences of each of these three components will be reviewed in the following sections.

### *2.3.1 Neonatal Environment*

Neonatal units are highly technological, clinical environments, purpose built to care for sick and small infants (Affleck et al., 1991). Likened to another world, families have described the unit as a foreign, confronting and frightening environment, with the capacity to dismantle cultural worldviews and undermine self-worth (Barr, 2015). The physical and psychosocial environment of a neonatal unit compounds to create an intense experience and sense of stress, through which feelings of shock, helplessness, fear and frustration are common (Sammons & Lewis, 1985).

Parents identify that the medical nature of the neonatal environment, inclusive of strange, noisy equipment, lack of privacy, and other unknown elements, are key sources of stress to them during their experience of admission (Baía et al., 2016). Overall, parents report high distress in response to the stress-provoking environment and identify this emotional reaction as negatively influencing their ability to parent and ultimately, the parent-infant relationship (Ballantyne et al., 2017). The prevalence of unknown, intimidating medical equipment, association with adult intensive care units and the crisis-focused atmosphere can lead some parents towards perceiving the situation as highly stressful and traumatic (Sammons

& Lewis, 1985). In addition, parents have reportedly found it difficult to orientate where the machines end and their infant begins (Sammons & Lewis, 1985). Research suggests that for parents with infants who stay for a shorter period, perceptions of environmental stress are higher when compared to parents of infants with longer hospital stays (Miles et al., 2002). Such findings suggest that parents may become more familiar with and comfortable in the unit over time. Parents may come to recognise the importance of the equipment as sustaining their infant's life, therefore not viewing it as distressing as they likely did initially.

In terms of long-term impact, the barriers to parenting created by the neonatal environment, as well as parents' emotional reactions to the environment, may negatively influence the developing parent-infant relationship and infant outcomes (Franck et al., 2005). Fernández Medina, et al. (2017) explored maternal perspectives on factors that impacted their ability to bond with their preterm infant and found that the complexity of the NICU environment, and the care that occurs within it, had a negative impact on maternal anxiety. The machinery and clinical nature of the unit was identified to increase feelings of fear and uncertainty, and mothers found themselves spending more time focusing on the unusual and threatening context, rather than getting to know their child. These findings suggest that mothers are significantly impacted by the NICU environment, and this is related to how they interact with the environment, staff and their infant.

However, these findings of distress associated with the neonatal environment are not universal. Some studies have identified lower stress scores for parents on the environment subscale of the Parental Stressor Scale: NICU, when compared to the other subscales (Dudek-Shriber, 2004; Miles et al., 1992; Miles et al., 1993; Shields-Poë & Pinelli, 1997). This measure aligns with the three key areas of the NICU associated with parental stress (e.g., parental role, infant-related factors, environment) and looks at self-reported ratings of distress for items across these areas (Miles et al., 1992; Miles et al., 1993). The findings related to reduced stress associated with environmental factors have been attributed to several things, including an understanding and acceptance that the environment is working to keep the infant alive and healthy and therefore, considering it necessary and supportive (Affonso et al., 1992). These findings may also be explained by the increase of media focus on intensive care units (Miles et al., 1992), and other personal experiences with intensive care units, resulting in increased familiarity and decreased stress (Shields-Poë & Pinelli, 1997). Increasing parents' familiarity with the unit has been seen to reduce stress, as evidenced by Gale and colleagues (2004), who found that when staff educated parents about the machines, isolettes and tubes, parental distress decreased.

### *2.3.2 Infant Related Factors*

Several studies have indicated that some infant-related factors negatively impact parental stress and experiences in the neonatal unit. Specifically, when stressors are compared, parents reported the second most stressful aspect of neonatal units to be the infant's appearance, followed by the parent-infant relationship (Dudek-Shriber, 2004; Miles et al., 1992). These findings were supported by Shields-Poë and Pinelli (1997) who identified (using the PSS:NICU) that parents were most distressed by infant appearance and behaviour, and this distress was connected to parents' perceptions of how sick their infant was. Premature infants are typically physiologically unstable (e.g., experiencing lack of oxygen, blue, yellow or translucent in colouring) and therefore, their physical appearance can sometimes be different to other infants (Dudek-Shriber, 2004). Premature infants are also often less responsive to interaction and are less social than infants born at full term (Dudek-Shriber, 2004). Understandably, these features can distress parents and impact their connection with their infant.

Particular infant characteristics have been shown to differentially impact parental experiences of the NICU. Mothers of very low birth weight infants report higher levels of stress, when compared to mothers of lower risk infants, such as low birthweight or normal for birthweight infants (Singer et al., 1999). Younger gestational age was also related to stress levels, with parents of infants born at less than 28 weeks gestation scoring higher on stress occurrence, as measured by the PSS:NICU, than parents of infants born at 28-36 weeks gestation (Dudek-Shriber, 2004). Similarly, a longer length of stay and the presence of cardiovascular complications were both associated with greater occurrence of stress for parents (Dudek-Shriber, 2004). Overall, cardiovascular disorder has been found to be the most prominent diagnostic predictor of parents experiencing a greater level of stress, indicating this may be a particularly distressing diagnosis for parents in the neonatal unit (Dudek-Shriber, 2004). The long-term nature and severity common with cardiovascular diseases may explain, in part, some of the distress reported for these parents.

### *2.3.3 Parental Role*

The abrupt, unexpected and then ongoing alteration in parental role has been identified by parents of neonates as the most stressful and difficult part of the neonatal experience (Baía et al., 2016; Miles et al., 1992; Seideman et al., 1997). The challenge of leaving a vulnerable infant in a neonatal unit is confronting and scary for many parents, defying typical expectations of having a child (Swift & Scholten, 2010). The change in expected parental role is seen to begin at the point of initial hospitalisation, whereby parents are not able to fulfil the anticipated role as main caregiver, in light of the need for nurses and doctors to take over aspects of caring for the infant (Seideman et al., 1997). Mothers specifically express feelings of alienation, despair and grief, all of which negatively impact their sense of motherhood (Lupton & Fenwick, 2001). The emotional turmoil associated with the birth and subsequent hospitalisation is seen to impede effective maternal role adaptation, whereas confidence in their own abilities and positive interactions with the neonatal environment have been found to support mothers' adaptation to their new role (Heydarpour et al., 2017). Younger parents specifically are seen to struggle with the adaptation to the role and experience significant stress associated with this, possibly due to feeling less prepared and unaware of what to do and/or expect (Dudek-Shriber, 2004).

The process of becoming a parent involves readjusting and developing a new identity. Effective maternal (and paternal) role adaptation involves increased self-confidence and satisfaction in parenting a child and the creation of a new identity to perform these parenting behaviours (Heydarpour et al., 2017). Whilst pregnant, mothers often develop expectations for their role as a parent, mentally exploring and evaluating how they will perform in this role (Reid, 2000). However, when an unexpected event such as a premature birth or admission to a neonatal unit occurs, their sense of identity as a parent may be delayed or jeopardised (Reid, 2000). Mothers of sick and low birthweight infants specifically have been shown to feel less confident in parental roles overall, as these infants are typically more challenging to care for and expectations of parenting abilities and role are not always met (Singer et al., 1999).

For mothers, the loss of the initial expected maternal role is a key source of distress associated with neonatal unit admission (Holditch-Davis & Miles, 2000). Specifically, mothers commonly report feeling as though their child is someone else’s baby, when neonatal admission occurs (Baía et al., 2016). Mothers describe not being ready or prepared to adopt the maternal role, due to the birth typically being unexpected, and experience a feeling of surrealism when spending time with their infant in the neonatal environment (Sim, 2000). Furthermore, mothers have identified that they feel both physically and psychologically separated from their infant in neonatal units due to the limitations in being able to hold, touch or interact with their infant (Ballantyne et al., 2017). Many parents experience feelings of helplessness due to this inability to fully participate in care of the infant (Lindberg et al., 2007). Specifically, feelings of guilt, self-blame and helplessness are considered as a possible negative influence on a new mother’s adoption of her maternal identity (Reid, 2000).

**2.3.3.1 Parental Self-Efficacy.** Perceived parental self-efficacy can be defined as beliefs or judgements a parent holds around their capabilities to organise and execute a set of tasks related to parenting a child (Bandura, 1997). According to Bandura's (1977) self-efficacy theory, in order for one to feel efficacious, one must have the requisite base of knowledge from which to obtain information. There are five major identified influences on self-efficacy: previous experience; vicarious experience; verbal persuasion; physiological state; and affective state (Bandura, 1977). More specifically, parental personal beliefs, their understanding of their capabilities, child characteristics, and their ability to organise as well as execute situationally-specific actions that produce the desired results, are all seen as having an impact on parental self-efficacy (Montigny & Lacharite, 2005; Teti et al., 2005).

The concept of self-efficacy and individuals' expectations of their own self-efficacy has been found to connect to the levels of effort expenditure and resilience in stressful situations (Bandura, 1977). Parental self-efficacy in particular, influences a new parent's resilience when faced with difficult situations and the levels of positivity, adaptive coping and problem-solving solutions displayed (Liyana Amin et al., 2018). Mothers with high parental self-efficacy are seen to persist despite the demanding nature of parenting, engage in self-blame less often and achieve a greater sense of satisfaction and accomplishment out of their parenting role (Coleman & Karraker, 1998; Page, et al., 2010). Based on these findings, it is theorised that within a neonatal context, a mother with high parental self-efficacy is likely to be more engaged in the hospitalisation process, be able to interpret infant signals correctly and respond appropriately and is therefore more likely to be successful in establishing a warm and sensitive relationship with their infant.

High parental self-efficacy in general is associated with positive psychological wellbeing and parenting satisfaction (Coleman & Karraker, 1998). Conversely, mothers with lower self-efficacy are more likely to become overwhelmed and report lower parenting effectiveness, insecure attachment and increased susceptibility to helplessness (Coleman & Karraker, 1998). When compared across genders within a neonatal context, mothers have been found to score higher than fathers on parental self-efficacy, possibly due to greater time spent with the infant or in the neonatal unit environment, although many of these principles can be applied to fathers' experiences of self-efficacy also (Salonen et al., 2009).

By supporting parents' adaptation to parenting, improving emotional well-being and enhancing attachment to the baby, strong parental self-efficacy plays an essential role in helping parents feel comfortable and confident within the neonatal experience and with parenting overall (Bandura, 1997; Coleman & Karraker, 1998). Maternal self-efficacy, in particular, is associated with enhancing mothers' ability to adapt to their new role and associated experiences (Leahy-Warren & McCarthy, 2011). Postpartum adjustment and positive parenting behaviours are largely influenced by new parents' feelings of parental self-efficacy, indicative of the wider role this construct plays in parental experiences (Liyana Amin et al., 2018).

**2.3.3.2 Developing a Maternal Identity.** Mothering a preterm infant in a neonatal unit is often considered a developmental process, shaped by the relationships between mother and child, mother and staff and internal experiences of vigilance and concern (Aagaard & Hall, 2008). When asked to describe experiences of becoming a mother in the NICU, mothers identified that over time they moved from outsider to an engaged parent (Heermann et al., 2005). Additionally, they advised that initially the neonatal environment was at the forefront of their attention and their infant was in the background (Heermann et al., 2005). As time passed and they became more comfortable in the neonatal environment, attention would vacillate between this and their infant (Heermann et al., 2005). Additionally, Heermann et al. (2005) found that as time passed mothers' attitudes towards the infant shifted also. Initially, they reported feeling disconnected from their infant, and identified NICU technology and the infant’s appearance as barriers in their ability to connect. As they became more comfortable with the environment, mothers felt a greater connection and took more ownership over their infants.

Caregiving was another domain explored by Heermann et al. (2005) where mothers were seen to shift along a continuum of passivity to activity. Initially, mothers expressed concern about how to care for their infant and did not consider themselves as having much to offer their infant at this stage. Later on, mothers took on a more active role as they became more informed about how to care for their infant. In the early stages, mothers also found it difficult to claim responsibility for infant care, but as time passed, they felt they were able to advocate for their child, rather than just observe. Whilst in the unit however, mothers have expressed concern that they would be perceived as a ‘difficult mother’ in their attempts to balance the nurse’s role and their own position, with this perceived conflict impacting their perception of themselves as a mother (Hurst, 2001). By playing an active role in adjusting their expectations to better suit the reality of having a fragile infant, educating and updating themselves on their infants’ medical condition, and participating in basic infant care, mothers report feeling more confident in their role (Berkowitz, 2005). Through expectation management and integrating themselves into infant care, mothers are more likely to develop a meaningful parental role within a neonatal unit (Berkowitz, 2005).

### 2.4 Understanding Parental Needs, Improving Parental Experiences and Infant Outcomes

Due to the widespread, often negative, effects associated with neonatal hospitalisation on parents (as well as siblings and extended family), research has focused on how best to improve the experience. Firstly, the importance of focusing on parental needs during this process is highlighted by Ballantyne et al. (2017) who identified that when parents’ needs go unmet, their likelihood of discontinuing with follow-up services is higher. Comparatively, when needs are met, parents are more engaged with the healthcare team, take on more opportunities to communicate, seek information and are better able to adjust to the specialised care their infant requires (Ballantyne et al., 2017).

Primarily, research has suggested that the most important need for parents in neonatal units is to receive accurate and understandable information (Bass, 1991; Cleveland, 2008; De Rouck & Leys, 2009; Lantz, 2017). NICU parents express that access to information, immediate attention to changes in their infant and cultivation of hope were most helpful in their experience, indicating these needs are vital to address (Seideman et al., 1997). Additional identified needs encompassed being included in the infant's care and decisions that were made, continued contact, positive relationships with staff, and individualised care for their infant (Cleveland, 2008).

Fathers have been found to have similar informational needs as mothers in response to the challenging NICU environment (Hollywood & Hollywood, 2011). Fathers considered that at times it was difficult to understand the medical terminology used and the perceived inconsistency of responses provided by staff acted as a significant stressor for them (Hollywood & Hollywood, 2011). Information sharing was considered paramount, in particular the way in which healthcare professionals explained and provided information to parents about their infant (Hollywood & Hollywood, 2011). When information was shared well and consistently, it was considered empowering by fathers (Arockiasamy et al., 2008; Griffin & Abraham, 2006; Hollywood & Hollywood, 2011). Fathers felt in control and their feelings of anxiety decreased, as has been seen in research exploring mothers' informational needs (Arockiasamy et al., 2008; Griffin & Abraham, 2006).

Research has indicated that the neonatal unit being a welcoming environment with supportive policies, (e.g., those that provide many opportunities for parents to become educated and comfortable in caring for their infant with guided practice), was rated as highly supporting parental needs (Cleveland, 2008). Encouraging parental presence in neonatal units and providing parents with education and support is seen to reduce their stress levels and improve their knowledge and confidence (O'Brien et al., 2015).

When information is shared and provided to families in an understandable manner, outcomes for parents (and by proxy, infants) have been seen to improve significantly (Melnyk et al., 2006; O'Brien et al., 2015). For example, a randomised control trial exploring an individualised intervention which focused on: coping skills; providing information about the NICU/procedures; infant health; and discharge, for parents whose infants were admitted for less than 4 weeks, was found to reduce anxiety and depression compared to standard care for parents in a neonatal setting (Cano Giménez & Sánchez-Luna, 2015). A discharge-focused intervention in the United Kingdom looked at facilitating communication between staff and parents throughout hospitalisation, using visual cues and parental booklets. Results suggested that parents found that this approach provided them hope (Ingram et al., 2017). Parents reported they felt in control and benefitted from the visual depiction of the discharge process (Ingram et al., 2017). Uniquely, this intervention also recorded positive involvement with fathers and wider family members, with all involved reporting they felt well prepared and positive about the discharge process as a result of the approach (Ingram et al., 2017).

Positive effects from targeted interventions can also take the form of physical changes in infant development. When parents participated in a training programme with the intention of helping them improve their communication with the admitted infant, infants' brains showed improved cerebral white matter micro-structural development evidenced through magnetic resonance imaging (Milgrom et al., 2013). Following an eight week period of regular skin-to-skin contact with mothers, infants showed accelerated functional brain maturation, compared to those who did not receive such contact (Milgrom et al., 2010). These findings indicate that various parent-focused interventions can also support and enhance infant development alongside.

### 2.5 Educational Interventions

The use of educational programmes has been prominent in the field of parenting to address common knowledge deficits about the early postnatal period as well as building on participants' strengths and resources to promote healthy emotional coping and skills development (He et al., 2018). Specifically, in a NICU setting, parent participation in educational programmes that provide opportunities for sharing and problem solving has been found to reduce feelings of anxiety and stress, whilst increasing confidence and competence (Bracht et al., 2013). Due to the unusual and confusing setting, clear and consistent information is deemed essential in order to engage families in care and support positive outcomes (McGrath, 2000). Parents identified that increased familiarisation with the NICU environment through education improved their parental role perceptions which enabled them to feel more confident and comfortable (Gangi et al., 2013). Fernández Medina and colleagues (2018) identified that information delivered in an individualised and targeted manner was pivotal in relieving pressure on mothers in neonatal units.

Utilising psychoeducational interviews to address maternal needs, Razurel and others (2017) found that speaking with mothers following the birth improved parental self-efficacy and the mother-child relationship, indicating that psychoeducation may a useful tool to improve parental self-efficacy postpartum. Another study identified that mothers who underwent a parental education-based programme, focusing on infant behaviour and parental roles, experienced reduced parental distress in the NICU as well as reduced symptoms of anxiety and depression (Melnyk et al., 2006). Fathers in the intervention group, however, did not differ when compared to controls (Melnyk et al., 2006). Fathers did score higher on involvement in physical care of the infant, perhaps suggesting that additional information provided to fathers helped them understand and engage in their infants' care (Melnyk et al., 2006). These findings suggest that psychoeducation can improve both maternal and paternal feelings of stress and enhance their involvement in infant care.

To address paternal needs for information and knowledge about prematurity, a study was performed whereby an educational DVD intervention around newborn behaviour was administered and fathers' understanding was measured through the Knowledge of Preterm Infant Behaviour Questionnaire (a set of multi-choice questions addressing preterm infant behaviours; Kadivar & Mozafarinia, 2013). Results showed that fathers who received the educational intervention increased their knowledge of preterm infant behaviour, demonstrating that educational interventions are effective in helping fathers learn necessary information to support their parenting (Kadivar & Mozafarinia, 2013).

As this section has outlined, there are a variety of interventions targeted at parental experiences in the neonatal unit that show promise in improving parental and infant outcomes. However, these interventions are typically only available in specific units and difficulties can occur when trying to move them across settings. There are clear similarities across successful interventions, namely integration into units and the nature of the support, be that informational, social or practical. In light of these commonalities and to combat difficulties in accessing such interventions, the use of technology and the internet have been considered as a method to meet parental needs in the NICU and will be discussed in the following section.

# 3. eTechnology and mHealth

The following section will provide an overview of eTechnology and mHealth, with the aim of supporting the reader's understanding of how this field has developed. Looking specifically at parents' use of mHealth initiatives, an argument for the use of mHealth within a neonatal context will be presented, leading into a discussion of the initiative at the focus of this research project, Babble, a mobile application developed to provide information and support to parents with an infant admitted to a neonatal unit in New Zealand.

## 3.1 Defining eTechnology and mHealth

With increased use of smartphones and accessibility to the Internet over the last twenty years, a market known as eTechnology has developed (Eysenbach, 2001). eTechnology refers to the integration of technology and the Internet (e.g., websites, software), to address a variety of consumer needs (e.g., accessible information, social support, and communication), across a diverse range of topics (e.g., business, personal, and healthcare; Eysenbach, 2001). Specifically, within eTechnology, a specific sub-category known as mHealth has arisen in response to the increased popularity and accessibility of smartphones in more recent years (Free et al., 2010). mHealth involves the use of mobile applications (apps) and other integrated mobile technologies to provide public health and healthcare-related services to a wide, heterogeneous audience (Free et al., 2010). The use of smartphones for healthcare purposes has become more common and has taken on varying formats, from text alerts and wearable monitoring devices to smartphone apps that record patient data and provide educational information (Istepanian & Woodward, 2017). mHealth has the ability to reach a significantly larger number of people compared with traditional healthcare formats, allowing for standardisation of information provision, facilitating access to content as needed, and reducing costs of programme delivery (Bull & McFarlane, 2011).

Alongside the normalisation of app use to meet various everyday needs, patient attitudes towards the ever-increasing mHealth field appear to be primarily positive. When looking at patterns of Internet and smartphone usage in a pediatric otolaryngology service, Glynn et al (2013), found that almost half of parents interviewed said they would make use of an app focused around their child's condition and a third of parents reported they intended to use the Internet for this purpose in the future. One quarter of Americans report trusting mHealth apps as much as their doctors, indicative of the stronghold mHealth has been steadily attaining over consumer interactions with healthcare (EHRIntelligence, 2012). Reflective of these positive attitudes towards mHealth, recent research has indicated that there are more than 60,000 health-oriented apps available (Smith, 2015), with around 23 billion downloads estimated to have taken place in 2017 (James, 2015).

mHealth has been utilised to address a variety of healthcare needs. Ventola (2014) explored the purposes of mHealth apps available and noted that 24% looked to retain and record medical information, 22% to monitor physical parameters, 18% to track disease, 16% focused on education and management and 6% for diagnosis. mHealth options may be useful for certain populations who may be more familiar with technology, those who have chronic conditions or those who are harder to reach, given the prevalence and accessibility of technology such as smartphones. mHealth apps have shown success with adult and adolescent populations experiencing Type 1 and Type 2 Diabetes, improving the frequency of blood glucose monitoring via notification reminders, ultimately supporting greater glycaemic control (Cafazzo et al., 2012; Hou et al., 2016). Other mHealth initiatives have included text messages supporting weight loss (Patrick et al., 2009), an app to help self-management of chronic obstructive pulmonary disease (Hardinge et al., 2015), and text messages to encourage smoking cessation (Whittaker et al., 2016). Mental health orientated apps are another area of mHealth that has demonstrated success and significant growth. For example, apps have been developed to support the self-management of bipolar disorder (Hidalgo-Mazzei et al., 2015), for monitoring mood and symptoms as an accompaniment to outpatient psychosis care (Niendam et al., 2018), and to provide mindfulness guides for overall wellbeing (van Emmerik et al., 2018).

As evidenced here, there exist a large number of mHealth apps and eTechnological approaches. However, very few have undergone adequate clinical trials to validate their usage and safety or to ascertain their efficacy (Buijink et al., 2013). The lack of evidence-based research focused on mHealth across various health areas has resulted in inconsistent conclusions around efficacy and effectiveness, indicating a need for more rigorous and innovative research in this area (Buijink et al., 2013; Grist et al., 2017; Wang et al., 2017).

## 3.2 mHealth Limitations

Continuing on from the aforementioned limitations, there are several other issues associated with the implementation of mHealth approaches that are worthy of note. In a recent survey, respondents identified the lack of standardisation, regulation and market transparency as the main barriers to mHealth adoption (research2guidance, 2010). The inability to regulate the use of mobile health applications, or the wide availability of health information available online, has been raised by other researchers as a primary limitation of mHealth approaches (Cortez et al., 2014). The lack of scientific evidence supporting the view that mHealth initiatives indeed improve health care outcomes or save costs is similarly a large area of concern (Agarwal & Labrique, 2014). Weisel et al. (2019) recently performed a meta-analysis exploring ‘standalone’ psychological interventions delivered through mHealth interventions (e.g., apps). Their findings indicated that there were few significant effects in improving mental health through app use alone, indicative of the limitations of mHealth in the sole provision of healthcare (Weisel et al., 2019).

The proliferation of international app accessibility presents further difficulties, due to differences between international health regulations and policies (Istepanian & Woodward, 2017). mHealth apps have suffered some criticism as to their ability to maintain privacy and protect data confidentiality, in particular when utilising a text messaging programme (Istepanian & Woodward, 2017). Research suggests that of the 24,405 m-Health apps surveyed, 96% indicated difficulties with information security and privacy infringements (Dehling et al., 2015).

As mHealth apps are typically constructed to avoid an interactive or two-way approach, due to the demand that would place on medical care providers, some researchers have expressed concern about the one-dimensional representation of information (Lupton & Pedersen, 2016). For example, when utilised in parenting, there is the possibility of mHealth aligning with dominant notions of what is best without offering alternatives, and in so doing, fuelling the 'good mother' rhetoric common in society (Lupton & Pedersen, 2016). As a result, users may feel distressed, self-blame or experience disappointment when their lives do not match the information provided in mHealth initiatives. Similarly, the possibility for over-reliance on one source of information (e.g., the Internet), that does not always receive professional oversight has raised some concern, as it may result in users receiving incorrect or conflicting information (Tripp et al., 2014).

Although evidence suggests that the accessibility of mHealth is a major strength, the potential exclusion of certain populations remains a potentially limiting factor. Reliance on the newest and latest technology may serve to widen the gap between those who are able to access this technology and those who are not (Cleary et al., 2008). Those without money to purchase the smartphones, apps or the data to run them, or those who lack the skills to utilise them may be disadvantaged in receiving health information and support through mHealth initiatives. For example, literacy, specifically computer literacy, has been raised as a concern, as well as the ability for certain populations (such as older adults or those of a lower socioeconomic bracket) to access information on apps (Meppelink et al., 2015). Additionally, mHealth initiatives are likely to align with dominant cultures (e.g., Western culture) and are unlikely to be translated into different languages, challenging the prominent notion of equal accessibility present within mHealth literature.

### 3.3 mHealth and Parents

Online interventions have been seen to offer unique and versatile care through provision of information as well as peer and professional support (Herman et al., 2005; White & Dorman, 2001). Specifically, the Internet has been identified as a key method to provide accessible and consistent health information and support to parents (Gooding et al., 2011). For example, most Canadian parents reported owning a smartphone in 2017 and up to 83% of parents used this device for Internet access (Orr et al., 2017). When looking at the availability of apps, 1500 pregnancy-related apps were identified across both Android and iOS in 2014, with informative apps being largest category (Tripp et al., 2014). However, despite the high volume of eTechnology interventions and mHealth apps available targeting parents, few empirical studies have explored the impact of these on the parental experience.

Pregnant women and young mothers turn to Internet resources for information and support during this time more so than any other times in their lives (Doty & Dworkin, 2014). In an Australian study, three quarters of participants surveyed reported using pregnancy apps, most commonly for informational support (Lupton & Pedersen, 2016). In Germany, pregnant women who utilised mHealth approaches were found more likely to be younger, in their first pregnancy, less healthy, and highly influenced by the information they retrieved through these services (Wallwiener et al., 2016). Mothers in Finland were found to utilise Internet-based social support to enhance and fill gaps within their provided maternity care, indicating that technology can be effective when used as an adjunct to traditional healthcare frameworks

(Palmén & Kouri, 2012). These findings are supported by a study performed in the United States of America which found that women used the Internet and other sources of eTechnology throughout pregnancy in addition to the prenatal care they received, as they felt standard care provision did not allow them to seek advice when it was most important to them (Kraschnewski et al., 2014). These findings suggest that in light of the popularity of mHealth approaches within this population, evidenced-based verified approaches should be prioritised to ensure that the information provided is accurate and regulated (Wallwiener et al., 2016). Furthermore, Daly et al. (2018) explored the use of mobile health strategies aimed to influence behaviour and develop knowledge for women during pregnancy across four studies. Each study indicated some beneficial change in maternal behaviours; however, no statistical differences were reported and it was not possible to perform a formalised meta-analysis due to heterogeneity. Such findings further highlight the sparse empirical evidence surrounding mHealth and parenting experiences.

mHealth has focused on a variety of areas of the parenting (and specifically the maternal) experience. When reviewed, mobile technologies focused on maternal and neonatal experiences have been found by Tamrat and Kachnowski (2012) to serve four key functions: improving the medical response (through education and identification of warning signs); supporting greater access (accessible in areas with low coverage of health professionals); health promotion (supports exchange of information for health promotion); and data collection/management. A meta-analysis by Feroz, Perveen, and Aftab, (2017) identified that mHealth intervention studies from middle to low income countries served to improve attendance to antenatal and postnatal care services. Feroz et al., included 14 studies of which the majority utilised text-messaging services and primarily focused on pregnancy and the care-visit structure. Their findings indicate the feasibility and efficacy of such initiatives, working in unison with traditional healthcare provision. In both these works, the authors have primarily focused on developing countries with lower access to healthcare, exemplifying the ability of mHealth initiatives to defy inaccessibility to healthcare and physical boundaries, to provide the necessary support.

mHealth for parents is not just limited to Internet-based approaches. In the United States of America, an intervention called Text4Baby looked at the method of text messaging to pregnant and postpartum women providing information around key health services and behaviours (Gazmararian et al., 2014). The service was widely accepted by most pregnant women and new mothers surveyed, and was considered to have the potential to prompt change in health behaviour, further supportive of the use of mobile-based technology for this population (Gazmararian et al., 2014).

Other mHealth interventions have looked at the early postpartum period and supporting maternal health throughout this time, due to the typical stress and associated anxiety experienced. Specifically, feeding was a focus of a mHealth service called Growing Healthy. The Growing Healthy approach included an educational free app, a website and an online forum providing evidence-based information and advice about infant feeding up to nine months of age (Russell et al., 2018). When compared to controls, however, users of this initiative did not differ on the outcomes measured of infant feeding practices/behaviour, satiety responsiveness or infant's food exposure/preferences, with the exception of one subscale regarding concerns of overeating/becoming overweight (Russell et al., 2018). These results were suggested as possibly due to ineffective measurement tools that did not map onto the app's focus and emphasise the need to consider the design and delivery characteristics when evaluating any mHealth intervention.

Enhancing knowledge through education provision about pregnancy has been another focus of mHealth research. In Australia, Dalton et al. (2018) explored the impact of an app providing health information, such as development, necessary tests and procedures, healthy living and advice, to women of lower socio-economic status during pregnancy. For those who did not access the app, anxiety scores were significantly higher, suggesting that information provided in the app was helpful in reducing feelings of distress for those who used it throughout the trial. Mothers responded positively to the app and thus, it was considered a feasible and appropriate method of providing health information to this population.

Women are seen to be the predominant health information seekers around parenting and as with traditional maternity and neonatal care formats, there is a larger focus on female experiences and information needs (Ybarra & Suman, 2008). Despite this, some research has focused on fathers' interactions with eTechnology and their experiences. For first-time fathers, an Internet-based intervention focused on the early postpartum period which provided information, discussion and contact with nurses was found to improve parental self-efficacy and satisfaction (Hudson et al., 2003). A socially connected, gamified mHealth app titled 'Milk Man' was developed to support fathers' understanding of breastfeeding and early infant feeding (White et al., 2016). Fathers rated the app positively, however, app use has not been evaluated alongside psychosocial outcomes as of yet (White et al., 2016). eTechnology may be more beneficial and supportive for fathers who are typically excluded from maternity and postnatal care and are considered, (at times), less knowledgeable about parenting (Hudson et al., 2003). Apps are not typically gender-specific and lend themselves to use by fathers who may not be able to access the same information when an infant is hospitalised or during the early postpartum period. Men have been suggested to generally have more positive attitudes towards technology than women, and commonly utilise the Internet to gather information and seek out social support, making them a prime population for mHealth initiatives (Morris et al., 1999).

### 3.4 mHealth in the Neonatal Context

Smartphones and mobile applications have been identified as particularly useful for parents of neonates as they are transportable, small enough to use while carrying an infant, personal, intelligent, and connected (Garfield et al., 2016). Parents of infants in a neonatal unit often split their time between the unit and home, and therefore it is likely that the connected nature of apps, alongside the ability to access information whilst away from the unit, is appealing for this population. Parents express significant needs for appropriate and accurate information on the health and wellbeing of their infants, the ability to connect socially with people experiencing a similar situation, and a desire to feel informed and in control of the decision-making process (Jackson et al., 2008). Evidence suggests that this population of parents are consistently turning to the Internet as a key resource for advice and health information specifically, suggesting that they consider such information to be useful and supportive (De Rouck & Leys, 2009; Gabbert et al., 2013; Spargo & de Vries, 2018). Most parents report spending around twenty hours a week seeking out information, most commonly online, during their neonatal stay (Orr et al., 2017). Recent research performed in New Zealand indicated that New Zealand parents express a desire for an informational support app and would be open to its integration with typical healthcare formats (Williams et al., 2020).

Unfortunately, a recent evaluation performed by Dol et al. (2019) deemed available websites providing information as to the health and wellness of premature babies for parents to be of moderate to low quality, meaning that parents who turn to the Internet are faced with inaccurate and inconsistent information. When met with unreliable information sources, parents have been theorised to feel displaced and disorientated in the neonatal unit, an experience contributed to by contradictory or unclear communication from staff (Platonos et al., 2018). Platonos and colleagues (2018) suggest that in response parents may then react or interact negatively with staff in attempts to regain some control over the situation yet damaging these relationships in the process. By ensuring information provided through online and mHealth options is verified and consistent with that provided by staff, this theorised pattern of behaviour may be mitigated.

The way parents in a neonatal unit with an unwell infant process and gather the necessary information is also important to consider, keeping in mind that throughout the course of their infant's stay informational needs and the process of accessing this information may change (Platonos et al., 2018). Parents in neonatal units may find it difficult to understand and encode the significant amounts of new information necessary to cope in this setting. Similarly, parents may approach the situation with differential learning preferences and backgrounds. It is important that any intervention directed at this population caters to these different learning preferences, education levels and backgrounds, and as such, needs to utilise a variety of methodologies including images, words, and videos to ensure the majority of those accessing the information are able to understand it. Apps and other mHealth approaches may be an appropriate method to address these issues for this population, due to the ability to present information in a format that is flexible and versatile to parental needs.

When information seeking behaviours were examined by Dhillon and colleagues, (2003), results showed that most families with infants hospitalised in the NICU found their information online through keywords rather than specific sites. Also, parents expressed that due to the stress and urgency associated with initial hospitalisation, they did not use the Internet as much at this stage of neonatal care (Dhillon et al., 2003). Tailored, consistently available information provided with professional oversight is likely then a suitable solution to supplement the information provided by staff at the neonatal unit, facilitate sharing of information with extended families and most importantly, meet parental informational needs (Rector, 2007). Put into practice, computer-based NICU technologies have been used to help parents obtain accurate and understandable information to support their involvement in the shared decision making process around care options (Frize et al., 2011). Frize and colleagues (2011) have received positive feedback around their initiative, indicating parents find the online tool informative and its modality helpful.

### *3.4.1 Informational Support*

Providing education and information to help parents feel knowledgeable and supported has been identified as an important and interesting use of mHealth apps. For example, as part of an integrated family delivered care project performed in NICUs in the United Kingdom, an app was developed providing parents with NICU-related information, a developmental timeline, glossary of medical terms and additional support resources (Platonos et al., 2018). The app, 'Integrated Family Delivered Neonatal Care' (IFDC) has been considered as good quality, providing highly accurate information, as evaluated in a recent meta-analysis by Richardson and colleagues (2019). IFDC includes both non-interactive and interactive components, allowing parents to learn a variety of relevant information related to the care of their infant (Platonos et al., 2018). Parents are able to access social support through a diary function where parents can input memories and experiences of their NICU journey (Platonos et al., 2018).

IFDC, and apps like this, arose in response to the realisation that if parents are expected to be experts in their infant's care and act as equal partners in the care process, they needed to receive consistent, accurate, high quality information and supportive education tailored to their needs in the neonatal unit (Platonos et al., 2018). Accessible parent education, therefore, enables parents to become involved in their infant's care and ameliorates the difficulties associated with accessing relevant and accurate information in a high stress environment, like the neonatal unit. Platonos et al. (2018) explored the use of the IDFC app alongside informal parental education sessions (the content of which corresponded with the app) and weekly self-care/support groups; parents found information provided through the app was relevant, necessary and supportive, indicative of the success of the format and support offered.

### *3.4.2 Self-Efficacy*

Information provided to parents through mHealth formats may enhance the ability of parents to feel more confident in their role as a parent, as this type of self-efficacy is based on one's understanding and knowledge of parenting. A study by Danbjørg and colleagues (2015) explored this philosophy and identified that during the postpartum period, parents expressed feelings of support and reassurance due to the information they received via an app. They additionally reported that the ease of accessing information and the ability to refer back to this was beneficial. Overall, they felt in control and viewed this as important in improving their parental self-efficacy. Other research based in Singapore determined that the use of a similar, education-based mHealth app 'Home but not Alone' resulted in enhanced self-efficacy for parents who did not require neonatal admission (Shorey et al., 2017). Shorey, et al. (2017) examined the use of 'Home but not Alone' through the use of a randomised-controlled trial study design. Parental self-efficacy, social support, postnatal depression and parenting satisfaction were measured in relation to usage of the app. Results indicated that, compared to controls, those who used the app demonstrated significant improvements in parental self-efficacy, social support and parenting satisfaction a month following the birth. It was considered that use of the app helped parents to gain knowledge independently and in their own time, which served to improve confidence (Shorey et al., 2017). As a result, parents were motivated to approach more difficult aspects of parenting and these mastery experiences helped improve their self-efficacy during the early postpartum period (Shorey et al., 2017).

Through a four-week pilot randomised control trial, Garfield et al. (2016) explored what impact a parent-empowerment focused mobile application called 'NICU-2-Home' had on parental self-efficacy, preparedness for discharge and length of stay during the transition home with their very low birthweight infants. The app itself focused on guiding parents through the discharge process, providing educational informational about infant care, baby tracking and a mood tracker, all based on Bandura's (1995) self-efficacy theory. Results indicated that regular usage of the app improved parental self-efficacy. Similarly, discharge preparedness was higher for parents who had access to the app, comparative to controls. These findings suggest that psychoeducational app usage is a helpful and important resource to be explored, as it is seen to improve outcomes for a neonatal parent population.

### *3.4.3 Parental Distress*

Physical barriers to social connections can result in feelings of isolation and a lack of access to information (Umberson & Montez, 2010). However, mHealth apps are not constrained by physical barriers. Further, the Internet has been seen to reduce social barriers, as it allows anyone with an internet connection to access information, education and social networks (Silva et al., 2015). It is therefore considered that by providing support and information remotely, mHealth apps may help buffer against the effects of stress, anxiety and depression that may occur in the postpartum period (Shorey et al., 2017).

Very few studies have explored the impact of mHealth apps on parental experiences of distress and thus, it is difficult to determine whether these theorised effects translate into reality. In the aforementioned study by Shorey et al. (2017), postnatal depression scores did not differ between the intervention group and controls, indicating that the use of the psychoeducational app ‘Home but not Alone’ had no significant effect on parents’ experiences of depressive symptomology. No research has yet explored the effects of an app targeted to a neonatal parent population on their experiences of distress.

In sum, the use of mHealth in relation to neonatal units has been demonstrated to be efficacious and supportive to parents of neonates across measures of self-efficacy and meeting informational needs. However, recent research has suggested that few available apps demonstrated an inclusion of appropriate, accurate and verified information, indicating the importance of greater research and reviews into this area (Richardson et al., 2019). At present, no apps solely provide informational support to parents about neonatal units or the experience of infant needs, care and hospitalisation during the admission period. Within this context of the identified needs for accurate, relevant and accessible information and in attempts to improve the experience for neonatal parents, the Babble app arose. Babble provides information to parents about the neonatal environment and their infant's care in the hopes of reducing parental distress, increasing parental self-efficacy and more generally, improving their neonatal journey.

### 3.5 Babble

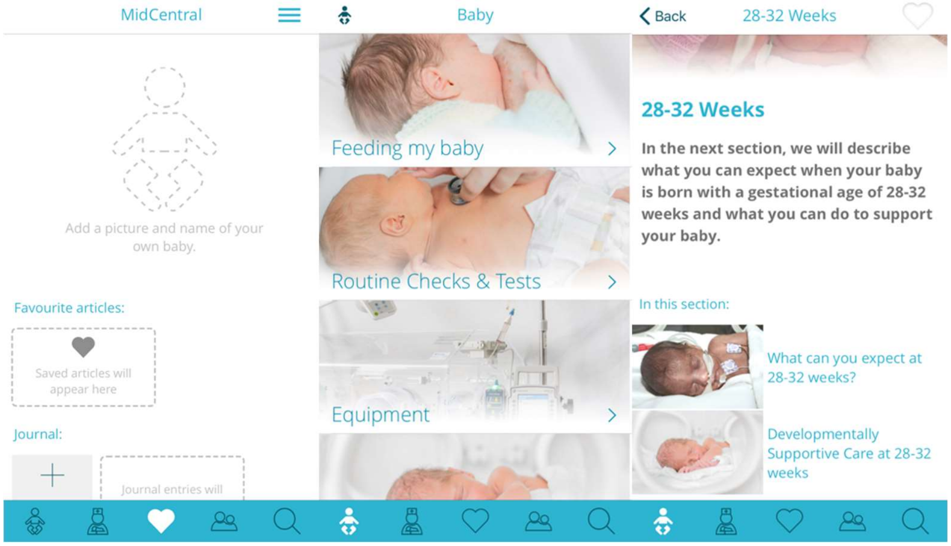
The Babble app was originally developed by MidCentral District Health Board in 2016 to inform and support parents with an infant admitted to the Level II+ neonatal unit at Palmerston North Hospital. Nonetheless, the majority of information included is transferrable to any New Zealand neonatal unit and updates continually occur to improve the applicability of the app to other units. With input from parents of the neonatal unit, neonatal nurses, a lactation consultant, a paediatrician, a software developer, a designer, a photographer and a project manager, the app was made accessible on both Android and iOS in May 2016 (Spargo & de Vries, 2018). In 2018, Counties Manukau DHB adopted the app and integrated information pertaining to its specific unit at Middlemore Hospital, Kidz First. Although parents across New Zealand have been seen to utilise the app, the developer, Dr Nathalie de Vries, a paediatrician at Palmerston North Hospital (MidCentral DHB), and Dr Chris McKinlay, a paediatrician at Middlemore Hospital (Counties Manukau DHB), are presently submitting an application to the Ministry of Health to support national rollout.

Babble contains information on a variety of relevant topics and requires internet access as it provides some links beyond the app itself. The app primarily consists of article-like pages where images and text are integrated to provide concise and relevant information to interested parties (see Figure 2). Generic neonatal topics include feeding; routine checks and tests;

equipment; gestational expectations; advice for Dads; expected problems; common neonatal diseases; how to keep babies safe; and medications. Dependent on your location, the app also includes specific information around the neonatal environment, staff and practices, preparing for discharge (including how to find help when discharged), as well as visiting hours and people to contact. For social support, the app additionally includes stories from parents who have experienced having an infant in the unit. Parents are able to interact and share on the app by adding their own journal entries and photographs which they can then show family and friends through email or social media.

**Figure 2**

*Examples of the Home Page in Babble Where Parents are Able to Save Information and Articles as well as Some Examples of the Type Information Provided in the Babble App.*



In the next section, we will describe what you can expect when your baby is born with a gestational age of 28-32 weeks and what you can do to support your baby.

The app is provided as part of the orientation process upon admission, helping parents feel more supported and informed following induction to the unit. Babble allows for parents and other family members to re-read and refer back to complex and potentially overwhelming information in their own time and at their own pace (Spargo & de Vries, 2018). The information that is included is designed to align with staff information, ensuring consistency between staff care and the app itself. When reviewed in terms of appropriate information inclusion and general quality (as measured by the Mobile Application Rating Scale), Babble ranked in the top five of neonatal apps available, indicating high accuracy and accessibility of information provided (Richardson et al., 2019; Stoyanov et al., 2015). The app can be used prior to admission for mothers identified as high-risk as it can be downloaded at any time and is freely available. Studies indicate that prior to a specific stressful event, if parents access and learn relevant information to help them cope with the situation, this can enhance parental coping mechanisms, allowing them to focus on preparing for the birth and subsequent neonatal admission (Spargo & de Vries, 2018).

Babble accommodates for discharge also. After becoming familiarised with the neonatal unit, parents may feel anxious or fearful about coping on their own without nursing or medical support (Spargo & de Vries, 2018). The typical time spent with a newborn bonding and feeding is altered in the neonatal unit, comparative to full term or healthy infants, and there also may be lingering health problems that parents are concerned about managing once discharged (Spargo & de Vries, 2018). The app includes links to community supports as well as specific information pertaining to discharge included within the app itself.

The area of mHealth has typically focused on changing behaviour and providing education with that purpose in mind. Babble is unique in its orientation towards informational support to help, not the ill or injured patient, but rather address the wider needs of the family that surround the patient. By providing verified information in an easy, accessible format, Babble looks to enable parents to process and manage the situation in the neonatal unit by empowering them with knowledge and support. Feedback from parents indicates that the app and the information included supports healthy and secure parent-infant attachment which then has the potential to improve overall developmental outcomes (Spargo & de Vries, 2018).

The use of a unique mHealth modality to provide parents with information and support whilst in the neonatal unit is yet to be empirically explored within a New Zealand setting and there is little research around the utilisation of an app as an adjunct to neonatal healthcare service provision in general. The present study therefore looked to better understand parents' experiences of the neonatal unit and the Babble app's role in meeting the needs of neonatal parents through both quantitative and qualitative means.

The remainder of the thesis primarily relates to the two articles exploring parental experiences of the neonatal unit and the role of Babble (e.g., Study One and Study Two). Each article is presented as its own chapter, complete with literature review, methods, results and discussion. Following this, there is a discussion chapter, pulling together the findings from each study, considering clinical implications and identifying limitations of the study as a whole. Finally, there is a conclusion chapter, outlining what the main findings were and where to from here.

# 4. Study One: Distress, Self-Efficacy, Feeling Informed and the Babble App: A New Zealand Neonatal Parent Sample

The following article has been submitted to Infant Mental Health. It is currently in the process of editorial review. The version shown is the submitted manuscript with minor typographical errors corrected and formatting changes for consistency. Supplementary materials pertaining to the article can be found in Appendix B. References for this article are included within the consolidated reference list.

## 4.1 Abstract

The present study aimed to investigate parental experiences of New Zealand neonatal units, and the effect of an informational support app, Babble, on measures of distress, self-efficacy, and how informed parents felt. A between-subjects post-test only quasi-experimental design, comparing participants grouped by Babble app use (yes/no) was used. Parents of infants admitted to any neonatal unit within twelve months were invited to participate in an online survey, with parental distress, parental self-efficacy, and how informed parents felt during their admission as the main outcome measures. 449 parents were included in the analyses. 44 participants reported having used the Babble app, yet the majority of participants who took part expressed an interest in the resource. There was no evidence of an effect of Babble app use on any of the outcome measures; distress, self-efficacy or feeling informed. Across the entire sample, there was a negative relationship between how informed parents felt and parental distress, which was partially mediated by parental self-efficacy. Findings suggest that interventions supporting parents to feel more informed may, in principle, reduce distress, although, there was little evidence of an effect of the specific intervention explored. Supporting parents with information-based interventions or greater information provision may be beneficial in enhancing parental self-efficacy, and thus, reducing parental distress.

### *4.1.1 Keywords*

neonatal unit, distress, feeling informed, parental self-efficacy, Babble, parent.

## 4.2 Introduction

Neonatal units provide care to infants born with various health conditions that require medical intervention, such as prematurity. Typically, the provision of care has been separated into three levels, depending on the infant's medical needs. Level III or Neonatal Intensive Care Units (NICUs) provide care to the sickest and smallest of infants; Level II and II+ units (special care baby units (SCBUs) or neonatal units) provide care to infants who are more medically stable; and Level I units provide care to those infants, typically stable full-term infants, who may require minimal, non-invasive support. Infants are admitted for varying lengths of time and with varying degrees of severity with regard to illnesses and long-term prognoses. International and New Zealand literature have consistently evidenced the negative emotional and relational impacts of such an admission for parents of the infant. Parents of neonates are seen to have significantly higher rates of mental health difficulties and general distress, compared to parents of full-term infants (Carter et al., 2005; Holditch-Davis et al., 2015).

Consistent and significant parental stress has been identified across different neonatal units internationally, evidence of the pervasive nature of distress experienced (Schappin et al., 2013). In particular, parents report elevated distress in response to the 'stress-provoking' environment of the neonatal unit, which has been seen to negatively influence parental perception of their abilities as a parent and ultimately, the parent-infant relationship (Ballantyne et al., 2017).

Parents report feelings of guilt, incompetency and failure associated with their neonatal experience, all of which negatively impact parental self-efficacy, ultimately affecting parents resilience and adaptive coping abilities (Reid, 2000). In a neonatal unit, a mother with high parental self-efficacy is likely to be more engaged in medical routines, and more able to interpret infant signals correctly and respond appropriately, therefore making her more likely to establish a warm and sensitive relationship with her infant (Coleman & Karraker, 1998). Conversely, mothers with lower self-efficacy are more likely to become overwhelmed easily, and report lower parenting effectiveness, an insecure bond with their infant, and increased susceptibility to feelings of helplessness (Coleman & Karraker, 1998). When compared across genders, mothers have been found to score higher than fathers on parental self-efficacy, possibly due to greater likelihood of significant time spent with the infant in the neonatal unit environment (Salonen et al., 2009). Understanding what factors contribute to and support the development of a strong sense of parental self-efficacy is essential to better support parent and infant wellbeing across the neonatal experience.

New Zealand-based research by Carter and colleagues (2005) determined that parents of NICU admitted infants experienced a higher incidence of anxiety, compared to controls. They identified that there was no significant difference in clinically relevant depressive symptomology between controls and NICU parents. Anxiety and depression scores were low for both controls and NICU parents, with modest clinical scale scores across the measures used, indicating that the experience was not associated with clinically significant depression or anxiety for either group. More general negative impacts, and the overall experience of neonatal admission across all levels of care, is yet to be explored within a New Zealand context. Given New Zealand's unique cultural and geographical landscape, understanding the general experience of, and distress experienced by, parents within this context is essential to ensure interventions and support are best targeted to support their unique and individual needs.

Parents often identify a need for consistent and reliable information during their neonatal stay, citing information as a tool that helps build their confidence, manage their distress and allows them to better prepare for the experience (Cleveland, 2008; De Rouck & Leys, 2009; Lantz, 2017). Despite the many efforts made by neonatal units to support families, parents continue to report a desire for more accessible, consistent and understandable information (Orr et al., 2017). Evidence suggests that interventions which provide informational support serve to reduce parental stress and improve overall wellbeing during the neonatal stay (Bracht et al., 2013; Melnyk et al., 2006). Various initiatives including support groups, information booklets and individual psychology sessions have been utilised across different units, each resulting in lowered parental stress and improved parental confidence across the admission period (Bracht et al., 2013; Melnyk et al., 2006).

One potentially effective method for providing information to parents of infants in neonatal units is the use of smartphone applications (apps). Recent New Zealand research demonstrated neonatal parents' positivity towards apps as information sources for use in conjunction with traditional care formats (Williams et al., 2020). The transportable, personal, intelligent, connected, low-cost and accessible nature of apps means that information delivered through such an approach has been considered particularly useful for the neonatal parent population (Garfield et al., 2016).

Information provided to parents through apps has been found to meet parental needs and enhance parental self-efficacy during the early postpartum period in previous international studies (Danbjørg et al., 2015; Garfield et al., 2016; Shorey et al., 2017). Shorey et al. (2017) explored the use of an app providing informational materials to parents in the early postpartum period through a randomised-control trial. Their sample consisted of 250 parents admitted to a tertiary-level hospital[3]. Half the sample received access to psychoeducational support through the app. Their findings suggested that users felt more confident, which resulted in greater engagement in parenting tasks related to their infant. Similarly, when provided with an

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[3] Hospitals that are typically affiliated with universities, where highly technical and specialised care that is provided for patients with severe, complex or uncommon health problems (National Centre for Biotechnology Information, 2013).

accessible internet tool designed to enhance communication with nurses, Finnish mothers of newborns reported feeling more in control, supported and reassured subsequent to use, suggesting positive impacts on their self-efficacy and distress levels (Danbjørg et al., 2015). Garfield and colleagues (2016), looked at the role of a similar informational support app, with a focus on parent-empowerment, for American parents of low-birth-weight infants who were approaching discharge from a neonatal unit. Compared to controls, parents who utilised the app regularly were seen to report enhanced self-efficacy and greater preparedness-for-discharge, indicative of the appropriateness of such a resource for the neonatal parent population.

In New Zealand, an app called Babble has recently been developed, with the aim of increasing support for parents across the entire neonatal experience (Spargo & de Vries, 2018). A portable and accessible tool, Babble is freely available and provides general information about the neonatal unit, medical equipment, unit processes and health of the infant. Few app-based interventions have looked to support parents across the entirety of the neonatal experience (i.e., pregnancy, birth, admission and discharge) and thus far, no one has investigated the effectiveness of the Babble app in helping parents to feel more informed, less distressed and more confident. Information support delivered through technological means has been found to enhance parental self-efficacy when controlling for regularity of use in previous work (Garfield et al., 2016). The provision of information through an app allows for families to review, or refer back to complex or confronting material throughout the neonatal stay, supporting their understanding and building their confidence (Danbjørg et al., 2015). By meeting the need for information and accessible support, it is theorised that the Babble app will support parents to feel less distressed and more confident and informed about their infant and the care provided throughout the neonatal experience.

### *4.2.1 Aim*

The main purpose of this study was to determine how the Babble app impacts on parents' levels of distress, their perception of self-efficacy, and how informed they felt. A secondary aim was to explore New Zealand parents' experiences of the neonatal unit including how they viewed the experience, their levels of distress, perception of parenting self-efficacy and how informed they perceived themselves to be. The following hypotheses were preregistered, and findings for each will be reported in the results section.

Level of unit, length of stay, parental age and parental role were considered to be potential confounding variables across the first three hypotheses and thus were considered necessary to control for. These variables were selected as they are evidenced as being likely to affect levels of distress, self-efficacy and how informed parents feel, and it is plausible that they may be correlated with a parent's choice to use the Babble app, indicating they possess the characteristics of confounding variables (McNamee, 2003; see Appendix B).

1. Parents of infants in neonatal units who have used the Babble app will report lower levels of distress than parents who have not, when controlling for level of unit, length of stay, parental age and parental role (mother/father).

2. Parents of infants who have used the Babble app will report higher levels of self-efficacy compared to parents who have not, when controlling for level of unit, length of stay, parental age and parental role (mother/father).

3. Parents of infants who have used the Babble app will report a greater sense of feeling informed than parents who have not, when controlling for level of unit, length of stay, parental age and parental role (mother/father).

4. As the app primarily provides information (and a lack of feeling informed is reported as a key factor in parents' distress), it is hypothesised that the effect of Babble on distress will be partially mediated by how informed parents feel (Danbjørg et al., 2015; Shorey, et al., 2017).

Specifically, Babble app use will help parents feel more informed, resulting in reductions of distress.

5. Parents in the neonatal unit often also report feeling less confident in their parental role, partly due to a lack of information (Danbjørg, et al., 2015; Shorey, et al., 2017). Thus, it is hypothesised that the effect of Babble on self-efficacy will be partially mediated by how informed parents feel. Specifically, Babble app use will help parents feel more informed, therefore improving their self-efficacy.

Additionally, a structural equation model was hypothesised, exploring relationships between Babble app use, parents' scores of feeling informed, parents' scores of distress, and parents' scores of self-efficacy. The model allows for simultaneous testing of the aforementioned hypotheses, whilst accounting for the potentially biasing effects of predictor measurement error.

Each hypothesis, exploratory research question and model presented here was pre-registered through Open Science Framework on the 7th of March 2019 (https://osf.io/28sn6/?view_only=55f68c3550534a858ac7cfdc5b7c79f6).

## 4.3 Materials and Methods

### *4.3.1 Design*

Given that the Babble app is freely available for download, it was not feasible to control distribution to parents, as would be required for a randomised control trial. Additionally, given admission to a neonatal unit is an unpredictable, uncommon event associated with very high stress making identifying and enrolling participants challenging, a pre-test - post-test design would have been difficult to conduct, and likely resulted in a very small sample size. Therefore, the present study utilises a between-subjects post-test only design, but with statistical controls for a range of plausible confounding variables (see Appendix B).

### *4.3.2 Participants and Procedure*

449 parents (438 mothers, *M* age = 31 years, range = 17 – 45 years), with an infant admitted to any neonatal unit in New Zealand from March 2018 to June 2019, participated in this study. The target sample size, determined through power analysis, was 265 parents with 100 Babble users.[4] Given the limited number of Babble users who engaged in the survey, the target number of Babble users was not reached, but the overall target sample size for the analyses chosen was. Primarily, parents were of New Zealand European/Pākehā descent (348 parents), and majority had obtained tertiary education at university level (209 parents). In terms of Babble use, 44 of the participants reported they had used the app throughout their neonatal stay. Several parents (12) reported that their partner had also completed the survey, indicating that it is likely some of the demographics are slightly inflated due to these parents providing data around the same infant.

On average, the infants of participants were admitted for 25.6 days (range = 1 - 358, *SD* = 40.67). There was some variance in the level of unit infants were admitted to, with 255 reporting admission to Level III units, 128 reporting admission to Level II units, and 66 reporting admission to Level II+ units. The average birthweight for infants whose parents took part was 2612 grams (range = 296 - 8000g), and the main reason for admission was prematurity (48.4%). Other common reasons included illness (20.8%) and the 'other' category where parents reported a variety of conditions inclusive of including trouble breathing, tachycardia and infection (23%). A small proportion of infants were admitted due to being small for gestational age (7.8%). Further demographic information is available in the Supplementary Information (see Appendix B).

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[4] More information pertaining to the power analysis and 'stopping rules' can be found in the pre-registration.

Participants were primarily recruited through social media, namely Facebook parenting and infant support groups, and the Facebook pages of neonatal support organisations in New Zealand, including Plunket and Bellyful. A link to the survey was also included in all versions of the Babble app[5] under the topic heading ‘Research’. Posters were placed around the Level II+ neonatal unit from which the Babble app originates, and in parent rooms within the hospital. Parents admitted to that Level II+ neonatal unit within the last twelve months were also sent a letter informing them of the study and inviting them to participate. The first author’s institution published an article on their website about the study as part of the final recruitment stages, directly requesting Babble users to take part.

### *4.3.3 Materials*

Participants completed an online, anonymous survey designed by the researcher and hosted on a Qualtrics survey system. The median completion time of the survey was 14.6 minutes. The survey included questions focusing on participants’ demographic information, the admission experience, parental needs, distress, self-efficacy, feeling informed, and the Babble app (see Appendix C).

**4.3.3.1 Experiences in the Unit.** Parents were asked to report how they found the experience in the NICU/SCBU on a Likert-type rating item, with response options ranging from 1 (*very negative*) to 5 (*very positive*).

**4.3.3.2 Parental Distress.** Parental distress was measured through a standardised scale of parental stress in the NICU, known as the Parental Stressor Scale: Neonatal Intensive Care Unit (PSS:NICU; Miles, Funk, & Carlson, 1993). The scale has been evidenced as valid and reliable across many different populations and is the most prominently used tool in assessing parental distress in the NICU (Baía et al., 2016; Dudek-Shriber, 2004; Schappin et al., 2013;

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[5] With the exception of the version available to consumers under Counties Manukau District Health Board.

Sweet & Mannix, 2012). The PSS:NICU consists of a general distress question and three subscales assessing specific areas of stress: environment (‘Sights and Sounds’), infant (‘Infant Appearance’), and parent (‘Parental Role Alteration’) related factors. Items were rated on a Likert-type rating scale from 1 (*not at all stressful*) to 5 (*extremely stressful*). Any item reported as ‘NA – not applicable’ was rated as 1 (*not stressful at all*), in order to measure overall stress, inclusive of situations that parents may not have reported experiencing (Miles et al., 1993). Responses were averaged across items to obtain the subscales and total score. The measure demonstrated good internal consistency of the overall scale scores for the study population ($\alpha = .92$).

**4.3.3.3 Parental Self-Efficacy.** Self-efficacy was measured by a novel, single-item, 5-point Likert scale of agreement ranging from 1 (*strongly disagree*) to 5 (*strongly agree*) with the statement: I felt confident in my roles and abilities as a parent during the admission period. Research suggests that a single-item self-efficacy question can offer a shorter, more user-friendly measure of self-efficacy comparable to larger, multiple-item scales (Hoeppner et al., 2011).

**4.3.3.4 Feeling Informed.** To assess how informed parents felt during their neonatal admission, a novel four-item scale was developed by the first author. Parents were asked to rate their agreement on the following Likert-scale type stimulus statements:

- I felt informed about my baby’s needs and care within the unit;
- I felt informed about the neonatal unit and the relevant policies and procedures;
- I felt informed about my role in caring for my baby in the neonatal unit; and,
- I felt informed about the discharge process and caring for my infant at home.

Responses to each of the four statements were then averaged to create a single score of how informed the parents felt about the whole experience. The measure demonstrated good internal consistency across the overall scale scores ($\alpha = .84$).

### *4.3.4 Ethical Approval*

Ethical approval for this study was granted by the Massey University's Ethics Committee Southern A (Application 18/64, 05/11/18; see Appendix A). Ethical approval for advertising was granted through MidCentral District Health Board on the 28th of February 2019 by the Clinical Executive of Child Health and the Chief Medical Officer at Palmerston North Hospital (see Appendix A).

### *4.3.5 Data Analysis*

Data analysis was completed using R version 3.5.1 (R Core Team, 2019). The pre-registration, a deidentified copy of the dataset, R Script, and survey are available online at https://osf.io/28sn6/?view_only=55f68c3550534a858ac7cfdc5b7c79f6.

### *4.3.6 Participant Exclusion Criteria*

Participants who did not provide a response to the Babble App Use question and/or answered less than 75% of items across each of the three main scales; distress (20/26 items), feeling informed (3/4 items) and self-efficacy (1/1) were excluded. Those who were admitted beyond the last twelve months or answered 'no' to the consent question were excluded. Responses that were identified as 'spam' (test/preview, imported, and duplicate responses, as well as any response flagged as spam by Qualtrics) were excluded. In alignment with these criteria, 165 parents were excluded from the final sample.

### *4.3.7 Missing Data*

Single imputation was utilised for participants who remained, as missing data can result in observations being excluded from the analyses. Specifically, the missForest (Stekhoven & Bühlmann, 2012) package within R was used to impute missing data for participants included in the final sample with missing responses (0.33%).

### *4.3.8 Assumption Testing*

Assumption testing was performed for the main analyses (see Appendix B).

## 4.4 Results

### *4.4.1 Descriptive Statistics*

Parents' experiences of the neonatal unit across the measures of distress, feeling informed and parental self-efficacy were explored. Generally, parents found the experience of admission moderately distressing. Disruption to the parental role was considered to be the most distressing aspect of the neonatal experience for parents, followed by aspects related to their infant and then, aspects related to the environment. Parents, on average, reported feeling somewhat informed about their infant, the unit and the care provided during their infant's neonatal stay. Primarily, parents felt they neither agreed nor disagreed with the statement 'I felt confident in my roles and abilities as a parent during the admission period'. Generally, parents viewed their neonatal experience positively. An overwhelming majority of parents (92%) reported that they would have been interested in utilising an information intervention like Babble, had they been aware of it at the time of their admission.

**Table 2**

*Means, Standard Deviations, and Correlations with Confidence Intervals.*

| Variable | *M* | *SD* | 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|---|---|---|
| 1. PSS:NICU | 3.14 | 0.77 | | | | | | |
| 2. PSS:NICU Infant | 2.64 | 0.81 | 0.81$^*$ | | | | | |
| 3. PSS:NICU Role | 3.68 | 1.04 | 0.84$^*$ | 0.56$^*$ | | | | |
| 4. PSS:NICU Enviro | 2.48 | 0.88 | 0.77$^*$ | 0.60$^*$ | 0.50$^*$ | | | |
| 5. Parental Self-Efficacy | 3.26 | 1.14 | -0.25$^*$ | -0.14$^*$ | -0.27$^*$ | -0.18$^*$ | | |
| 6. General Experience | 4.11 | 1.05 | -0.32$^*$ | -0.16$^*$ | -0.31$^*$ | -0.19$^*$ | 0.36$^*$ | |
| 7. Feeling Informed | 3.59 | 0.92 | -0.29$^*$ | -0.11$^*$ | -0.30$^*$ | -0.23$^*$ | 0.45$^*$ | 0.59$^*$ |

*Note.* M = mean. SD = standard deviation. $^* p < 0.05$.

In general, parents who viewed the neonatal admission positively were more likely to report experiencing reduced distress, enhanced parental self-efficacy and a greater sense of feeling informed. Correlations between measures of general distress, distress related to the environment, distress related to the infant, distress related to the parental role, self-efficacy, general experience and feeling informed appear in Table 2.

### *4.4.2 Hypothesis 1: Babble and Distress*

The hierarchical multiple regression exploring the impact of various variables on distress determined that the control variables: level of unit; length of stay; parental age; and role, together explained a small, but significant portion of the variance in distress, $R^2 = 0.08$, $p < 0.05$. Adding the Babble app made no noticeable change to the explained variance, $R^2 = 0.08$, and the coefficient for Babble app use was not statistically significant (see Table 3). Thus, hypothesis one was unsupported.

**Table 3**

*Results of the Multiple Regression Exploring the Role of Babble on Parental Distress as Measured by the PSS:NICU.*

| **Predictors** | | B | B 95% CI | β | p |
|---|---|---|---|---|---|
| Intercept | | 3.75 | [3.29, 4.20] | -0.00 | 0.00 |
| Babble App Use | | -0.02 | [-0.26, 0.21] | -0.03 | 0.88 |
| Level of Unit (Level II+) | | -0.04 | [-0.27, 0.19] | -0.02 | 0.79 |
| Level of Unit (Level III) | | 0.21 | [0.05, 0.37] | 0.14 | 0.01 |
| Length of Stay | | 0.00 | [0.00, 0.00] | 0.15 | 0.00 |
| Age | | -0.03 | [-0.04, -0.01] | -0.17 | 0.00 |
| Relationship to Baby | | -0.23 | [-0.68, 0.22] | -0.05 | 0.32 |
| $R^2$ | 0.08 | | | | 0.00 |

*Note. B* = unstandardised regression weights. *B* 95% CI = confidence intervals presented as lower limit, upper limit. β = standardised regression weights.

### *4.4.3 Hypothesis 2: Babble and Parental Self-Efficacy*

Neither the model with control variables only, $R^2 = 0.01$, $p < 0.05$, nor a model with Babble app use included explained any significant variation in parental self-efficacy (see Table 4). The coefficient for Babble app use was likewise not statistically significant. As such, hypothesis two was found to be unsupported.

**Table 4**

*Results of the Multiple Regression Exploring the Role of Babble on Parental Self-Efficacy.*

| **Predictors** | B | B 95% CI | β | p |
|---|---|---|---|---|
| Intercept | 3.23 | [2.54, 3.92] | -0.01 | 0.00 |
| Babble App Use | 0.17 | [-0.19, 0.53] | 0.15 | 0.36 |
| Level of Unit (Level II+) | -0.11 | [-0.46, 0.24] | -0.03 | 0.54 |
| Level of Unit (Level III) | -0.16 | [-0.41, 0.09] | -0.07 | 0.21 |
| Length of Stay | 0.00 | [-0.00, 0.00] | 0.07 | 0.18 |
| Age | 0.00 | [-0.02, 0.02] | 0.01 | 0.83 |
| Relationship to Baby | 0.43 | [-0.26, 1.10] | 0.06 | 0.22 |
| $R^2$ | 0.01 | | | 0.42 |

*Note. B* = unstandardised regression weights. *B* 95% CI = confidence intervals presented as lower limit, upper limit. β = standardised regression weights.

### *4.4.4 Hypothesis 3: Babble and Feeling Informed*

The final hierarchical multiple regression indicated that parental role, and the level of unit an infant was admitted to, were significant predictors of change in how informed parents felt within the context of the overall model, $R^2 = 0.01, p < 0.05$. The addition of Babble in the second stage indicated that Babble app use did not significantly predict how informed parents felt, indicating that hypothesis three was not supported (see Table 5).

**Table 5**

*Results of the Multiple Regression Exploring the Role of Babble on How Informed Parents Reported Feeling During Their Infant's Neonatal Admission.*

| **Predictors** | B | B 95% CI | β | p |
|---|---|---|---|---|
| Intercept | 3.63 | [3.07, 4.19] | -0.02 | 0.00 |
| Babble App Use | 0.17 | [-0.12, 0.46] | 0.18 | 0.26 |
| Level of Unit (Level II+) | -0.12 | [-0.41, 0.16] | -0.05 | 0.40 |
| Level of Unit (Level III) | -0.21 | [-0.41, -0.01] | -0.11 | 0.04 |
| Length of Stay | 0.00 | [-0.00, 0.00] | 0.01 | 0.77 |
| Age | 0.00 | [-0.01, 0.02] | 0.01 | 0.84 |
| Relationship to Baby | 0.63 | [0.08, 1.18] | 0.11 | 0.03 |
| $R^2$ | 0.03 | | | 0.07 |

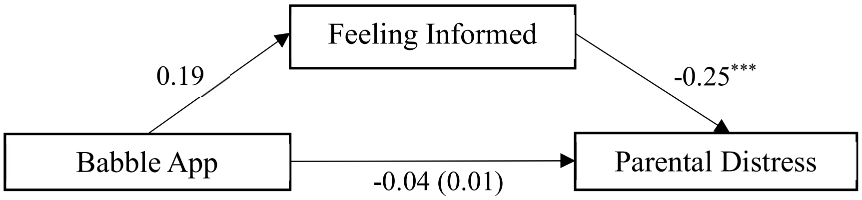
*Note. B* = unstandardised regression weights. *B* 95% CI = confidence intervals presented as lower limit, upper limit. β = standardised regression weights.

### *4.4.5 Hypothesis 4: Babble App, Feeling Informed and Distress*

A mediation analysis was performed, testing the relationship between Babble app use, how informed parents feel and parental self-efficacy. As Figure 3 illustrates, there was no evidence of an indirect effect of Babble app use on parental distress through how informed parents felt during their neonatal admission ($\beta = -0.04$, $p = 0.13$) . As such, hypothesis four was seen to be unsupported. There was, however, an effect of how informed parents felt on the distress they reported experiencing. Specifically, the more informed parents were, the less distress they were seen to experience.

**Figure 3**

*Mediation Analyses with Babble App Use as the Predictor Variable, Parental Distress as the Outcome Variable and Feeling Informed as the Mediator Variable.*



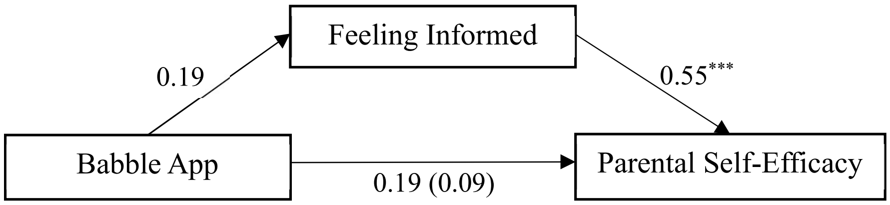
Note. *p < .05; ***p < .001 (2-tailed).

### *4.4.6 Hypothesis 5: Babble App, Feeling Informed and Self-Efficacy*

A mediation analysis was performed, testing the relationship between Babble app use, how informed parents feel and parental self-efficacy. As Figure 4 illustrates, there was no evidence of an indirect effect of the Babble app on parental self-efficacy through how informed parents felt during their neonatal admission, meaning that hypothesis five was unsupported. There was evidence, however, of a positive direct effect of how informed parents felt on their reported parental self-efficacy.

**Figure 4**

*Mediation Analyses with Babble App Use as the Predictor Variable, Parental Self-Efficacy as the Outcome Variable and Feeling Informed as the Mediator Variable.*



Note. *p < .05; ***p < .001 (2-tailed).

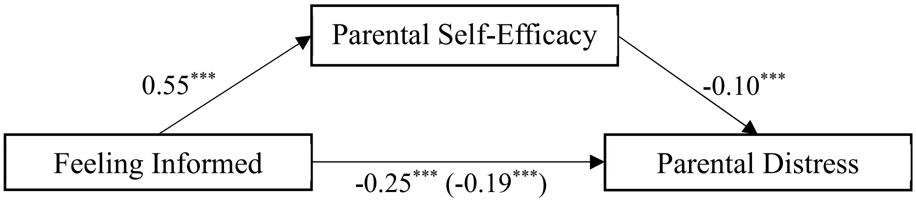
### *4.4.7 Exploratory Analysis: Feeling Informed, Parental Self-Efficacy and Parental Distress*

The results of the two pre-registered mediation models suggested that how informed parents feel is positively related to self-efficacy, yet negatively related to distress. Subsequently, it seemed reasonable to suggest that how informed parents felt may reduce distress via an effect on parental self-efficacy. Thus, an additional exploratory analysis was performed testing this theory.

A mediation model exploring whether parental self-efficacy could explain some of the relationship between how informed parents feel and parental distress was performed. As Figure 5 illustrates, the regression coefficients for both the effect of feeling informed on parental distress and for the effect of parental self-efficacy on parental distress, were significant. The effect of feeling informed on parental distress remained significant when controlling for the effect of parental self-efficacy, meaning there was no evidence to suggest complete mediation. However, the 95% confidence interval for the indirect effect did not include zero, indicating that parental self-efficacy *partially* mediated the relationship of feeling informed and parental distress (*95% CI* = -0.10. -0.02). With parental self-efficacy mediating 24% of the total effect of how informed parents felt on their experience of distress, the analysis suggests that lowered levels of distress are predicted by a greater sense of feeling informed, and some of that change can be explained by parental self-efficacy.

**Figure 5**

*Mediation Analyses with Feeling Informed as the Predictor Variable, Parental Distress as the Outcome Variable and Parental Self-Efficacy as the Mediator Variable.*



Note. *p < .05; ***p < .001 (2-tailed).

### *4.4.8 Structural Equation Model*

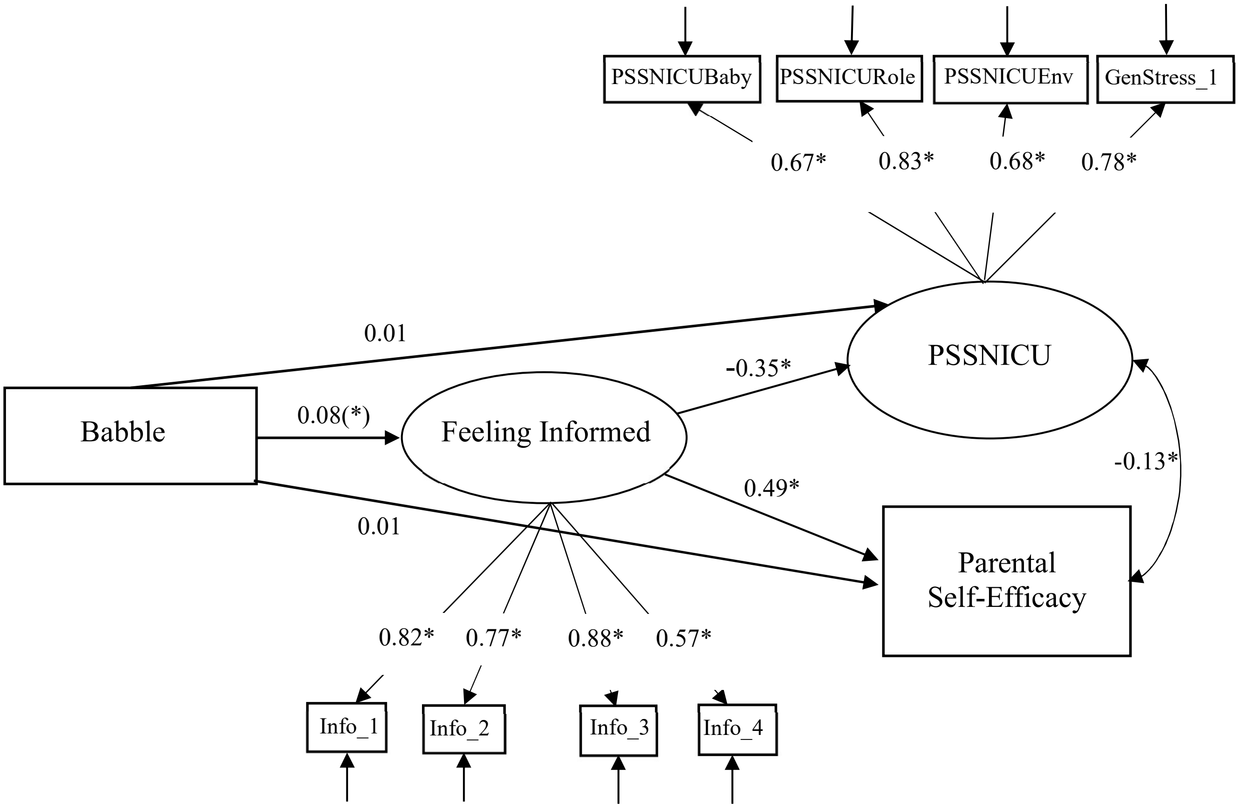
The relationships between the key variables of Babble app use, feeling informed, distress, and self-efficacy were assessed through structural equation modelling, utilising diagonally weighted least squares (DWLS) as the estimation method. This method was chosen due to its demonstrated efficacy with ordinal data and smaller samples (Lei, 2009), and robustness against variable type and possible deviations in normality (Mîndrilă, 2010). Multiple indices of model fit are reported alongside the chi-square test. A non-significant chi-square test at an alpha level of 0.05 was considered suggestive of good fit. The comparative fit index (CFI) reflects the fit of the model against the null model, and values of 0.95 or greater are indicative of good fit (Bentler, 1990). The root mean square error of approximation (RMSEA) estimates the degree of model misfit relative to model complexity. In alignment with pre-registered fit criteria, values less than, or equal to, 0.06 were deemed as indicative of close fit. The standardised root mean square residual reflects the standardised difference between the predicted correlation and the observed correlation matrix. Values below 0.08 are generally considered to indicate a good fit (Hu & Bentler, 1999). As per the pre-registration model fit criteria, the model (see Figure 6) indicated good fit, ($\chi2$ (31) = 44.64, p = 0.05, CFI= 0.99, RMSEA= 0.03 (0.00, 0.05), p=0.94, SMSR=0.04).

All factor loadings were significant at an alpha level of 0.05, indicating that the observed items were related to their intended latent variables. The regression coefficient for the relationship between feeling informed and self-efficacy was positive and significant ($\beta$ = 0.49, $p < 0.01$). Similarly, the regression coefficient for the relationship between feeling informed and distress was negative and significant ($\beta$ = -0.35, $p = 0.00$), indicating that the more informed a parent feels, the less distress they report experiencing. These findings indicate good local fit for these components of the model. Additionally, the model demonstrated a statistically significant correlation between distress and self-efficacy, whereby higher self-efficacy scores were seen to be related to reduced distress ($\beta$ = -0.13, $p = 0.00$).

The pre-registration did not include specific details as to how standard errors would be calculated, and stated only that diagonally weighted least squares (DWLS) estimation would be used. In lavaan, the abbreviation “DWLS” is used to select DWLS estimation without robust standard errors, so the use of this abbreviation in the pre-registration could be read as implying the calculation of (non-robust) standard errors based on the assumption of a multivariate normal distribution. In retrospect, inclusion of robust standard errors was likely appropriate, given the non-normal data collected (e.g., ordinal and dichotomous items). When DWLS estimation and calculation of standard errors without an adjustment to ensure robustness was utilised, the two indirect effects (e.g., the effect of Babble on parental self-efficacy, mediated by how informed parents felt, and the effect of Babble on parental distress, mediated by how informed parents felt), as well as the direct path of Babble to feeling informed, were statistically significant. However, when using robust standard errors to account for non-normality inherent in the data, these effects were no longer significant. Furthermore, the total effects of Babble on parental self-efficacy and distress remained non-significant regardless of the robustness of standard errors. As such, the model provided only tentative evidence of an effect of Babble on how informed parents felt, but no evidence of effects of parental self-efficacy and distress. In sum, parts of the model were supported, but not others, meaning that the inferential criteria required for the model as a whole to be supported were not met.

**Figure 6**

*Path Diagram Illustrating Complete Standardised Parameter Estimates.*



*Note. *p < .05 (2-tailed).*

### 4.5 Discussion

The present study looked to enhance our understanding of New Zealand parents' experiences of the neonatal unit and explore the role of the Babble app within these experiences. There was no evidence of any effect of the Babble app on parental distress or parental self-efficacy across the hierarchical regression models. There was only tentative evidence of an effect of Babble on how informed parents felt within the structural equation model, which was negated when robust standard errors were included to account for non-normality. There was no evidence of an effect of Babble on feeling informed across the hierarchical regression model. There was no evidence as seen in either the mediation analyses or the structural equation model, of any mediating effect of how informed parents felt when using the Babble app, on any of the outcome variables explored.

Across the sample, relatively few participants (9.9%) reported having used the Babble app, and there was no measure of how frequently the app was used by these parents. The small number of app users in our sample may be due to a lack of awareness and promotion of the resource. Other research exploring the role of an app designed for supporting parents through NICU discharge determined that there was an effect of the app on parental self-efficacy only when mean app usage was taken into account (Garfield et al., 2016). It is possible that, similar to Garfield et al.'s (2016) findings, any effect on distress, self-efficacy and how informed parents felt are only present when paired with significant and regular use. Those who reported using the app may have only downloaded it or used it sparingly, hence the lack of findings suggesting its efficacy. Alternatively, it may be that the app acts as a supplementary resource, in addition to the information provided by other staff members or support systems, meaning that the app alone does not significantly contribute to how informed, confident or distressed a parent reports feeling during their infant's admission. Further research exploring the effects of exposure to the app or the impact of app usage is warranted.

In recent qualitative research performed, parents have reported finding the app useful and supportive (Gibson, Ross, Williams & De Vries, under submission); however, these positive effects may not be represented in the outcome variables tested in the present study. Other research looking at a more general support app for the postpartum period determined that there were no statistically significant effects on parental self-efficacy, postnatal depression and social support, but considered that the satisfaction with the app was high, possibly indicating a positive effect on the psychological experience of parents (Shorey et al., 2017).

However, parents viewing an app positively does not necessarily indicate it provides any direct benefit to them in the areas of self-efficacy, distress or how informed they feel about the neonatal experience. Further research is required to tease out the mechanisms of possible support the app may provide, perhaps through more open, general measures or further qualitative research.

When considering other influential factors in the parental neonatal experience, parents being younger, being admitted to a higher level of unit (e.g., Level III), and being admitted for a longer period of time were all seen to predict parental report of greater distress. Considering each of these findings in turn, other research has determined that in general, younger parents are likely to have less experience of parenthood, greater medical complications and may lack resources (e.g., financial support) that may protect older parents from experiencing such significant distress (Dudek-Shriber, 2004). As infants who are admitted to higher level of units (e.g., NICUs) experience greater health difficulties, are born earlier and undergo riskier treatments compared with infants admitted to lower level of units, it is understandable that parents of these infants experience greater distress compared to parents in lower levels of care (Donoghue, 2004). Finally, a longer admittance to hospital was seen to result in greater distress for the sample surveyed. While more time spent in the environment could lead to greater habituation (which should, in turn, reduce distress; Miles et al., 2002), longer admittance is also seen to be correlated with the severity of infant health condition, possibly explaining why parents may experience greater distress in response to a greater length of stay (Dudek-Shriber, 2004).

A relationship between how informed parents felt, and how distressed they reported being was found across the mediation analyses, with an exploratory mediation analysis indicating that this effect may be partially mediated by parental self-efficacy. Reduced parental distress was predicted by parents feeling more informed, with this relationship being partially mediated by a greater sense of parental self-efficacy. These findings suggest that the provision of information likely supports the acquisition of self-confidence in parental abilities, which in turn leads to a reduction in distress experienced. Indicating that information provision reduces distress through enhancing of self-efficacy, the relationship found here could be pivotal in the development of new, supportive interventions.

Bandura's (1977) theory of self-efficacy may provide insights into why acquisition of information (and thus, sense of feeling informed) enhances self-efficacy. Bandura (1977) posits that a prerequisite for self-efficacy is a secure and appropriate knowledge base. It is likely that parents who report a greater sense of feeling informed have acquired such a knowledge base, from which they are able to build a greater sense of self-efficacy. Such a conclusion is supported by the findings of the structural equation model, whereby feeling informed was associated with increased self-efficacy. Enhanced self-efficacy has been seen to act protectively, with high parental self-efficacy resulting in increased tenacity, less self-blame, more positive psychological wellbeing and enhanced parental satisfaction (Bandura, 1977; Coleman & Karraker, 1998). Future interventions should focus their attention on the interweaving nature of these three variables in their design and implementation. The inclusion of information and support designed to develop parental confidence, may then result in reductions in distress across this population.

### *4.5.1 Limitations*

Reflecting on the distinction between 'feeling informed' and actually 'being informed' is important when considering the results presented here. Previous studies have found that people do not excel at accurately assessing their level of knowledge, with a tendency to be overconfident (Kruger & Dunning, 1999). A study exploring medical health decisions and the differences in participants' sense of feeling informed and how they performed knowledge-based questions determined that there was no relationship between how well participants scored and how informed they considered themselves to be (Sepucha et al., 2010). In this study, the measure of feeling informed was selected to best understand what sense parents had of the information they were provided with, and what relationship this perception had with the other variables explored. However, their assessment is not necessarily an accurate reflection of their factual knowledge or understanding of the situation. Further research is required to better understand how accurately and comprehensively informed parents are, within the neonatal care setting, to ensure information provision best meets parental informational needs.

Accurate recall of experiences may have been impacted by the great variation in length since admittance seen across participants. Parents with an infant admitted within the last twelve months were invited to participate, yet these twelve months coincided with the first year of their infant's life, a time of significant change and adaptation, resulting in possibly greatly impacted recall. Particulars of the experience may have lost salience over time. Despite evidence suggesting the PSS:NICU's reliability and validity for use retrospectively (Schappin et al., 2013), the prevalence of mid-point responses may be due to an inability to remember reactions to the very specific aspects of the experience queried in the measure. Narrowing the inclusion criteria or specifically exploring the experiences of parents during the admission period may mitigate such concerns in future.

The design of the present study limits the causal inferences which can be drawn. The post-test only quasi-experimental design indicates that whilst the study explored the effects of Babble on the psychological outcomes, these estimates come with significant uncertainty attached. Furthermore, the number of Babble users within the study was small and the target sample size was not obtained, limiting the statistical power of the findings and reducing the ability to detect an effect of the Babble app. Future research should look at performing a study utilising a true experimental design, and including a larger sample of Babble users. Such research would further support the findings presented here, and allow for more confident causal conclusions as to the effect of the app to be drawn.

Convenience sampling was used to obtain the required participant numbers and specifically to involve Babble users. Consequently, our sample may have been unrepresentative of the wider population of parents with infants in neonatal units in New Zealand. Although neonatal admission can affect any family, younger parents, much older parents, Māori and Pasifika families, and families of lower socioeconomic status are over-represented in neonatal units across New Zealand (Chow et al., 2015). Such views are lacking in the present work and findings outlined here should not be considered representative of their experiences. Participants in our study, in light of their shared characteristics (e.g., early 30s, well educated), may have greater support or access to resources compared to more disadvantaged populations, possibly reducing the overall distress experienced. Furthermore, these characteristics may have contributed to them having greater access to informational support and ability to dedicate time to learning more about the postnatal period. As such, these participants may have already had their informational needs met through various other sources, possibly contributing to lack of an evidenced effect of the Babble app. Perhaps more disadvantaged or resource poor populations would rely primarily on a single information source, and their experiences of information gathering may be more limited to readily available and accessible means (e.g., staff). More research focused on the experiences of those of ethnic minorities and lower socioeconomic status, and what intervention may suit these people, is needed. The importance of accessing these hard-to-reach populations and obtaining information about their experiences is essential to ensure that neonatal units are best informed to manage the needs of these populations.

### 4.6 Conclusion

When exploring the role of the Babble app in the experiences of parents admitted to a neonatal unit within New Zealand, there was no evidence of any effect of the app on the outcome variables of distress, self-efficacy and how informed parents felt. Parental distress was seen to be reduced by an increased sense of feeling informed, in part through, enhanced parental self-efficacy. In light of these findings, informational resources and support, specifically those targeted at developing a greater sense of self-efficacy and reducing distress, are considered important in supporting the neonatal parental population. Future research should explore the development of such interventions, targeted to inform and actively develop parental self-efficacy, and look to better understand the experiences of populations less prevalent in the present work, specifically fathers, ethnic minorities, lower socioeconomic groups and Babble app users.

# 5. Study Two: The Experiences of Mothers in a Neonatal Unit and Their Use of the Babble App

The following article has been submitted to SAGE Open. It is currently in the process of peer review. The version shown is the manuscript with minor formatting changes for consistency and any typographical errors corrected. Supplementary materials pertaining to the article can be found in Appendix C. References for this article are included within the consolidated reference list.

## 5.1 Abstract

To better understand the experiences of mothers with an infant admitted to a neonatal unit and their perspectives on an available information support app, Babble, eight mothers with an infant admitted to a Level II+ neonatal unit were interviewed. Thematic analysis was utilised, and responses indicated that mothers of neonates experienced challenges around adapting to the maternal role and managing their expectations of motherhood. Relationships with staff were seen as pivotal in the development of maternal confidence and essential to the overall experience. Mothers prioritised informational support, but how mothers sought out this information depended on their individual needs. Mothers who reported using the Babble app found it to be a helpful supplementary resource, tailorable to their individual situation. Results suggest that greater staff awareness of parental perspectives and the development of adaptable and diverse resources, ensuring parents are provided with individualised and appropriate care, is needed.

### *5.1.1 Keywords*

motherhood; neonatal; admission; Babble; information; staff.

## 5.2 Introduction

For infants born with health difficulties or born prematurely, admission to a neonatal unit often occurs to ensure the infant is provided with the necessary medical support and intervention that enables them to develop and thrive. Such hospitalisation has however, been associated with various adverse outcomes for the parents and the family as a whole (Carter et al., 2005; Davis et al., 2003). Parents of an admitted infant appear to experience greater distress (inclusive of increased anxiety, depression and trauma symptoms) when compared with parents of 'healthy' infants (Carter et al., 2005; Gangi et al., 2013; Holditch-Davis et al., 2015). Parents specifically report fears for their infant's survival and more generally, their future wellbeing, expressing that they feel out of control or helpless with regard to their parental role (Davis et al., 2003; Joseph et al., 2007).

Qualitative research has been prominent in the area of neonatal literature, likely due to the depth and richness of data that can be obtained through individual or group interviews (Al Maghaireh et al., 2016; Fenwick et al., 2008; Holditch-Davis & Miles, 2000; Obeidat et al., 2009; Treherne et al., 2017; Turner et al., 2015; Wigert et al., 2006). Reviews of qualitative studies exploring the topic have determined that almost all parents interviewed found the experience of neonatal admission stressful (Al Maghaireh et al., 2016; Obeidat et al., 2009).

Other common themes included parental report of stress related to the infant's condition, difficulty with parental role alteration, and a general impact of hospitalisation on parental psychological and emotional health (Al Maghaireh et al., 2016; Obeidat et al., 2009). Parents have additionally reported struggling with the balance of joy and grief, the disruption of parental expectations (specifically the denial of a 'normal' experience with a healthy full term baby), and general challenges adjusting to the NICU environment (Arnold et al., 2013; Whittingham et al., 2014).

For mothers, the admission to a neonatal unit can be a particularly emotionally confronting experience. Mothers report struggling with separation from their infant, both physically and psychologically, as they are often unable to hold, touch or interact with their infant during their neonatal stay (Ballantyne et al., 2017). In particular, mothers of neonates expressed finding adoption of the maternal role after admission challenging, reporting feelings of disenfranchisement and an impacted sense of ‘being a mother’ (Fenwick et al., 2008; Lupton & Fenwick, 2001).

Mothers often develop expectations for their role as a parent during pregnancy, exploring and evaluating how they intend to perform this role (Reid, 2000). Thus, when events such as premature birth disrupt or delay their sense of identity as a new parent, mothers of sick or low birth weight infants appear to demonstrate less confidence in their parental role, as their expectations are not met (Reid, 2000; Singer et al., 1999). This loss of expected maternal role is evidenced as a key source of distress for mothers during neonatal unit admission (Al Maghaireh et al., 2016; Holditch-Davis & Miles, 2000).

The majority of research performed has focused on the experiences of parents of very medically fragile infants (those who are very premature or of low birth weight) admitted to Level III units, also known as Neonatal Intensive Care Units (NICUs). Within a New Zealand context, there are six NICUs located in major centres, servicing a highly culturally diverse and geographically dispersed population. New Zealand additionally has multiple Level II+ units to support these higher-level facilities. These Level II+ units provide care to infants born at or above 28 weeks’ gestation and born weighing 1000 grams or above, or those discharged from a Level III unit, whose homes may be more conveniently located closer to a Level II+ unit. Given the unique nature of Level II+ units in the context of the New Zealand population, little research has been performed exploring parents’ experiences of these units. A Level II+ neonatal unit is the focus of the present work with the goal of exploring the specific challenges faced by this group of parents.

Within New Zealand, a smartphone application (app), Babble, has been developed with the aim of enhancing parents’ access to information and general support during their neonatal stay (Spargo & de Vries, 2018). Parents of neonates are reported to spend around twenty hours a week seeking out information, most commonly online, during their neonatal stay, suggestive of this population's desire to access informational support (Orr et al., 2017). However, evidence suggests that there are concerns about the accuracy of much of the information provided online, and parents report that under stress, they often do not know where to turn (Cleveland, 2008; Spargo & de Vries, 2018).

Several studies have explored new parents' utilisation and engagement with an app for meeting information needs. These studies found that the ability to easily access information helped support their learning, leaving them feeling more reassured and in control, thus improving their confidence (Danbjørg et al., 2015; Shorey et al., 2017). Recent New Zealand literature suggests that parents are open to online initiatives, such as a neonatal care app (Williams et al., 2020). In light of these findings, the Babble app presents itself as a suitable support for this population, aiming to meet parental needs, supplement information from healthcare providers and support parental involvement in decision-making processes.

Although widely available, Babble is primarily used by those admitted to the mid-sized, urban Level II+ unit from which the app originates and those admitted to the largest Level III unit (NICU), located in the largest city in New Zealand. Babble provides information about the neonatal experience for parents, including information about the neonatal unit itself and care in general (Spargo & de Vries, 2018). Babble additionally includes other parents' stories and parents are able to write journal entries, take photos and record key milestones, all of which can be shared with their friends and whānau through email or social media (Spargo & de Vries, 2018). At this stage, no research has been performed on how parents experience the Babble app and their views of its feasibility and usefulness during the neonatal experience.

### *5.2.1 Present Work*

As reviewed here, the experiences of parents in the neonatal unit has been a prominent area of research for many years. Much qualitative research has taken place, exploring the impact of the neonatal admission and discharge process on parents. However, little has been done to explore the experiences of New Zealand parents in a Level II+ unit setting, or the role of an app targeted to this population. The present study therefore has two primary aims: (1) identify and explore (from the parents' own perspective) experiences in a neonatal setting, specifically in a Level II+ unit; and (2) assess the feasibility and usefulness of the Babble app across the neonatal experience.

## 5.3 Methods

### *5.3.1 Participants*

Any parent with an infant admitted to the unit of interest, for any reason and any length of time, in the previous twelve months was invited to take part. Eight mothers participated in an interview exploring their experiences of their admission, discharge, and Babble. The mothers interviewed were aged between 22 and 35 (M = 30, SD = 4.87). Six identified as New Zealand European (Pākehā), one participant identified as Pākehā and Māori (the indigenous people of New Zealand), and another as American. Their infants were admitted for 15 days on average, and for reasons ranging from prematurity, hypoglycaemia, small for gestational age, and intrauterine growth restriction. Interviews lasted around 53 minutes on average and took place between 1 to 12 months post-discharge.

### *5.3.2 Procedure*

Recruitment occurred between March 2019 to June 2019, through various avenues including posters and letters to parents in the neonatal unit. Additionally, an invitation to participate was presented in a nationwide, online survey, which was part of an overarching study looking at parental experiences of the neonatal unit and the role of the Babble app. Ethical approval for this research was granted by the first author's university ethics committee.

Interviews were held in a location of participants' choosing; six participants opted to have the interview in their home, with one participant offering to host herself and another participant. Two of the eight interviews were completed over Skype. Interviews were audio-recorded, and the interviewer took additional field notes. Recordings were then transcribed and identifying information removed.

As per qualitative research conventions, interviews were concluded when no new information emerged, and data saturation had been achieved (Holloway & Galvin, 2016). Such criterion was met at eight participants.

### *5.3.3 Materials*

A semi-structured interview schedule was used consisting of five topics, encompassing 29 open-ended questions. Questions focused on parents' experiences of the birth (e.g., how was your pregnancy and birth experience?), the admission (e.g., what was the experience of neonatal admission like for you?), information access (e.g., how did you learn about your baby and the care they were provided?), the Babble app (e.g., how did you find the app to use?) and the discharge process (e.g., how was the discharge process for you?). General socio-demographic information was obtained at the beginning of the interview and data about the infant's health and wellbeing was obtained through questions spread throughout the interview.

### *5.3.4 Analysis*

Inductive thematic analysis, as per Braun and Clarke's (2006) guidelines, was used to carry out qualitative analysis of the interview transcripts, in order to identify, analyse and report themes and patterns within the data. Braun and Clarke (2006), suggest that thematic analysis offers an accessible, systematic and theoretically flexible approach to analysing qualitative data. Thus, it was considered an appropriate method for the present work. In addition, thematic analysis has been used widely to investigate parents' experiences in the NICU, supporting this decision (Arnold et al., 2013; Russell et al., 2014; Treherne et al., 2017; Turner et al., 2015; Whittingham et al., 2014).

An inductive approach was utilised to avoid potential assumptions and biases and to ensure the findings were grounded in participant responses. In line with the Braun and Clarke's (2006) thematic analysis method, transcripts were firstly read and then re-read, so as to allow for familiarisation with the data. Initial codes of interest were then generated based on commonality and saliency of responses across the data. These initial codes were organised in potential themes and were reviewed and refined in relation to consistency across the entire dataset. Finally, themes were named and defined with a written analysis completed to accompany each theme identified.

## 5.4 Results

Three key themes were identified pertaining to maternal experiences of the neonatal unit and their perspectives on their use of the Babble app. These themes were: 1) adjusting to neonatal motherhood; 2) relationships; and 3) the power of information.

### *5.4.1 Adjusting to Neonatal Motherhood*

Establishing a maternal identity, managing expectations, connecting with their infant and embracing the parental role were all identified as significant aspects of the neonatal experience related to motherhood. Mothers primarily found that the experience of being a parent in a neonatal unit was marred by feeling distant from their infant, experiencing negative emotions and a lack of control. In contrast, some mothers interviewed reported that they appreciated their neonatal stay for the time it afforded them to learn about their infant and the care they needed.

**5.4.1.1 Expectations: "I didn't know what to expect and it wasn't what I expected."** All mothers identified that their expectations of the birth and postnatal period impacted their neonatal experience. Around half of mothers interviewed reported that they were aware of (or expected) the need for admission, either as a result of their own research or medical professionals informing them during pregnancy. Those who were aware that the admission could be a possibility reported that this knowledge minimised the shock and allowed them to prepare for this experience, both mentally and practically (e.g., organising caregivers for other children, protecting against negative emotions), with one mother reporting “from the start we expected to go so we wouldn’t be... I guess, disappointed?”

In contrast, mothers who were unaware of the need for neonatal admission reported significant distress and uncertainty when the admission occurred. The lack of knowledge and assurance experienced by these mothers meant that they were less able to prepare and consequently seemed more negatively impacted by the process as a whole. These mothers emphasised feeling that their baby was ‘taken away’ and appeared to experience the absence of their infant to a greater extreme, possibly attributable to the lack of opportunity to mentally prepare or put coping strategies in place prior to the birth. One mother stated that she had “no indication that there was going to be any trouble whatsoever and it’s like, I’m groggy, waking up from anaesthetic, here’s your baby, oh no, we’re taking him away.” Even mothers who reported they were aware of the need for admission, considered there were aspects that they were unable to prepare for (e.g., infant being sicker or smaller than expected). These reports indicate that even when the admission is anticipated, there are often factors that are outside of a mother’s control that may impact their experience of the admission process and their understanding of their maternal role.

**5.4.1.2 Embracing Motherhood: Whose baby is it?** A majority of mothers interviewed expressed an impacted sense of ‘feeling like a parent’ and observed various effects on their sense of their own motherhood. Most mothers reported a prominent, omnipresent feeling their babies were not ‘theirs’ whilst admitted. They often battled with feeling that they should ask for permission to engage in parenting tasks (e.g., picking their baby up, holding them or caring for them), which affected their sense of motherhood and bond with their infant. One participant considered this to be an incredibly difficult part of the experience, stating;

> Like you have to ask permission to hold your child. You can't just go and pick them up, you have to be like oh is it okay? Is it okay if we pick him up now? Can we do this? Can we change him? Can we give him a bath? You know, like, everything!

Many mothers reported feeling as though they had no input in the admission or in the various care processes and decisions that followed, leaving them disempowered and uninvolved in their infant's care and decision-making processes. When this occurred, mothers were more likely to withdraw and allow nurses to take over, feeling undermined in their role as a parent and their parental choices. Many mothers recognised that the nurses were simply doing their job and acting out of necessity, but still struggled with their perceived lack of parental autonomy and inability to 'have a say' in the medical care of their infant, with one mother stating "I feel like all of our decisions got taken away."

Some mothers combatted the negative feelings associated with their diminished sense of parenthood by involving themselves fully in the care of their child, working to re-establish their position as the primary caregiver of the infant. One mother reported that her greatest coping strategy was "trying to make sure I was doing as much as I could for them, so that I didn't feel removed from [them] or felt that somebody else was looking after them." For her and others like her, this further grew her confidence in caring for her infant and her role as a mother, ultimately strengthening her relationship with her infant.

Mothers reported taking comfort and seeking reassurance from staff members during the early stages of admission, expressing that they did not want to question or challenge staff about their infant or the care provided. For some mothers, this resulted in fear of taking over the parenting role as discharge approached, as they felt they had not grown into that role during the admission period, and therefore lacked confidence in their mothering abilities. Being discharged from the unit meant a need to learn to be a 'parent' in a different context, without staff or readily accessible medical support. One participant reflected that "it was really easy to kind of just let the nurses be the experts and then all of a sudden it was like oh my god, I've got to do this myself." However, through supported involvement and communication with staff, some mothers reported that they were able to make the transition to home easily and adjusted to their role as the parent more smoothly.

**5.4.1.3 The Emotional Fallout: "If I wasn't as strong of a person as I am, it probably would have definitely broken me. Like it did break me for a long time."** Many mothers reported experiencing varying degrees of emotional distress during their infant's neonatal stay. These results indicate the diversity of the parental experience, both across different people and within one's internal experiences. Almost all mothers reported some degree of emotional distress (e.g., crying, feeling worried or nervous), and some reported significant emotional distress (e.g., postnatal depression, anxiety, trauma responses). Being away from family and support systems were seen to be particularly challenging as articulated by this participant,

> It was quite difficult in the sense... Like I struggled, 'cause I couldn't see my daughter, you know? That made everything worse. So, I quite often cried whilst in the hospital, like I struggled.

Even mothers who themselves did not experience significant emotional distress, acknowledged that aspects of the situation could have been highly distressing for themselves (under different circumstances) and expressed significant empathy for other mothers in more difficult circumstances.

Some mothers reported a concern with the lack of support available to them generally, as well as for their experience of emotional distress; one participant stated "I never actually got any help. And I feel like at the time I definitely needed it." The reported lack of support indicated that some mothers felt isolated and distressed during their infant's neonatal stay, finding needs were going unmet in relation to aspects of their experience.

By ‘putting it into perspective’ and ‘comparing their situation to other, smaller, sicker babies’, several mothers interviewed found they were able to protect themselves against significant stress or gain perspective in particularly stressful moments. This ability to ‘perspective take’ was enhanced when there was an absence of visual cues indicating that their infant was unwell and other information mothers were able to obtain in that context to support their view (e.g., talking to nurses, talking to peers, seeing their baby get bigger and healthier). Mothers also spoke about recognising that their baby was in the right place, staying relaxed, and maintaining their routine, as important ways in which they managed their mental state throughout the experience. One mother stated,

> I think I was able to put it into perspective quite well. There were a lot of other really sick and really prem babies around us, whereas he seemed happy and healthy.

Some mothers were unable to identify a specific coping strategy that protected against distress. For some, the nature of the experience was all-consuming and overwhelming, leading to a degree of avoidance of emotions in order to be able to manage. As one participant reported:

> I kind of just bottled it down and pushed through? I felt like I didn’t really have another option... what was I meant to do like sit there and cry while I’m trying to learn to feed my son kind of thing?

### *5.4.2 Relationships*

The impact of the admission on various relationships within a mother’s world was identified as a common theme throughout the experiences of the mothers interviewed. Changes across personal relationships were evidenced, and mothers often spoke of the relationship between themselves and other staff members, considering communication, support and connection as important to these interactions.

**5.4.2.1 Friends, Family and Whānau.** Just over half of the mothers interviewed reported some impact of their baby’s health status and admission on their relationships with their friends, family and whānau. Some mothers reported that their family struggled with the choices that were made within the neonatal context (e.g., some mothers limited extended family access to the infant whilst they were admitted). Others reported that family members found it difficult to interact with the baby after discharge, given the medical needs and appearance of the infant. Some mothers reported that they did not have a large amount of social support, due to wider circumstances unrelated to the neonatal admission. These mothers acknowledged that this lack of support was difficult and spoke of being saddened by this.

Perceived lack of social support reportedly increased mothers' feelings of isolation and distress compounded by disrupted expectations of the parental experience and the experience of a 'different' postpartum period. One parent reported that others found it difficult to empathise and understand what she had been through, distancing her from her usual support people. Another participant echoed this sentiment, stating:

> It was really hard to explain to someone how... what happened and how you're feeling at the time? And for them to fully understand how, and what was going on. And I didn't feel like they were listening.

Several of the mothers interviewed additionally acknowledged an impact of the neonatal admission on their parenting of their other child(ren). Specifically, siblings of an admitted infant were reported to find the time their mother spent away from them difficult; and mothers reported finding it hard to manage their other children's needs, alongside the needs of the admitted infant.

When significant others were considered, the majority interviewed reported that the experience had a positive impact on their relationship with the baby's father, their partner. These mothers reported that they turned to their partner for support and found that this was a positive influence on their experience.

**5.4.2.2 Relationships with Staff: "The staff are definitely the star of the show."** The importance of the relationship that is built between staff and parents and the communication that takes place within this relationship was evident across each interview, emphasised by the prominence of staff interactions within maternal narratives.

Most mothers interviewed reported various negative and anxiety-provoking incidents related to a perceived lack of communication during their neonatal experience. These reports of poor communication included, but were not limited to, staff communication with mothers, communication with other services and communication within the neonatal service. Perceived poor communication was seen to extend beyond content, into tone, timing and the mothers' pre-existing relationship with the deliverer of information. One mother found her experiences of poor communication from staff challenging, stating, "just being told what happened or what was going on… it would have been nice."

Mothers found the perceived lack of communication became more pronounced as they approached discharge. Some mothers reported that they considered they were not given adequate information about discharge or their infant's needs; as a result, from their perspective, further care or management that was required was neglected. These experiences left mothers feeling confused and worried about their infant's future wellbeing. Additionally, in these instances, mothers struggled to come to terms with the avoidable nature of the perceived miscommunication.

Despite these incidences of reported poor communication, the majority of mothers reported that staff (namely nurses), and the relationship they developed with these staff members, were essential supports throughout their neonatal experience. The nature of these findings reiterates the importance of staff communication and relationship building for mothers throughout their infant's admission. Examples where communication was poor were readily recounted, likely due to the negative impact on the mother's confidence, general wellbeing and overall experience. Conversely, examples of where staff were supportive and helpful were also readily remembered, due to their significant positive impact on the mother's confidence, general wellbeing and overall experience.

Overwhelmingly, mothers reported that the nurses who cared for their infants were 'lovely', 'amazing' and 'supportive'. Mothers identified specific traits such as calmness, confidence, knowledge, trust, and willingness to help, as essential to enhancing their neonatal journey. These traits helped mothers feel connected to, and thus, able to build relationships with staff, which in turn, helped them feel more supported and confident. Mothers reported taking comfort in staff expertise and found that staff being accommodating and willing to answer any question increased their sense of capability in their maternal role. Acknowledging the important informational role that staff play, one mother stated, "the nurses were the biggest information [source]. They're like the whole world in there!"

Mothers were quick to acknowledge when they felt staff had gone 'above and beyond' what was considered required of them. These incidents were reported to be the most meaningful and memorable for mothers. Mothers identified things such as: listening to parent requests; supporting feeding and caring for the infant; helping mothers with practical things (e.g., food, payments, parking); and taking the time to explain things, as aspects of nursing they would consider 'going above and beyond'. A participant recounted:

> she [a nurse] taught me how to feed them both together which was incredible because I know that's completely outside their scope as a nurse, but she made me being able to feed them together possible. Which was just incredible.

These examples of 'going above and beyond' left mothers feeling supported and encouraged in their parental role, enhancing their experience in general.

### *5.4.3 The Power of Information*

A significant portion of the interviews discussed the important role of information for mothers of neonates, specifically how information helped empower mothers and build their confidence. The Babble app was cited by those who used it as one such essential information source, and parental perspectives on the app are discussed in-depth as a subtheme here.

**5.4.3.1 Information-Seeking Behaviour.** Over half the mothers interviewed reported the importance of researching and gathering information as a way to manage their neonatal journey. These mothers acknowledged their personal informational needs and engaged in information-seeking behaviours accordingly. Some considered themselves as people who needed to know everything, and others considered themselves as needing to manage their information intake to avoid feelings of anxiety. One mother embodied the former, stating "I'm someone who likes to be prepared for everything. So, I did a lot of research online myself, like talking to other people who had had their twins early." Another spoke to the importance of managing herself with regard to the information she accessed, "I really have a tendency to overthink, so I have to be careful to get the right balance of getting the right information versus overinforming."

Information sources that were referenced were primarily staff, the Babble app, the Internet, peers, and social media sites dedicated to mothers in neonatal units. Given the lack of control and disempowerment mothers reported feeling at times, getting as much information as they were able to may be seen as a way of mothers attempting to gain control over the situation, and an understanding around the experience of parenting a neonate in general. Additionally, mothers also reported that the manner in which information was delivered was important to them in helping them feel in control and capable in their role.

Mothers acknowledged that they often engaged in information-seeking behaviour prior to admission (e.g., whilst in the maternity ward, awaiting induction) and spent significant time gathering as much information as possible. Mothers acknowledged the importance of balancing the information they gathered from less reliable sources such as the Internet, recognising there is a large amount of variability with regard to trustworthiness in the information available through such mediums. Being provided with inaccurate information was considered to be destabilising and disempowering. Comparatively, accurate, consistent and understandable information, (like that available from staff or the Babble app), was rated as highly important for mothers to feel empowered and in control during their neonatal experience.

**5.4.3.2 The Babble App.** Of the eight mothers interviewed, five actively used the Babble app during their infant's admission. Some of those interviewed who did not use Babble expressed thoughts around the app and provided an explanation as to why they did not use it. Their perspectives have therefore been included when considering this theme. Use of the Babble app was seen by mothers to empower and support their experience, by providing them with accessible, trusted information.

Mothers who used the app reported it to be a useful supplementary tool alongside the information provided by nurses and other staff members involved in maternal care. They identified that it met several of their needs, including the ability to research and educate themselves in their own time, share in peer experiences, get visual guidance on different aspects of the care, and provide a starting point for gathering more information. Mothers reported appreciating that the information came from a trusted source and allowed for consolidation of information they had received from nurses, doctors and other staff. Additionally, the provision of other families' stories outlined in the app was seen as important in preparing them for what their own journey could look like. The visualisation elements provided in the app further helped parents become more familiar with and provided context to, some of the more challenging visual stimuli present in the unit. One mother stated, “it was good to see what a baby looks like with a CPAP on and stuff, ‘cause I can’t really visualise that.”

Mothers also spoke about the delivery and manageability of the information provided, finding that what was included in the Babble app was relevant and easily understood. One participant said:

> The information that’s in there [the Babble app], was really relevant and not too in-depth that you got lost, and you couldn’t understand it because I guess, that’s where you should be asking the nurse or the doctor.

By providing a resource that mothers could access in their own time and on an as-needed basis, the information provided in the app reportedly helped mothers feel more confident and comfortable in the neonatal environment. The ability to review and reconfirm the information provided by staff was highly praised by parents, with many mothers using the app proactively, as is indicated by one mother stating: “I had questions for the nurse when she came in because I’d read about it you know [on the app], and I could go more into detail with it.”

Additionally, some mothers reported that their partners used the Babble app also. These mothers considered it was beneficial for their partners, as they were not always able to be involved or present in the unit and care of their infant to the same extent. The app also provided support to extended family members who are typically disempowered throughout the neonatal experience. When empowered with information, these family members were seen as more capable of supporting the immediate family, leading to a reduction in these mothers feeling isolated and alone.

Mothers who did not use the Babble app referred to it as ‘not being what was wanted or needed’. These mothers reported thinking that it was not targeted at them (e.g., for sicker babies only), or that they did not have the time to go through the app as they were only admitted for a short period of time.

## 5.5 Discussion

The present work identified three main themes encompassing the maternal experience of a Level II+ neonatal unit in New Zealand and their perspectives of the Babble app. As identified, mothers spoke to the impact of the admission on their sense of motherhood, altering their expectations and views of their role and relationship with their infant. Commonly, mothers also identified the importance of staff support, specifically the essential nature of communication and connection within staff-parent relationships. Mothers also expressed the importance of information in empowering them and enhancing their security in their parental role. Specifically, the Babble app was cited as an important supplementary tool, for use in conjunction with staff support.

Although the present research uniquely explored the experiences of Level II+ units in New Zealand, many of the findings of past research across varying neonatal levels were echoed. Mothers in the study reported some emotional distress associated with the neonatal experience, similar to that of past work performed internationally (Al Maghaireh et al., 2016; Obeidat et al., 2009). Such similarities are perhaps indicative of the universality of aspects of the neonatal journey, suggesting that perhaps the level of unit has little impact on the overall experience itself.

Previous work has repeatedly identified the difficulties mothers have with the adoption of the maternal role following neonatal admission and the impacted sense of ‘being a parent’ that many parents report (Al Maghaireh et al., 2016; Holditch-Davis & Miles, 2000; Lupton & Fenwick, 2001; Miles et al., 1992; Russell et al., 2014; Seideman et al., 1997). Mothers in the present work expressed similar sentiments but identified that engaging in parenting tasks and asserting themselves as the parent were helpful strategies in supporting their maternal identity.

Such proactive involvement echoes past research determining that performing parental duties were seen to help parents better assimilate to the parental role and connect with their infant (Heydarpour et al., 2017; Lupton & Fenwick, 2001; Russell et al., 2014; Wigert et al., 2006).

In alignment with previous work, mothers in the present study emphasised the relationships developed with staff members as essential to their experience (Russell et al., 2014). One parent identified that staff are ‘the whole world in there’ and this sentiment was evident throughout many of the responses given. The importance of staff communication was reiterated, with mothers expressing the value of clear, warm, considered and accurate information being provided to them by staff. Communication was seen to be highly influential on parental perception of the general experience of admission, with good communication being seen as significantly improving the experience, and bad communication significantly worsening it. Beyond communication, mothers identified that staff investing time into building relationships with them and ‘going above and beyond’ allowed mothers to learn more than they would have otherwise, and as a result, their confidence as a parent developed, and their general wellbeing improved. Considering the consistency with which parents report the importance of communication and staff relationships, the integral nature of staff to the experience of being admitted to the unit is clear and important for units to reflect on, to ensure the best care is provided.

Mothers placed significant emphasis on staff relationships and interactions, indicating that the Babble app did not replace human connection, with staff being the primary support sought. Although parents reported positive experiences with the Babble app, as a one-dimensional, electronic resource, it is incapable of replacing these rich and multi-layered connections. As not all mothers interviewed here used the Babble app, the findings around its usefulness may not be truly reflective of its potential. As only just over half the sample utilised the app, perhaps future research looking at a wider population of app users may be more appropriate to determine its efficacy.

Our findings thus emphasise the importance of individualised care, and the importance of recognising each parents' informational needs; some parents will not find the app helpful or necessary and will prefer staff contact exclusively. Parents within the unit need to be considered as individuals with unique preferences; some parents may want all the information they can access, and others may find that overwhelming. Several studies have explored such a concept, supporting the nuances of individual informational needs and coping styles evidenced here (Lalor et al., 2008; Miller et al., 1988; Miller, 1980). Striking the balance between the provision of necessary support, and overwhelming parents with excessive information was identified as essential for improving parental experiences. Our findings suggest that an app, like Babble, may be capable of meeting parental needs across this continuum, given it is up to parents how much they use it.

Consistent with previous research looking at the hospitalisation of children with chronic illnesses, the mothers in our study spoke about the difficulties that extended family or grandparents had with managing the infant's hospitalisation (Nabors et al., 2018). Mothers reported that some of their family members struggled with their choices about the care of the infant or found it difficult to interact with the 'sick' infant, due to medical needs or the appearance of the infant.

Although such exploration was beyond the scope of the present work, our research uniquely found mothers considered the admission had impacted their relationship with their other children. These mothers found it difficult to manage their other children's needs whilst the infant was admitted, and as to be expected, these children found spending time away from their mothers and newborn sibling difficult. Some research has been performed around the impact of the infant's admission on the siblings of the infant (Camhi, 2005; Latva et al., 2007), yet further research as to the experiences of wider networks surrounding families experiencing neonatal admission, including the siblings of the admitted infant, is needed. A better understanding of familial perspectives, and how to better support these family members, is essential to ensure they are best placed to then support the parents of the hospitalised infant.

It became evident throughout the interviews that there were some common aspects to the experience of having an infant admitted to a neonatal unit across the mothers interviewed. However, these experiences were also overwhelmingly diverse and affected by many different factors, inclusive of individual vulnerabilities, resource access and different support. All mothers interviewed asserted that their own experiences and other life factors (e.g., family conflict, relationship breakdowns, relationship difficulties, and financial stressors), independent of the neonatal experience, were influential on their neonatal journey. Future research looking at the role of psychosocial assessments for parents designed to best understand their unique situation and needs may be warranted in light of these findings. Given the varying degrees of emotional distress reported, individual vulnerabilities and wider circumstances should be taken into consideration for any future targeted support.

The importance of staff building relationships with parents, and communicating appropriately within that relationship, were key takeaway points from the interviews. Balancing expertise and empowering parents are essential for staff to ensure that infants leave the unit accompanied by confident and capable parents. For parents, relying on staff expertise, and balancing this with developing their own skills, requires a gradual release of responsibility by staff, and an increase in responsibility for parents. It was clear from the interviews that, from the mothers' perspectives, all parties wanted the best for the infant; therefore, this shift of power was essential (yet difficult at times), as staff and parents navigated and negotiated the needs of the admitted infant and their roles within the neonatal context. These findings highlight that staff involvement and positive interactions cannot be emphasised enough as essential to supporting parents. Better understanding the maternal views on these relationships may be useful to help staff better understand the patient-family perspective and adapt their support as necessary.

Mothers described engaging in various approach (leaning into the experience and taking on caring tasks) and avoidance (sitting back and letting staff take over) coping tactics. Some mothers identified their own tendency to ‘push through’, potentially predisposing them to experience any negative emotions later on, once discharged and away from support. Staff noticing those who withdraw or who are ‘pushing through’ may be an important step to providing necessary support to enhance parental wellbeing and the parental relationship with the admitted infant. The accounts outlined in this study may be useful for staff to educate themselves with, working to identify signs that parents under their care may be taking an avoidance approach. Staff should take note of the importance of parent-staff relationships and consider the role that this relationship plays in building confidence and supporting parents more generally. However, given the pressures on staff and the importance of staff within the neonatal experience, learning more about staff perspectives and how to support the wellbeing of staff may be an important direction for future neonatal research.

Mothers spoke to the provision of, and access to, information as key in empowering them in their parental role. In previous studies, mothers have identified the importance of information in their experiences (Ballantyne et al., 2017; Cleveland, 2008; Heermann et al., 2005; Vazquez & Cong, 2014). However, this notion was distinctly framed in the present work. Mothers considered that information provided helped empower them in their maternal role and was pivotal in their development of confidence in their abilities. Mothers in previous studies, as well as the present study, have repeatedly reinforced their need and desire for clear, coherent and consistent information (Aagaard & Hall, 2008; Cleveland, 2008). Given the emphasis on information and the evidenced need for informational support, healthcare professionals and neonatal units should consider how best to ensure that parents are provided with appropriate and accurate information throughout their neonatal stay.

Babble was uniquely profiled in the present study, and as such, the present work opens the door for future research around such initiatives targeted to support parents in the neonatal unit. Parents who used the app viewed it positively and considered it to be a useful addition to the information and support provided by staff. Mothers found the ability to access information in their own time (as needed) empowering; meaning they were more prepared and readily able to advocate for themselves and their child. Most commonly, the app was cited as a resource allowing parents to return to, and consolidate information provided by staff. Rather than replacing the relationship between staff and parents, the app was seen to support information provided within the context of that key relationship. Mothers recommended its use as an adjunct to traditional care formats (as it is designed for) and thus, promoting and introducing it as such is important. These findings suggest that introducing the app as early as possible is helpful to parents, allowing them time to prepare and explore information related to the possible admission at their own pace, with several mothers reporting that use prior to the birth was helpful.

### *5.5.1 Limitations*

Interviews with parents were conducted between one week to one-year post-discharge from the neonatal unit. As there is significant variation in time passed since admission, it is possible that the experiences reported by mothers who were admitted longer ago were less reliably recounted. However, other research has utilised similar timeframes and found that as the neonatal experience is particularly monumental, details are remembered well (Russell et al., 2014; Wereszczak et al., 1997).

The use of the qualitative approach was deemed appropriate to gather a rich data set, allowing parents to express themselves in-depth and gathering nuanced descriptions of the experience. Mothers who participated in the research were highly motivated and eager to be interviewed. Although attempts were made to include hard-to-reach participants (e.g., rural, disengaged or disenfranchised parents), the majority of those interviewed were well-educated mothers. Additionally, whilst a focus on the experiences had by parents in a small, regional neonatal unit, presents as a strength of the study, there is potentially a lack of generalisability to bigger cities or bigger units within New Zealand. The themes found here are tied to the participants included and the time period collected, providing specific accounts as to the experiences of mothers in a Level II+ unit in New Zealand. Future research would benefit from exploring other neonatal perspectives in New Zealand (e.g., Level III and Level II units, bigger cities, exclusively rural populations).

Although fathers were invited to participate, exclusively mothers opted to take part in the present research. Future research is necessary to explore the experiences of fathers in New Zealand. Mothers interviewed reported that fathers of the infant felt excluded from their care and perceived that their needs went unmet, with the primary focus of staff being on the maternal experience. Fathers were also theorised (by the mothers in this study) to benefit from the Babble app, with two mothers reporting that their partners used and appreciated the Babble app, given their feelings of exclusion from traditional care formats.

Although the research was completed prior to the COVID-19 pandemic, it is likely that in more recent times, resources such as the Babble app are even more pertinent for parents. This may be particularly the case for fathers, where access to infants in neonatal units has been significantly limited to prevent infection (Flahive, 2020). Exploring paternal perspectives of the app may be worthwhile to further understand the role of Babble for wider family members as well as the ways in which it may be able to bridge the gap between parent and unit, especially in unique circumstances, such as those presented by the COVID-19 pandemic.

## 5.6 Conclusion

In conclusion, our findings largely suggest that mothers find managing their expectations and developing a sense of their own motherhood particularly challenging in the context of the neonatal unit. Strong connections with family and staff, and the importance of clear communication were identified as essential in helping mothers manage throughout the admission. Mothers emphasised the importance of information and utilised a variety of information-seeking styles, aligning with their individual needs. The Babble app was seen by users as an essential adjunct to personally delivered information in the context of supportive relationships, and as a way to enhance relationships with other family members and friends, through the sharing of information. Such findings suggest the need for healthcare professionals to recognise the important role of their relationship with parents, consider the individual and unique needs and experiences of parents, and develop targeted support informed by these perspectives to improve outcomes for this population.

# 6. Discussion

The following section collates the findings of Study One and Study Two to present a conclusive discussion, taking into consideration the findings, limitations and implications of the thesis as a whole. Both sets of findings will be summarised, divided into the primary areas of interest: distress; parental self-efficacy; information; and Babble, with links to theory as appropriate. Subsequently, the significance and contribution of Study One and Study Two findings (when considered together) are discussed as well as possible practical implications of these results. In closing, limitations of the overarching study as a whole, as well as areas for future research are discussed. By bringing together the two works, it is hoped that a more comprehensive viewpoint of the experiences of parents with an infant admitted to a neonatal unit and the role of the Babble app is presented. Thus, more general conclusions about these circumstances and the role informational interventions may play as support can be drawn.

## 6.1 Summary of Findings and Comparison to Past Literature

Taken together, the two studies present a holistic viewpoint on New Zealand parents' experiences of admittance to the neonatal unit and the role of the Babble app. The findings presented in Study One indicated that generally, parents feel moderately informed and confident in their abilities, during admission, alongside experiencing a moderate degree of distress. The second study further concluded that mothers reported that having a child admitted to neonates had a significant impact on their sense of motherhood; specifically, that they found it difficult to establish a sense of motherhood and experienced their own internal challenges related to seeing or connecting with their infant in the unit. Furthermore, mothers reported substantial effects on their relationships, be that feeling more distant from their friends and family, feeling greatly supported by staff or feeling let down by staff. Ultimately, mothers highlighted the importance of feeling empowered in their role, citing things such as the Babble app, staff support, familiarity and information as pivotal in this process.

The results of Study One suggest that parents who feel more informed tend to feel less distressed and that this relationship is mediated by a positive effect of feeling informed on self-efficacy. These findings suggest that it is plausible an intervention targeted to developing self-efficacy, and helping parents feel informed, may reduce parental distress levels. However, there was little evidence that the specific intervention tested in this study had effects on how informed parents felt, their self-efficacy, and distress. Study Two evidenced the importance of informational support, such as that provided by the Babble app, in helping mothers feel confident and capable during their neonatal stay. Mothers expressed that they appreciated the introduction to Babble, and the ability to adapt its use to their individual needs. However, use varied dependent on how mothers were introduced to the app and their perception of its role within the unit itself. When considering both studies as a whole, the importance of staff, the importance of information and the variability of the parental experience were all emphasised.

### *6.1.1 Distress*

Previous research performed has identified that parents experience significant distress when their infant is admitted to a neonatal unit (Affleck et al., 1991; Baía et al., 2016; Barr, 2015; Carter et al., 2005; Davis et al., 2003; Dudek-Shriber, 2004; Holditch-Davis et al., 2015; Holditch-Davis & Miles, 2000; Lupton & Fenwick, 2001; Miles et al., 1992; Nyström & Axelsson, 2002; Seideman et al., 1997; Shields-Poë & Pinelli, 1997; Singer et al., 1999). Study One's findings determined that, surprisingly, New Zealand parents did not report the levels of significant distress that have been previously identified across various international studies, presenting an interesting contribution to the literature. When considering PSS:NICU scores, parents reported on average having experienced moderate levels of distress overall and across all subscales, with the exception of the Infant-Related Factors subscale where parents were seen to typically report 'little to no distress'. Significant variability was evidenced across each of these scales however, indicating that these experiences of distress were diverse in nature (e.g., a large proportion of parents were very distressed, and a similar number reported no distress). In the interviews, parents expressed some emotional distress, but generally considered that the admission was a positive experience. Similarly, Carter and colleagues' (2005) New Zealand-based research focusing on the parental response to neonatal admission in the Christchurch NICU found that although New Zealand parents whose infants were admitted to a neonatal unit experienced greater anxiety compared to controls, the anxiety experienced did not reach clinically significant levels, as measured by the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983).

Several possible theories may explain, in part, why New Zealand parents did not demonstrate the degrees of distress reported for parents located elsewhere in the world. It may be that there are reduced financial pressures given healthcare is governmentally funded, as suggested in the introductory chapters of this thesis. Family support may be more accessible as families are more easily able to travel to each other, should they need to, compared to larger countries like the United States of America or Australia. Perhaps, DHBs within New Zealand are more aware of the value of cultural, social and whānau support, and thus, these types of support are more catered to, and encouraged than in other countries where a more individualised, medical approach to childbirth is taken. It may be that New Zealanders have generally better healthcare and that neonatal care provision is more parent-centred than some countries included in other studies. ID Medical Group (2019) recently performed an analysis of healthcare in OECD countries and found that New Zealand placed 19th out of 100 countries for best healthcare provision, when considering GDP spent on healthcare, number of hospital beds, doctors, nurses and average life expectancy. Alternatively, it may be that given the breadth of time between responses and admission, the participants memories of distress had been impacted by the effects of time, possibly leading to a tendency towards minimisation. Finally, it is possible that differences in unit policies, practices and interpretation of terms across countries may have impacted the psychometric properties of the PSS:NICU scale, leading to less reliable and comparable results (Franck et al., 2005).

Distress is a subjective concept. As aforementioned, parents spoke at length in interviews about finding aspects of the admission difficult (e.g., being away from their infant), but few expressed acute mental distress (e.g., the onset of mental health disorders or diagnoses) during the admission experience. Instead, in the interviews, they chose to focus primarily on staff relationships and their impacted sense of parenthood. Interestingly, those interviewed were primarily well-educated, which may indicate a greater availability of resources and support systems, acting in a protective manner for parents in this situation. Similarly, those surveyed fit into a similarly highly educated category (e.g., majority had obtained tertiary degrees). As indicated previously, these parents reported moderate levels of distress, suggestive of a lack of acute distress during the experience across this wider population also. Again, such findings may indicate that for those who are well-educated, accessing resources and support is easier and more effective, comparative to other groups.

**6.1.1.1 Influential Factors on Reported Distress.** Additional analyses in Study One indicated that being a younger parent was seen to predict parental report of greater distress. These findings sit in line with previous international literature suggesting that younger mothers evidence greater distress when compared to older mothers (Dudek-Shriber, 2004; Meyer et al., 1995). It is theorised that younger parents (e.g., <21 years) are likely to have less experience of parenthood, greater medical complications and may lack resources that protect older parents from experiencing such significant distress (Dudek-Shriber, 2004). Given that younger mothers are more likely to experience neonatal admission than other groups (with the exception of mothers who are of advanced maternal age, e.g., > 35 years), greater support from staff or awareness of the impacts of being a younger parent admitted, may be helpful in protecting young parents against some of these increased experiences of distress (de Jongh et al., 2012; Kang et al., 2015).

Being admitted to a higher level of unit (e.g., Level III) was seen to predict greater distress. As infants who are admitted to higher level of units (e.g., NICUs) experience greater health difficulties, are born earlier and undergo more complex treatments compared with infants admitted to lower level of units, it is understandable that parents of these infants would experience greater distress compared to parents in lower levels of care (Donoghue, 2004). Furthermore, higher level of neonatal units are typically more clinical in design and facilities. Previous literature has suggested that the complexity of the NICU environment, inclusive of strange, noisy equipment, lack of privacy and other unknown elements were key sources of stress to parents, alongside the crisis-focused atmosphere (Báia, et al., 2016). These factors are all enhanced in higher level units, thus, perhaps explaining in part the greater distress reported.

A longer stay in hospital was also seen to be associated with greater distress for the sample surveyed. While more time spent in the environment may lead to greater habituation (which should, in turn, reduce distress; Miles et al., 2002), longer admittance is also seen to be correlated with the severity of infant health condition, possibly explaining why parents in Study One indicated greater distress when experiencing a greater length of stay (Dudek-Shriber, 2004).

Variation in stress across the length of admission was further explored in Study Two. At the early stages of admission, mothers reported feeling more comfortable sitting back and letting the nurses perform the role of primary caregiver. As a result, some mothers reported finding the move towards discharge anxiety-provoking, expressing fear at their ability to manage on their own. Others reported that with help from staff and involving themselves in care, they found they were able to make the transition home smoothly and considered that they comfortably adjusted to the parental role, whilst withstanding inevitable challenges associated with parenting any newborn. These findings highlighted the importance of the differential stress points mothers experience throughout the admission, evidenced at length in previous works (Heermann et al., 2005; Wigert et al., 2006).

Previous literature exploring distress longitudinally suggests that declines in stress (or consistently reported levels of distress) are more common the longer parents are admitted to a neonatal unit (Lau & Morse, 2003; Schappin et al., 2013; Singer et al., 2010). Comparatively, our findings found that the longer the admittance, the more distress experienced. As such, it is indicated that continuing to provide support to parents who are admitted for long periods is necessary, without assuming that parents will become habituated to the unit environment. Additionally, within Study Two, mothers reported that stress increased as discharge approached and many experienced fears at losing the support present within neonatal units upon discharge. Thus, the importance of prioritising discharge planning, addressing the needs of parents who are admitted for longer, and ensuring that support is available for parents upon discharge, is evidenced here.

### *6.1.2 Parental Self-Efficacy*

Parental self-efficacy within Study One was not seen to be predicted by any of the variables explored, (e.g., age, gender, parental role, level of unit or Babble app use), aside from feeling informed. Despite prior literature indicating various influential factors on parental self-efficacy such as age, gender, parental role, and experience within the unit, our findings did not echo such results, indicating that contributing factors to enhanced parental self-efficacy may be more complex in nature (Salonen et al., 2009).

In Study Two, parents frequently and spontaneously spoke to the idea of empowerment, identifying actions they took to feel capable and confident in their role as a parent (also known as, their sense of parental self-efficacy). Strong parental self-efficacy has been evidenced as essential in helping parents adapt to parenting, improve their emotional wellbeing, and enhance attachments to the infant. Such is indicative of the importance of working to better understand how to enhance this for parents (Bandura, 1997; Coleman & Karraker, 2000; Leahy-Warren & McCarthy, 2011).

Participants in Study Two spoke of the development of confidence in their abilities as attributable to their engagement in parenting tasks, their relationships with staff, their support systems, and various external factors (e.g., finances and past experiences). It became clear that mothers who had greater access to support, or had additional supportive factors (such as peer support or past experience), appeared to dwell less on the difficulties of the neonatal experience, built stronger relationships with staff, took on more parenting tasks, and reported greater confidence in their abilities. It is possible that these mothers were more able to build positive relationships with staff, due to the presence of aforementioned external supportive resources, thus, reducing reliance on staff and demands made. In contrast, mothers who did not have access to such support spoke at length at the difficulties associated with this and the impact this had on their sense of motherhood and confidence in their abilities. These variations in support, coping and confidence indicate the complexities inherent in the development of self-efficacy and the importance of understanding individualised needs and abilities, as well as the importance of building strong staff relationships for those with fewer social supports. Further research around the mechanisms and interventions that contribute to the development of self-efficacy in a neonatal parent population, is warranted.

**6.1.2.1 Bandura's (1977) Theory of Self-Efficacy.** Study One results suggested that greater reported parental self-efficacy was significantly associated with how informed parents felt, in alignment with Bandura's (1977) self-efficacy theory as it pertains to a neonatal parent population. Bandura suggests that in order to feel efficacious, one must have a requisite base of knowledge from which one can obtain further information (Bandura, 1977). Such a base of knowledge can be developed through previous experience or information provision (Bandura, 1977). Mothers in Study Two spoke of the information provided by staff (and ability to engage in parenting tasks) as essential in empowering them and enhancing their self-efficacy. Although the Babble app was hypothesised to provide parents with information (thus, helping to develop the requisite knowledge base for self-efficacy), Study One's findings suggest that there was no significant effect of the Babble app on self-efficacy across the sample. Furthermore, the Babble app did not demonstrate a significant effect on how informed parents felt across the sample either. However, the more informed parents considered themselves to be the greater their reported self-efficacy was, suggesting that parents feeling more informed did indeed enhance their self-efficacy, supporting Bandura's (1977) theory. Taken together, our findings reiterate the importance of information and the role that this plays in building parental self-efficacy. It is possible that merely feeling informed is enough to enhance one's sense of self-efficacy, indicating that the parents' perceptions of their own knowledge, be that accurate or inaccurate, may take prominence over the acquisition of knowledge or information provided.

### *6.1.3 Information*

Information-seeking behaviours, information access and information provision were key interests of the thesis. Both Study One and Two explored the role of information in detail, with the survey specifically looking at information behaviour and access, and interviews focusing more on the subjective experiences of information provision and informational needs as reported by participants. Neither study suggested that parents felt particularly informed about their infant or neonatal care during their neonatal stay, but the importance of information in supporting parents and helping them feel empowered was clearly evidenced throughout the interviews. Exploratory analyses in Study One found parents primarily accessed information at all times throughout the day during their neonatal admission, with only a slighter greater number accessing information from 6am to 12pm.

Considering both studies, parents reported accessing information through staff and the Internet most commonly to learn more about their infant and the care provided to them. Interestingly, other research exploring neonatal parent information habits have identified the dominance of the Internet as a resource (De Rouck & Leys, 2009; Gabbert et al., 2013; Orr et al., 2017; Spargo & de Vries, 2018; Williams et al., 2020). Exploratory analyses for Study One determined that the Internet was utilised as an information source secondary to staff, by a large margin. Dhillon et al. (2003) found that during the initial admission stage, parents were less likely to rely on the Internet, demonstrating a preference for staff support at this time. As parents who were recently admitted were included in the survey, there is a possibility that Internet usage was eclipsed by reliance on staff during the early days of admission, influencing the responses gathered. Across the interviews, mothers referred to using the staff primarily as information sources, identifying the Babble app as their next most common, followed by the Internet. However, this is likely a reflection of the specific population who took part in the interviews. All mothers interviewed were admitted to a unit where Babble is offered to parents and use of the app is encouraged, as part of the care provided. Mothers who used the Babble app in the interviews considered it to be an essential secondary source for use in accompaniment with staff, rather than a primary source of information to be used in isolation.

Having information available through an app allowed for the mothers interviewed to access information whenever it suited them. Several mothers interviewed expressed concern with utilising ‘Dr Google’ given the wide variety of information present, and ultimately, lack of reassurance as to accuracy and reliability of that information. They considered one of the greatest benefits of the Babble app was the accurate and consistent information that corresponded exactly with the information provided by staff.

Informational interventions have been prioritised in the literature and evidenced as highly effective in reducing parental distress and increasing their general self-efficacy (Bracht et al., 2013; Dalton et al., 2018; Danbjørg et al., 2015; Fernández Medina et al., 2018; Gangi et al., 2013; Garfield et al., 2016; Melnyk et al., 2006; Razurel et al., 2017). Although the Babble app was not seen to impact how informed, distressed or self-efficacious parents felt in the survey, mothers in the interviews reported that the app was useful in validating the information provided by staff and they appreciated the ability to access information in their own time, based on their needs.

### *6.1.4 Babble*

The research presented here was the first of its kind to explore the role of an informational app for parents experiencing neonatal admission. Past research has been conducted however, on apps available to parents of infants who do not require neonatal admission, and for parents during discharge from a neonatal unit. Specifically, Danbjørg et al. (2015) looked at information provision through an app for mothers during the early postnatal period and their views on such a service. Mothers of this group identified that they felt more in control, due to the greater support and reassurance they accessed through the app, echoing the sentiments of the mothers interviewed in the second component of this project. Previous work by Garfield et al. (2016) looked at the role of an app focusing on supporting parents of very low birthweight infants through discharge and considered the impact of the app on parental self-efficacy, preparedness for discharge and length-of-stay. Regular use of the app was seen to improve parental self-efficacy, when time spent on the app was taken into consideration. Given these results, it was expected that the Babble app would have a similar effect; however, in Study One, no such findings were identified. In the qualitative study, parents spoke to the empowerment they experienced as a result of the app, indicating that the app provided them with information from which they were able to make informed decisions, ask questions to staff, and become a more engaged participant in their infants' care. All such descriptions indicate that it is likely in these cases, the app supported the development parental self-efficacy, alongside other information and support provided. Had frequency and duration of use been taken into consideration as a quantitative variable, similar results to Garfield and colleagues (2016) may have been identified.

Additionally, mothers interviewed suggested that the way in which the app was introduced and promoted, heavily influenced their usage. For example, mothers who spoke of downloading the app but not being inducted into its use, reported they did not utilise the app or spoke of misinformation as to its role. These findings suggest that the availability of resources without integration and supported use is not enough. Rather more positive effects are seen when parents are taken through resources by staff and these resources are integrated into care provision. The way Babble was introduced and integrated into the care provision had significant impacts on regularity of use, as indicated in Study Two. As the app is only integrated into practice in two of the 23 units (despite having users across the country), it is possible its impact was not accurately assessed by this thesis. In light of these reflections, future research should consider the role of frequency of app usage, as well as the way in which it is integrated and introduced for use by units, in any further studies conducted on the role of neonatal apps.

Although Study One did not indicate any evidence of Babble supporting parents in the measured outcome variables, the app user sample was very small comparative to the sample of non-app users, limiting statistical power. Further, as the sample reported moderate scores across each of the outcome variables, indicating they already felt moderately informed, distressed and self-efficacious, it is possible that the app did not have a visible impact on their experiences. Perhaps, was the sample more distressed, less confident and requiring greater informational support, the app may have played a larger role in improving those outcomes and meeting parental needs. The qualitative research presented in Study Two delved deeper in parents' perspectives of the app, with five out of the eight interviewed reporting having used the app regularly. Primarily, interviewed mothers who used the Babble app found it to be supportive and described it as a useful supplementary tool, used to refresh and expand on the information they were provided by staff. The idea of the app being a visual, interactive and trusted source were all emphasised, alongside the accessibility for other family/whānau members. These findings suggest that the effects of the Babble app are likely more generalised and widespread, and not accurately addressed by the measures utilised in Study One.

## 6.2 Clinical Implications and Recommendations

The important role staff play in ensuring a functioning and supportive neonatal ecosystem cannot be understated. Across both Study One and Study Two, staff were cited as primary information sources, and heavily influential over parents' perception of the entire experience. In light of these findings, it is considered that staff should reflect on their interactions with parents and acknowledge that (as primary information sources) they should strive to ensure information provided is consistent, clear, delivered appropriately and in a supportive manner. Such clear and consistent communication has been indicated as beneficial in reducing parental distress and building maternal confidence in the present work. The Babble app presents an opportunity to maximise communication efforts. The inclusion of regular updates (which are typically provided through phone calls) as notifications on the app, may be a way to allow for timely, clear and consistent information when parents are off-site.

The structure of support for parents and information provided within the neonatal context may require reconsideration within a New Zealand setting. The results presented here indicate that informational support for parents should be seen as a core component of neonatal care provision, alongside the medical care provided to the infants. Within the interviews, mothers often spoke of emotional distress and a neglected emotional wellbeing during this time. This was particularly evident in cases where mothers experienced a lack of social support, as well as other personal difficulties (e.g., finances, health conditions, difficult birth). Study One findings reiterate the discrepancies experienced when support is unavailable or not easily accessible, as seen in the different influential factors that were seen to impact experiences of distress. Additionally, although distress was seen to fall within a moderate range across the sample, the range varied from those extremely distressed to those who were not distressed at all. As seen here, the experiences of neonatal admission are varied, with diversely impactful personal circumstances and inequitable access to external supports. As such, there is a need for staff to ensure there is sufficient provision of interventions and support through the neonatal unit itself. Taking time to understand people's circumstances, levels of support and additional stressors would help to tailor levels of support for parents as required. The therapeutic relationships with staff may serve to help gather information about parents needs and how best to meet them. Reflecting on ways to address the needs of those who are not able to access external support services and interventions may be worthwhile, to moderate some of the impacts of neonatal admission on the family as a whole.

As our study has shown, helping people to feel more informed is likely to support the reduction of distress of parents of admitted infants. Given the prevalence and variability of distress reported across international literature, including the present work, the value in reducing this distress is clear (Affleck et al., 1991; Baía et al., 2016; Barr, 2015; Carter et al., 2005; Davis et al., 2003; Dudek-Shriber, 2004; Holditch-Davis et al., 2015; Holditch-Davis & Miles, 2000; Lupton & Fenwick, 2001; Miles et al., 1992; Nyström & Axelsson, 2002; Seideman et al., 1997; Shields-Poë & Pinelli, 1997; Singer et al., 1999). Our study indicates that enhancing parents' sense of feeling informed (through information provision), reduces distress, in part by way of enhancing self-efficacy. Such findings support the furtherment of informational interventions as integral resources within a neonatal context and the need for greater informational support.

Despite Study One's findings of no effect of the Babble app, it is of relevance to note that it was not evidenced to cause harm. Furthermore, Study Two's findings suggested the app was supportive and helpful to mothers (and wider whānau) who utilised it. Given the previous evidence suggesting the importance of information and the identification of information as a primary need for parents in the neonatal context (Cleveland, 2008), it is worthwhile considering whether merely having more options to access information is 'good enough'. As Babble is a low-cost and easily implementable intervention, which is not evidenced to do any harm, the fact it supports some people and is able to be made widely available is likely enough justification for promotion of its use. Over 90% of survey participants identified that had they been aware of the Babble app during their admission period, it would have been helpful and supportive during their experience, indicative of the demand and desire for greater informational support through mHealth means. Future developments to the app which may improve its effectiveness could include the integration of explanatory sections pertaining to specific parental cares (e.g., videoed demonstrations), to enhance the knowledge base from which a greater sense of parental self-efficacy can be developed. Further research dedicated to the enhancement of available informational resources, and the potential development of new interventions, which are easily understood, accessible and well-integrated into healthcare provision, is worthwhile.

## 6.3 Limitations and Directions for Future Research

Limitations pertaining to each study have been discussed in depth in the discussions of each article, and thus, general limitations of the overarching study design will be discussed here. Specifically, several methodological limitations present themselves, unique to the manner in which the research was completed but affecting both studies. Firstly, the majority of data included in the study was collected retrospectively. In both the survey and interviews, parents were often required to reflect back on their experiences in the unit. Originally the study was open to parents with an infant admitted in the last six months, but in an effort to include more Babble users, this window was extended to twelve months. Although this change increased the

Babble users and overall sample, it likely came at the cost of accurate recall as those who were admitted a year prior were required to remember specifics of an event that occurred some time ago. Given that this time coincided with their child's first year of life and thus, included many important moments and milestones, it is possible that reflecting back was difficult for participants. As there was wide variation in time since experiences reported in both components in studies, it may be worthwhile to explore a smaller window of time (e.g., admitted within the last three months) in future research.

The present work aimed to utilise a semantic and inductive thematic analysis for the second article, providing results that were data driven by participants. Throughout the analysis process (and interviews to an extent), the researcher experienced difficulties in maintaining this inductive approach, likely due to the order in which the research was completed. The quantitative component was analysed first due to constraints within the clinical programme itself. Therefore, the researcher was made aware of the findings (e.g., lack of a significant effect on Babble on the outcome variables) prior to entering analysis of the interviews. It is possible that an awareness of the findings affected the lens through which the researcher considered the data, created codes and collated themes. Attempts were made to rectify and minimise the effects of this possible bias, by way of sharing data with supervisors and their input was requested to ensure themes were representative of the findings. Themes were revised and adjusted depending on each interpretation of data, and finalised when it was agreed that they were accurate. Themes derived were seen as supported by the raw data by all three members of the research team. In addition, significant time was taken between completing each analysis and analyses were completed at separate points in time, with minimal crossover.

It would be remiss to not reflect on the implicit influence of the researcher on all stages of the research itself. The study was advertised as part of a Doctor of Clinical Psychology and was conducted by a clinical psychology student, which may have meant, those who participated were more interested in discussing possible mental health difficulties they experienced. Such a stance may have been particularly pronounced in the interviews, given their similarity to clinical interviews. It is possible that mothers who had a history of mental health difficulties or struggled particularly with the neonatal experience, may have focused on these components of the experience more so than if they were interviewed by a researcher with a different background. It is also important to note that the researcher is young, female and without children. Many of the interview participants correctly assumed that the researcher did not have children. In response, they may have focused on explaining their experience of motherhood, possibly assuming the researcher could not relate to their experiences. As research was advertised through the Palmerston North Hospital, it is possible that parents held back detailing some of their more negative experiences, due to a perceived conflict of interest. Although the researcher was quick to explain that the research was independent of the hospital, it is possible that participants were cautious about blaming or negatively reflecting on their experience of the hospital for fear of repercussions.

Across the study as a whole, there was a lack of representation of Babble users. Although all efforts were made to recruit Babble users specifically, it appears that the prevalence of the app is limited. Recent analytics indicate that there have been 1766 total users since the app's creation in 2016, with around 50 active users a month across the last two years. Primarily, these users are based in MidCentral and Counties Manukau DHBs. Comparatively, the largest proportion of participants of the study were located in Christchurch, Auckland and Wellington DHBs. Therefore, indicating that the highest population of users of the app were possibly not effectively reached by the survey methods utilised. It also may be that some of these parents are aware of the app but may not have downloaded or used the app regularly as it is not yet integrated into care provision at other DHBs. Our findings therefore are not necessarily reflective of the full potential of the app as a support resource for parents in the neonatal unit.

Additional work is needed with a larger population of users, and/or with a greater integration of the app into units, to best understand the extent of possible influence the app may have on parental experiences.

New Zealand is a culturally diverse landscape and not all groups are fairly represented in either aspect of the present work. Participants in both components of the study were primarily female, married, university educated, and of New Zealand European/Pākehā descent. Although interviews included a slightly more diverse population, the sample was primarily made up of mothers with similar characteristics (e.g., New Zealand European/Pākehā, university educated), which is not the case in neonatal units themselves. Māori and Pasifika are overrepresented in New Zealand neonatal units, and the lack of their perspectives included in this research is of importance to note (Chow et al., 2015). These harder to reach populations are important to include in future research, as they are most likely to experience difficulties in accessing support and subsequently, may have a more challenging or distressing experience. The nature of the study sample may be attributable to the recruitment methodology chosen. Previous literature by Nolte and colleagues (2015) has suggested that participants who take part through websites or social media are more likely to be readily connected to resources and support, which may be the case for the sample surveyed.

Historically, parenting and infant literature has primarily focused on dominant discourses of heteronormativity (e.g., nuclear families, mother and father dynamics), typically excluding perspectives that fall outside of this mould. The research presented here, in particular when considering the qualitative component, consists of a sample of primarily mothers and fathers, who identified as being in heterosexual relationships. As a result, the thesis lacks perspectives and discussion regarding non-traditional family structures and diversity within families (e.g., gay and/or lesbian relationships, single mothers and/or fathers). Given advances in technology (e.g., in vitro fertilisation and surrogacy), diverse family structures that differ from heteronormativity are increasingly becoming a feature of neonatal units (Logan, 2020). Thus, there is a need for future research to consider these experiences moving forward.

Furthermore, in both components of the study there was a lack of paternal perspectives. The second study exclusively explored maternal perspectives and there was a small population of fathers included in the first study. These findings suggest that fathers are hard-to-reach within the neonatal context. Internationally, fathers have been seen to find their infant's neonatal admission difficult and a lack of resources targeted for their support has been evidenced (Carter et al., 2007; Hollywood & Hollywood, 2011; Joseph et al., 2007; Lundqvist & Jakobsson, 2003). Several of the mothers interviewed reported that their partners, the father of the child, utilised the Babble app and found it beneficial, in some cases using and relying on it more than mothers did themselves. Better understanding New Zealand fathers' perspectives, in particular their thoughts around the Babble app, is essential to ensure that the support provided in New Zealand is adequate and effective for the paternal population.

The findings of both studies have emphasised the importance of neonatal staff in parental experiences. The pivotal role of staff in 'making or breaking' parental experiences was evidenced, with staff primarily cited as key informational sources and support throughout the journey. Despite their prominence in parental narratives, it was beyond the scope of the present research to explore staff perspectives on the neonatal journey. Through informal discussions with the researcher, staff spoke to the pressure placed on them by parents to support them whilst also managing significantly difficult social factors in the family's life (e.g., domestic violence, drug and alcohol abuse). Staff spoke of difficulties they experienced in working with these more complex families, and being torn between needing to support parents, whilst advocating for the admitted infant. The tension of this role held by staff to support parents and their patient, the infant, is ever present within a neonatal context. Future research should prioritise the exploration of staff perspectives to support identification of gaps where greater support could be provided for staff to ensure they are equipped to support parents and infants.

Despite these limitations, our study fills a key gap in the literature by exploring New Zealand parental experiences of neonatal units and the role of the Babble app within these experiences. Only a handful of studies have explored the role of an information support app for the early postpartum period, let alone during neonatal care provision. Although research focused on higher level units has been plentiful internationally, the present work considered parents' experiences of neonatal units of all levels and explored Level II+ units in more depth, presenting a distinct contribution to the neonatal field. Given the unique and diverse culture associated with different countries and their own needs and background, it is essential for research informing any interventions or practices to be implemented in a certain place, to be performed in that place. Having a good understanding of New Zealand parents' experiences provides a solid and informed base from which interventions, policies and practices for the New Zealand population can be derived.

# 7. Conclusion

To conclude, the findings presented here provide unique insights into the experiences of New Zealand parents of neonates, and better understanding as to the role of information in enhancing self-efficacy and reducing distress for these parents. Taken together, both studies suggest that parents find the experience of neonatal admission somewhat distressing, with some aspects causing greater distress than others and individual circumstances playing a role. Parents considered they were appropriately informed during their admission; however, they reiterated the importance of information across the admission and discharge process. Information was considered essential in helping parents feel more confident, and able to advocate for themselves and their infant. Parents in both studies were evidenced to struggle with their sense of parenthood and/or parental self-efficacy, indicative of the importance of enhancing and supporting parents to develop such a sense during neonatal admission. Information, engaging in parenting tasks and having access to support that met their individual needs, were seen as influential in their acquisition of confidence in their abilities.

When considering the role of the Babble app in New Zealand parents' experiences of the neonatal unit in Study One, there was no evidence of an effect of the Babble app on the outcome variables of distress, self-efficacy and how informed parents felt. Within Study Two, mothers reported the usefulness of Babble as an accompaniment to information provided by staff. Mothers further indicated Babble's value in the ability to adapt the information to their individual needs and utilise it on an 'as needed basis'.

In Study One, parental distress was seen to be reduced by an increased sense of feeling informed, in part through, enhanced parental self-efficacy. In light of these findings, future research should explore the development of interventions, targeted to provide support and actively enhance parental self-efficacy. Staff should reflect on the value of provided information and working to improve parental self-efficacy through engagement, information and relational support, keeping in mind the role this plays in reducing parental distress. Babble has demonstrated itself as a useful starting point to further support the information provided by staff and serve individual informational needs. The integration of information pertaining to parenting tasks into the Babble app may further complement staff support to develop greater parental self-efficacy via imaginal exposure.

Staff relationships were evidenced as pivotal in the present work. Parents reported accessing information primarily through staff in Study One; in Study Two interviews, mothers explored the ways in which staff provided support they appreciated (e.g., going 'above and beyond', communicating, kindness) and ways staff hindered the experience (e.g., not communicating with parents, not taking the time to build a relationship). The value of staff relationships, staff communication and information provision by staff cannot be understated. Such findings suggest it may be useful for staff to reflect on the relationships they build with parents, and ways to enhance the quality of these relationships through trust, communication and consistency.

In sum, our findings suggest that having an infant admitted to a neonatal unit is a challenging, life-changing experience which affects different families in different ways. The desire for information and staff support comes through clearly, indicating there is a need for these families to feel more supported and connected. The Babble app proves itself as a useful resource when integrated into neonatal care, yet further development of information interventions is indicated. An important contribution to the field of neonatal literature, the present work is novel in its approach to enhancing understanding about the experiences of New Zealand parents and the interventions offered to them, during an important and vulnerable period of their infant's life. As such, it is hoped that future researchers and neonatal staff will consider the findings presented here in their work to improve the wellbeing of New Zealand families experiencing neonatal admission.

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# 9. Appendix A: Ethics and Recruitment Information

## 9.1 Ethics

MASSEY
UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Date: 05 November 2018

Dear Charlotte Gibson

Re: Ethics Notification - **SOA 18/64 - Parental Experiences of the Neonatal Unit and the Role of the Babble App**

Thank you for the above application that was considered by the Massey University Human Ethics Committee: **Human Ethics Southern A Committee** at their meeting held on **Monday, 5 November,**

Approval is for three years. If this project has not been completed within three years from the date of this letter, reapproval must be requested.

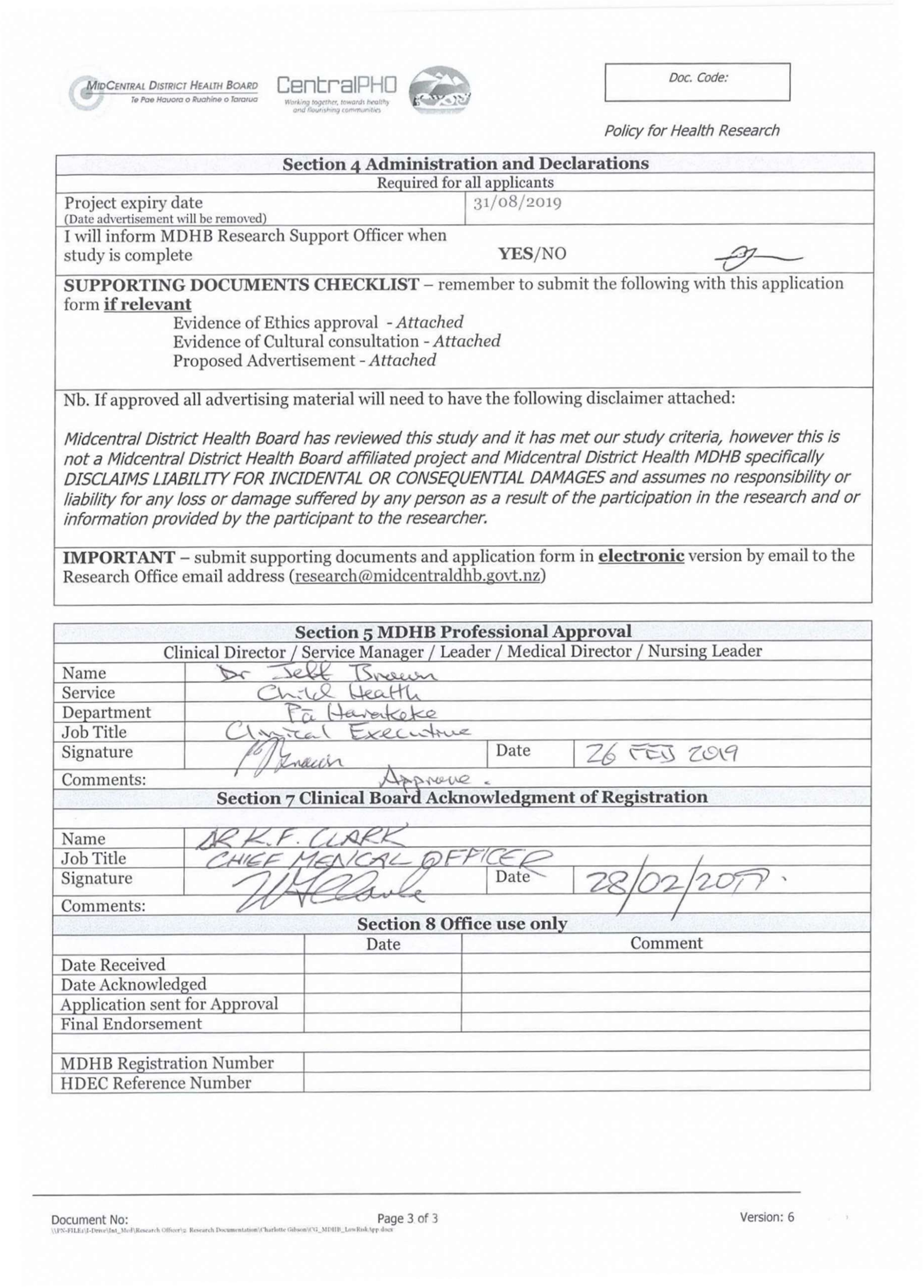
If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

Professor Craig Johnson
Chair, Human Ethics Chairs' Committee and Director (Research Ethics)

**Research Ethics Office, Research and Enterprise**
Massey University, Private Bag 11 222, Palmerston North, 4442, New Zealand **T** 06 350 5573; 06 350 5575 **F** 06 355 7973
**E** humanethics@massey.ac.nz **W** http://humanethics.massey.ac.nz

## 9.2 MidCentral DHB Ethics Approval Form



MidCentral District Health Board
Te Pae Hauora o Ruahine o Tararua

CentralPHO
Working together, towards healthy and flourishing communities

Doc. Code:

*Policy for Health Research*

| | |
|---|---|
| **Section 4 Administration and Declarations**<br>Required for all applicants | |
| Project expiry date<br>(Date advertisement will be removed) | 31/08/2019 |
| I will inform MDHB Research Support Officer when study is complete | **YES**/NO |

**SUPPORTING DOCUMENTS CHECKLIST** – remember to submit the following with this application form **if relevant**

Evidence of Ethics approval - *Attached*
Evidence of Cultural consultation - *Attached*
Proposed Advertisement - *Attached*

Nb. If approved all advertising material will need to have the following disclaimer attached:

*Midcentral District Health Board has reviewed this study and it has met our study criteria, however this is not a Midcentral District Health Board affiliated project and Midcentral District Health MDHB specifically DISCLAIMS LIABILITY FOR INCIDENTAL OR CONSEQUENTIAL DAMAGES and assumes no responsibility or liability for any loss or damage suffered by any person as a result of the participation in the research and or information provided by the participant to the researcher.*

**IMPORTANT** – submit supporting documents and application form in **electronic** version by email to the Research Office email address (research@midcentraldhb.govt.nz)

**Section 5 MDHB Professional Approval**
Clinical Director / Service Manager / Leader / Medical Director / Nursing Leader

| | | | |
|---|---|---|---|
| Name | Dr Jeff Brown | | |
| Service | Child Health | | |
| Department | Pā Harakeke | | |
| Job Title | Clinical Executive | | |
| Signature | | Date | 26 FEB 2019 |
| Comments: | Approve. | | |

**Section 7 Clinical Board Acknowledgment of Registration**

| | | | |
|---|---|---|---|
| Name | DR K.F. CLARK | | |
| Job Title | CHIEF MENICAL OFFICER | | |
| Signature | | Date | 28/02/2019. |
| Comments: | | | |

**Section 8 Office use only**

| | Date | Comment |
|---|---|---|
| Date Received | | |
| Date Acknowledged | | |
| Application sent for Approval | | |
| Final Endorsement | | |
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| MDHB Registration Number | | |
| HDEC Reference Number | | |

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## 9.3 Recruitment

### 9.3.1 Facebook Ad

***Parents in the Neonatal Unit/NICU***

Have you had a baby/pēpi admitted to a neonatal unit/SCBU/NICU in New Zealand in the last twelve months? Be a part of a Massey University study exploring your journey as a parent of a neonate. Take our short questionnaire and tell us about your experiences.

Click here to find out more and take part!

https://massey.au1.qualtrics.com/jfe/form/SV_bmjRz2psfaF8U0l

Facebook Ad Parameters:

*Target Population*:

Location – New Zealand

Age – 18+

Gender - All

Interests – Parenting, Neonatal nursing, Whānau, Infant, Parent, NICU Nurse, World Prematurity Day, Family, Motherhood, Fatherhood or Birth, Parents: New parents (0-12 months)

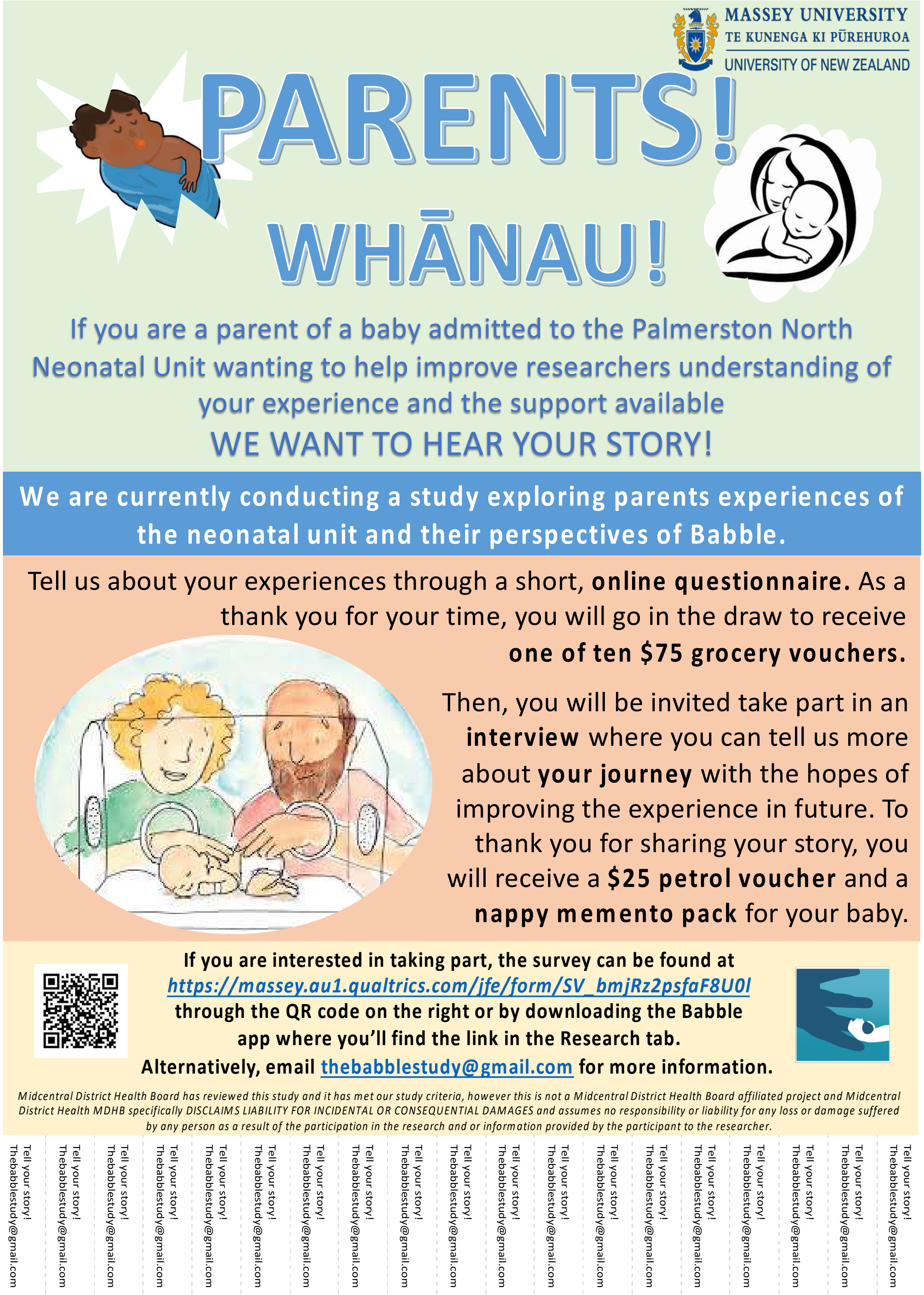
*Budget*:

Lifetime Budget – $200.00

Dates - 01/03/2019 - 31/06/2018

Predicted daily reach: 240-300 people

## 9.4 Poster



MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

# PARENTS!

# WHĀNAU!

If you are a parent of a baby admitted to the Palmerston North Neonatal Unit wanting to help improve researchers understanding of your experience and the support available

WE WANT TO HEAR YOUR STORY!

**We are currently conducting a study exploring parents experiences of the neonatal unit and their perspectives of Babble.**

Tell us about your experiences through a short, **online questionnaire.** As a thank you for your time, you will go in the draw to receive **one of ten $75 grocery vouchers.**

Then, you will be invited take part in an **interview** where you can tell us more about **your journey** with the hopes of improving the experience in future. To thank you for sharing your story, you will receive a **$25 petrol voucher** and a **nappy memento pack** for your baby.

**If you are interested in taking part, the survey can be found at** ***https://massey.au1.qualtrics.com/jfe/form/SV_bmjRz2psfaF8U0l*** **through the QR code on the right or by downloading the Babble app where you'll find the link in the Research tab.**

**Alternatively, email thebabblestudy@gmail.com for more information.**

*Midcentral District Health Board has reviewed this study and it has met our study criteria, however this is not a Midcentral District Health Board affiliated project and Midcentral District Health MDHB specifically DISCLAIMS LIABILITY FOR INCIDENTAL OR CONSEQUENTIAL DAMAGES and assumes no responsibility or liability for any loss or damage suffered by any person as a result of the participation in the research and or information provided by the participant to the researcher.*

Tell your story! Thebabblestudy@gmail.com
Tell your story! Thebabblestudy@gmail.com
Tell your story! Thebabblestudy@gmail.com
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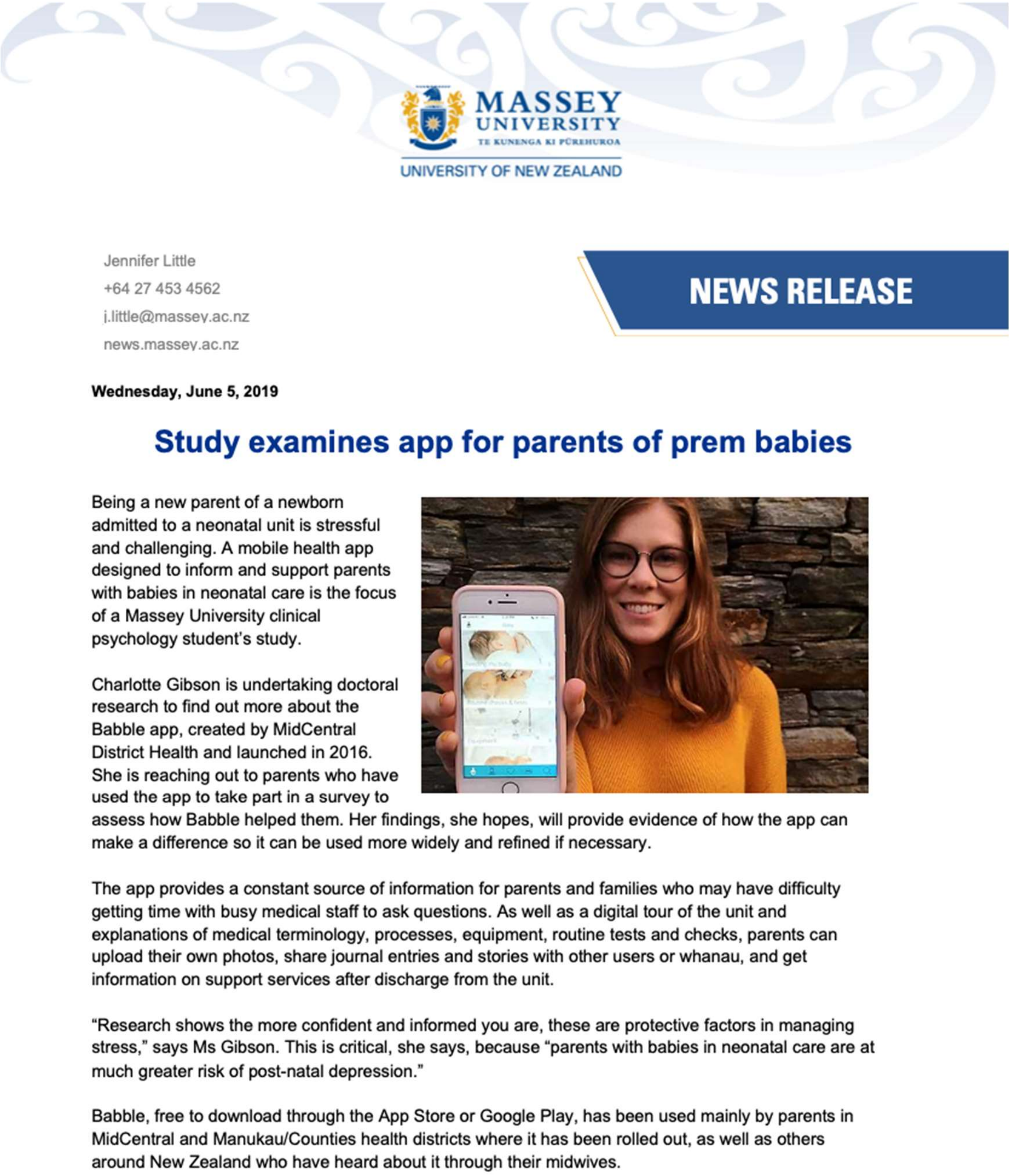
## 9.5 Press Release



MASSEY UNIVERSITY
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UNIVERSITY OF NEW ZEALAND

Jennifer Little
+64 27 453 4562
j.little@massey.ac.nz
news.massey.ac.nz

**NEWS RELEASE**

**Wednesday, June 5, 2019**

### Study examines app for parents of prem babies

Being a new parent of a newborn admitted to a neonatal unit is stressful and challenging. A mobile health app designed to inform and support parents with babies in neonatal care is the focus of a Massey University clinical psychology student's study.

Charlotte Gibson is undertaking doctoral research to find out more about the Babble app, created by MidCentral District Health and launched in 2016. She is reaching out to parents who have used the app to take part in a survey to assess how Babble helped them. Her findings, she hopes, will provide evidence of how the app can make a difference so it can be used more widely and refined if necessary.

The app provides a constant source of information for parents and families who may have difficulty getting time with busy medical staff to ask questions. As well as a digital tour of the unit and explanations of medical terminology, processes, equipment, routine tests and checks, parents can upload their own photos, share journal entries and stories with other users or whanau, and get information on support services after discharge from the unit.

"Research shows the more confident and informed you are, these are protective factors in managing stress," says Ms Gibson. This is critical, she says, because "parents with babies in neonatal care are at much greater risk of post-natal depression."

Babble, free to download through the App Store or Google Play, has been used mainly by parents in MidCentral and Manukau/Counties health districts where it has been rolled out, as well as others around New Zealand who have heard about it through their midwives.

**Parents' needs vital for positive future**

Not being able to hold and cuddle their new baby is just one of the massive disruptions to the expectactions of new parents. "This often follows high-risk pregnancy or difficult birth, so there's already that extra element of stress," she says. "Parents find that their needs compete with those of the infant – a neonatal unit is a hospital for babies and the priority isn't the parents experience."

For the study she has also surveyed parents of newborns in neonatal care who have not had access to the app to find out more about their experiences and understand what support would have helped Many have shared the pain of not being able to hold their newborn baby in the first hours or days after birth – a contradiction of a parent's deepest natural instinct.

One mum told her most stressful part is not so much the neonatal unit but "seeing her baby and not knowing what his future life will be like. It hit me that it's not just this point in time – it affects the future."

She is seeking parents whose baby has been admitted to a neonatal unit, including special care baby units (SCBU) or neonatal intensive care units (NICU), in New Zealand within the last twelve months.

The need for such an app is timely, says Ms Gibson, as globally more babies are being admitted to neonatal units because there are more older parents and higher use of IVF, which can result in multiple births needing specialist care.

Anecdotally, neonatal unit admissions are rising due to the impact of drugs, alcohol and poverty, Ms Gibson says. One of nurse told her: "you can see what's playing out in society being played out in the neonatal unit."

Ms Gibson studied socialising behaviours of 10-month old babies for her undergraduate honours degree in psychology (at the University of Auckland) and says she is "very passionate about early development and family work – I feel those areas are so pivotal to how we grow."

One of Ms Gibson's surpervisors, Dr Kirsty Ross, a clinical psychologist at Massey's Psychology Clinic on the Manawatū campus, has been a mother to two premature babies (now healthy adults). "It's quite a different entry into parenthood," says Dr Ross. Often parents are too emotionally overwhelmed and sleep-deprived to take in information from medical staff. Having access to the Babble app means they can seek information whenever they need it, she says.

Firsthand experience combined with her psychological knowledge has highlighted for her the potential of the Babble app and the value of research to investigate its efficacy.

Babble app creator, Dr Natalie de Vries, a MidCentral Health Board paediatrician, says "quote…."

For more information on the survey, click here.

**Caption: Charlotte Gibson.**

### 9.6 Letter Sent to Parents at Palmerston North Unit

Dear **[Name]**,

MidCentral District Health Board has been asked to assist researchers from Massey University, who are doing a research project entitled:

*Parents Experiences of the Neonatal Unit and the Role of the Babble App*

This project is trying to better understand New Zealand parents' experiences of the neonatal unit, specifically how parents who use the Babble app find that it impacts their journey, through a short online survey. As a thank you for participating in the survey, parents go into the draw to win one of ten $75 grocery vouchers. Subsequent to the completion of the survey, parents are invited to take part an interview exploring these experiences in more depth if they wish. The information gained from the research hopes to better inform and improve future parents' experiences in neonatal units/NICUs/SCBUs across New Zealand.

The Massey University researchers have asked MidCentral District Health Board to help them to find suitable people who may wish to take part in this research study. You have received this letter because you meet some important criteria for this study and you have received care from the neonatal unit at Palmerston North Hospital at some time in the past.

It is important for you to know that MidCentral District Health Board has not given any information about you to the researchers. We are simply sending you this letter to tell you about the study so that you can decide whether to contact the researchers for more information.

It is also important for you to understand that this study will be done by Massey University and is not a MidCentral District Health Board research project. However, this study has been reviewed according to MidCentral District Health Board research policies.

It is your choice whether you would like to take part in this study or not, and your health care will not be affected at all by the decision you make. Before you decide, you may also want to talk about the study with other people, such as family, whānau, friends, or healthcare providers.

If you think you would like to take part in this study or you would like more information about the research, please contact the Principal Investigator (main researcher) at Massey University:

Charlotte Gibson

thebabblestudy@gmail.com

If you want to contact someone at MidCentral District Health Board about this study, you can contact:

Kelly Butler

MidCentral DHB Research Support Officer

Phone: (06) 350 8036

Email: kelly.butler@midcentraldhb.govt.nz

Thank you for considering taking part in this research.

Yours sincerely,

| | |
|---|---|
| Charlotte Gibson<br>Doctor of Clinical Psychology<br>Candidate<br>Massey University | |

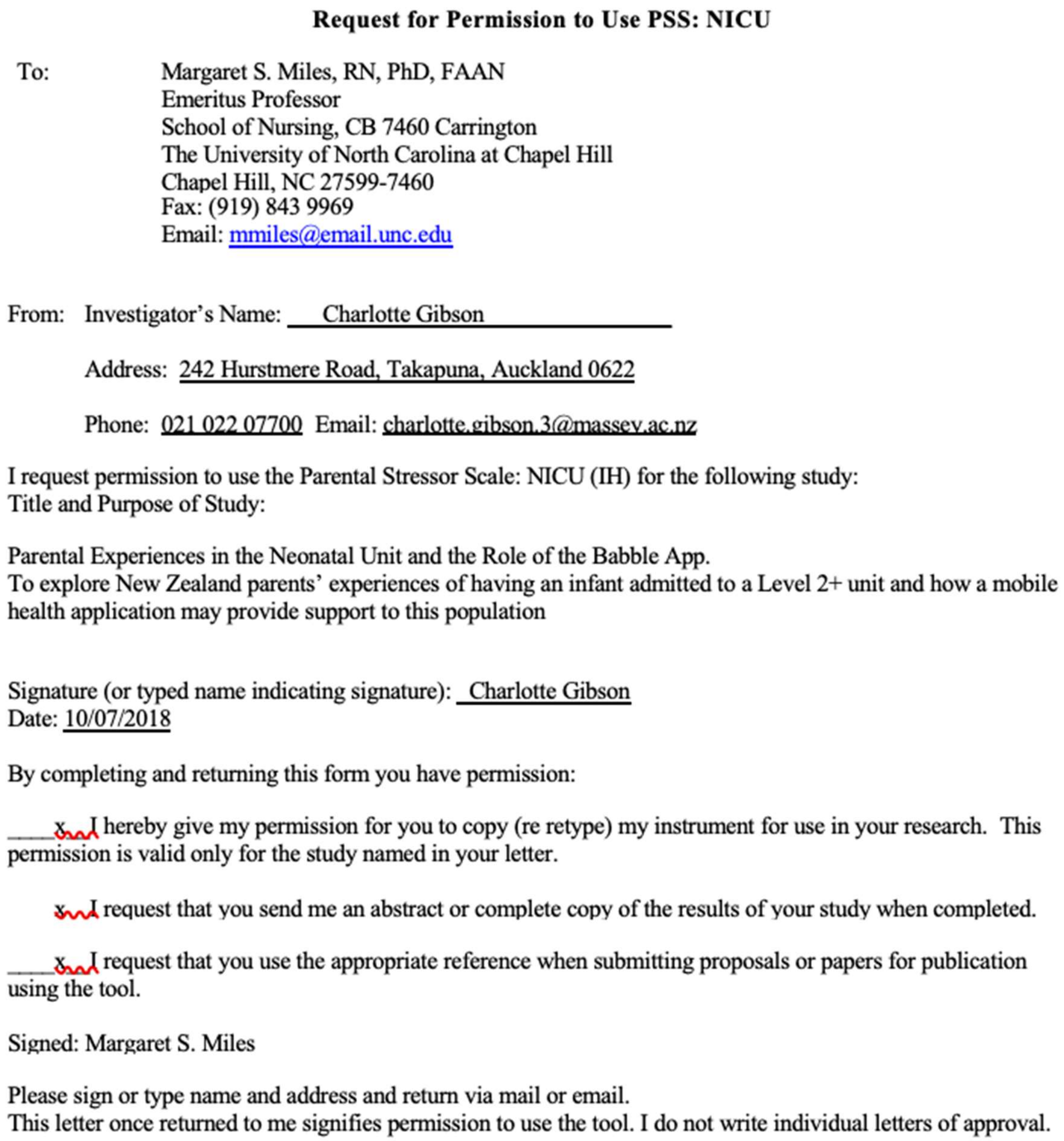
## 10. Appendix B: Supplementary Materials for Study One

This Appendix contains supplementary information about the method and results of Study One. This supplementary information document was submitted alongside the manuscript for review. The version included here is the same as was provided to the journal with exceptions made for formatting to ensure consistency with the rest of the thesis, and some typographical errors corrected. References cited in this version are included within the consolidated reference list at the end of the main body of this thesis.

The areas covered include:

- signed permission to use PSS:NICU;
- participant information schedule and questionnaire;
- an explanation of variables controlled for across the multiple regressions performed;
- how the measures were scored;
- necessary (yet unexpected) alterations from the pre-registration;
- complete sample demographic information;
- assumption tests for the multiple regressions performed; and,
- exploratory analyses around information-seeking behaviours.

## 10.1 Permission to Use PSS:NICU



**Request for Permission to Use PSS: NICU**

To:

Margaret S. Miles, RN, PhD, FAAN
Emeritus Professor
School of Nursing, CB 7460 Carrington
The University of North Carolina at Chapel Hill
Chapel Hill, NC 27599-7460
Fax: (919) 843 9969
Email: mmiles@email.unc.edu

From: Investigator's Name: Charlotte Gibson

Address: 242 Hurstmere Road, Takapuna, Auckland 0622

Phone: 021 022 07700 Email: charlotte.gibson.3@massey.ac.nz

I request permission to use the Parental Stressor Scale: NICU (IH) for the following study:
Title and Purpose of Study:

Parental Experiences in the Neonatal Unit and the Role of the Babble App.
To explore New Zealand parents' experiences of having an infant admitted to a Level 2+ unit and how a mobile health application may provide support to this population

Signature (or typed name indicating signature): Charlotte Gibson
Date: 10/07/2018

By completing and returning this form you have permission:

____x I hereby give my permission for you to copy (re retype) my instrument for use in your research. This permission is valid only for the study named in your letter.

x I request that you send me an abstract or complete copy of the results of your study when completed.

____x I request that you use the appropriate reference when submitting proposals or papers for publication using the tool.

Signed: Margaret S. Miles

Please sign or type name and address and return via mail or email.
This letter once returned to me signifies permission to use the tool. I do not write individual letters of approval.

## 10.2 Participant Information Sheet and Questionnaire

Due to the use of a survey platform, the design of the Participant Information sheet and Questionnaire differed from what is presented. A more readable format has been utilised here, yet the content remains the same.

**Researcher Introduction**

Kia Ora! My name is Charlotte Gibson and I am a Doctor of Clinical Psychology candidate at Massey University's School of Psychology. I am interested in finding out more about parents' experiences in the neonatal unit, alongside their perspectives on the app Babble. My supervisors are Dr Kirsty Ross and Dr Matt Williams, both from Massey University's School of Psychology.

**Participant Information**

You are invited to take part in research looking at experiences of being a parent/mātua to a baby/pēpi admitted to a neonatal unit and the role a mobile health application may play in supporting parents during this time.

If your baby/pēpi is currently or has been admitted to a neonatal unit (or a SCBU or NICU) within New Zealand within the last 12 months you are welcome to participate.

**The Research Project**

The current project involves you completing a short online questionnaire exploring your experiences in the neonatal unit and views on an informational support app, specifically your experiences (if any) with a currently available app called Babble.

The questionnaire will ask you about:

- Your needs within the neonatal unit
- Your experiences in the neonatal unit and how you have found certain aspects;
- Your feelings about your role as a parent/mātua within the unit;
- How informed you feel about the neonatal unit and your baby's care and needs;
- Your views around the usefulness of a mobile health application, such as Babble.

As a thank you for your participation in the survey, you will go in the draw to win 1 of 20 $50 supermarket vouchers.

For parents/mātua admitted to the Palmerston North neonatal unit, we are also particularly interested in learning more about your experiences specifically. The secondary phase of this project would involve interviews with parents/mātua who had a baby/pēpi admitted to Palmerston North Unit in the last 12 months. If you are interested, there will be an opportunity to enter your email for more information at the end of the survey.

***Possible Risks and Benefits.*** We understand that this may be or may have been a very sensitive time for you and your family. As the nature of the study addresses your experiences in a neonatal unit, we may ask you to think about experiences that you may have found stressful during your baby's stay. We do not expect there to be any long-term risks to participating in the study but some parents may become distressed remembering or discussing these experiences. The researcher will provide avenues to access appropriate care is provided during the study. Following the online questionnaire, a variety of specialized support services have been listed for you to access as needed. The results of the study may help inform improve services for parents of babies admitted to neonatal units in New Zealand, and improve the Babble app to better met parental needs during their baby's stay.

If you choose to participate, clicking on the next button will take you to the questionnaire. To get a good idea of parental experiences of their baby's neonatal admission and the impact of the Babble app, we are looking to get at least 400 participants for the online questionnaire. The questionnaire will take approximately 10-15 minutes to complete (if English is your second language this may take longer). When you submit your answers to the questionnaire, your results will be automatically sent through to a database.

**Data Management**

Should you choose to take part, all information you give in the questionnaire will be kept anonymous and confidential. The information you provide will be used in my doctoral thesis and submitted for assessment, and the findings may be published in scientific journals or presented at scientific conferences in Aotearoa New Zealand and overseas. Research data will be made available in an openly accessible online repository so that other researchers can follow on and build on the results of this study. However, this data will be de-identified and anonymous.

**Your Rights**

You are under no obligation to accept this invitation. If you decide to take part, clicking the 'Next' button means you agree to participating. You have the right to decline to answer any particular question.

**Ready to begin?**

Please click on the 'Next' button below when you are ready to begin.
Many thanks
Charlotte Gibson

**Project Contacts**

If you have any further questions please contact the researcher or chief supervisor. If you would like to receive a summary of the research findings following completion, please provide your email address as part of the survey, and one will be provided to you as soon as it is available.

| Researcher | Chief Supervisor |
|---|---|
| Charlotte Gibson | Dr Kirsty Ross |
| School of Psychology | School of Psychology |
| Massey University | Massey University |
| Albany Campus | Turitea Campus |
| Auckland | Palmerston North |
| Ph: 021 022 07700 | Ph: +64 (06) 356 9099 ext. 84968 |
| thebabblestudy@gmail.com | K.J.Ross@massey.ac.nz |

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 18/64. If you have any concerns about the conduct of this research, please contact Dr Lesley Batten, Chair, Massey University Human Ethics

Committee: Southern A, telephone 06 356 9099 x 85094, email humanethicsoutha@massey.ac.nz.

Clicking Begin indicates you consent to taking part in the following questionnaire:
Begin

Within the last twelve months, was your infant(s) admitted to a neonatal unit, special care baby unit or neonatal intensive care unit in New Zealand?

Yes
*No → Unfortunately you are not eligible to participate in this study. Thank you for your time!*

**Questionnaire Begins**

For many parents and family members, the experience of neonatal admission is a stressful and challenging time. This questionnaire is designed to gather some information around your experience of having an infant in a neonatal unit in New Zealand within the last 12 months. All the information you provide to us is confidential and will only be used for the purposes of this study.

The following questions primarily focus on the possible levels of stress you experienced whilst in the unit, your feelings of confidence as well as general questions about yourself and the admitted infant(s). We are also interested in exploring your perspective about an app, Babble, which focuses on supporting parents in the neonatal unit. For all the questions, please consider your experiences whilst in the unit specifically, whether this was a few months ago or if your infant is currently admitted.

There are no right or wrong answers to these questions and it's most important that your answers are true and accurate for you. Our primary interest is in your personal experiences and opinion. Please choose responses that fit best with your circumstances.

If you have any concerns about a question or the study, please do not hesitate to contact the researcher through thebabblestudy@gmail.com. Please note that you are free to stop the questionnaire at any time and do not have to answer any questions that you do not feel comfortable with.

**Thank you for your participation!**

**Parental/Infant Information**

| | |
|---|---|
| What is your age? | |
| What is your gender? | M / F / Other |
| What ethnic group do you identify with? (Please select more than one if applicable) | NZ Euro/ Pākehā / Māori / Asian / Pacific peoples / Other (please specify) |
| What is your marital status? | Single (never married) / married or de facto relationship / divorced or separated / widowed |
| What are your usual living arrangements? | Living with partner or spouse and children / living with partner or spouse and no children / sole adult with children / living alone / living with other adults (e.g., relatives, friends) / other (please specify) |
| What is your employment status? | Employed full time / employed part time / unemployed / retired / working at home / a student / a sickness benefit / maternity/paternity leave |
| At what level did you complete your formal education? | Primary school / secondary school / technical or trade certificate / university or polytechnic diploma / university degree |
| [redacted] | |
| What is your relationship to the infant? | Mother / Father |
| Which unit was/is your infant admitted to? (if you were admitted to more than one unit, please select the unit you spent the most time in) | Auckland Hospital NICU<br>Middlemore Hospital NICU<br>Waikato Hospital NICU<br>Wellington Hospital NICU<br>Christchurch Hospital NICU<br>Dunedin Hospital NICU<br>Hawke's Bay NNU<br>Taranaki NNU<br>Palmerston North NNU<br>Whangarei SCBU<br>North Shore SCBU<br>Waitakere SCBU<br>Auckland Hospital SCBU<br>Tauranga SCBU<br>Rotorua SCBU<br>Whakatane SCBU<br>Gisborne SCBU<br>Whanganui SCBU<br>Wairarapa SCBU<br>Hutt Valley SCBU<br>Nelson SCBU<br>Timaru SCBU |

| | |
|---|---|
| | Southland SCBU |
| What was the reason for admission? | Prematurity<br>Small for Gestational Age<br>Illness (please specify)<br>Other (please specify) |
| Is the admitted infant a "multiple" (e.g., a twin or triplet) | Yes / No |
| If you have been discharged from the unit, how long was your infant admitted for? | ______ weeks ____ days |
| If you have been discharged from the unit, how long ago were you discharged? | _____ months ______ weeks _____ days |
| How many other children do you have? | 0 / 1 / 2 / 3 / 4+ |
| (if 1+) Did any of your other children experience admission to a neonatal unit? | Yes / No. If yes – please specify why. |
| Were you aware of need for neonatal admission prior to the birth? | Yes / No |
| Was your infant transferred at any stage from one neonatal unit to another? | Yes / No |
| Did you need to travel away from your home because of your infant's admission to the unit? | Yes / No |
| **Experience in The Unit** | |
| For this section, we would like to generally explore your experiences in the unit. | |
| How did you find your overall experience in the unit? 1 = (the worst it could be) → 5 (The best it could be) | |
| Please list any needs you experienced during your neonatal stay for yourself as the parent/mātua of the infant? Needs may include things like more communication from staff or greater physical contact with my infant for example. | |
| Please list any ways in which you tried to meet these needs. For example, some parents/mātua who find they require more information about their infant's condition may do their own research on the internet. | |
| Did any of your needs go unmet? Please list them below if so. | |
| **Distress** | |
| We are interested in how the environment and experiences in a neonatal unit affects parents. The neonatal unit, also known as neonatal intensive care unit, is the room where your baby is receiving care. Sometimes, this is called an NNU or NICU for short. We would like to know about your experiences as a parent with an infant presently in an NNU. This questionnaire lists various experiences other parents have reported as stressful when their baby was in the NICU. If you are admitted to the neonatal unit at present, we would like you to indicate how stressful each item listed below has been for you. If you have been discharged, please think back to your experiences in the unit when considering your | |

responses. If you have not had this experience, we would like you to indicate this by selecting the N/A box, meaning that you have 'not experienced' this element of the NNU.

**By stressful, we mean that the experiences have caused you to feel distressed, upset, anxious or tense.**

Scale:

1 – not at all stressful (the experience did not cause you feel upset, tense or anxious)
2 – at little stressful
3 – moderately stressful
4 – very stressful
5 – extremely stressful (the experience upset you or caused a lot of anxiety or tension)

Here is a list of various SIGHTS AND SOUNDS commonly experienced in an NICU. We are interested in knowing about your review of how stressful these SIGHTS AND SOUNDS are for you. Select the box that best represents your level of stress. If you did not see or hear the item, select the NA box meaning 'not applicable.

1. The presence of monitors and equipment
2. The constant noises of monitors and equipment
3. The sudden noises of monitor alarms
4. The other sick babies in the room
5. The large number of people working in the unit
6. Having a machine (respirator) breathe for my baby

Next is a list of items that might describe the way your BABY LOOKS AND BEHAVES while you are visiting in the NICU as well as some of the TREATMENTS that you have seen done to the baby. Not all babies have these experiences or look this way, so select the NA box if you have not experienced or seen the listed item. If the item reflects something you have experienced, then indicate how much the experience was stressful or upsetting to you by selecting the appropriate box.

1. Tubes and equipment on or near my baby
2. Bruises, cuts or incisions on my baby
3. The unusual colour of my baby (for example, looking pale and yellow jaundiced)
4. My baby's unusual or abnormal breathing patterns
5. The small size of my baby
6. The wrinkled appearance of my baby
7. Seeing needles and tubes put in my baby
8. My baby being fed an intravenous line or tube
9. When my baby seemed to be in pain
10. When my baby looked sad
11. The limp and weak appearance of my baby
12. Jerky or restless movements of my baby
13. My baby not being able to cry like other babies

The last area we want to ask you about is how you feel about your own **RELATIONSHIP** with the baby and your **PARENTAL ROLE**. If you have experienced the following situations or feelings, indicate how stressful you have been by them by circling the appropriate number. Again, circle NA if you did not experience the item.

20. Being separated from my baby
21. Not feeding my baby myself
22. Not being able to care for my baby myself (for example, diapering, bathing)
23. Not being able to hold my baby when I want
24. Feeling helpless and unable to protect my baby from pain and painful procedures
25. Feeling helpless about how to help my baby during this time
26. Not having time alone with my baby

Using the same rating scale, please indicate how stressful in general the experience of having your baby hospitalised has been for you (NA 1 2 3 4 5)

**Parental Self-Efficacy**

The following section focuses on your experiences in your role as a parent of an infant admitted to a neonatal unit and your feelings of confidence around this. For the following question please select the number that best corresponds to your views:

I felt confident in my role and abilities as a parent/mātua during the admission period → 1 (strongly disagree) to 5 (strongly agree)

**Information**

The following questions focus on the levels of information you have received about your infant's condition, the unit itself and your sense of satisfaction with the information provided to you. For the following questions please select the number that best corresponds to your views:

I felt informed about my infant's needs and their care within the unit → 1 (strongly disagree) to 5 (strongly agree)

I felt informed about the neonatal unit and the relevant policies and procedures → 1 (strongly disagree) to 5 (strongly agree)

I felt informed about my role in caring for my infant whilst they are admitted to the neonatal unit → 1 (strongly disagree) to 5 (strongly agree)

I felt informed about the discharge process and caring for my infant at home → 1 (strongly disagree) to 5 (strongly agree)

Where did you most commonly access information pertaining to your infant and the neonatal unit experience?

1. Internet
2. Specific Website: _______
3. Babble
4. Apps
5. Specific App: _______
6. Books
7. Staff

8. Other (please specify)

When did you most commonly access information pertaining to your infant and the neonatal unit experience?

1. 6am – 12pm
2. 12pm – 6pm
3. 6pm – 12am
4. 12am – 6am

**Babble**

Have you downloaded the Babble app? Yes/No

If No to Download:
Babble is an app that provides information and support to parents' in the neonatal unit in New Zealand. Topics include feeding, routine checks and tests, equipment, gestational expectations, common neonatal diseases, and general parenting/discharge information. Users are also able to share their stories through journal entries and record key milestones, which can then be shared through email and social media.
Given this information, do you feel Babble would have been helpful during your neonatal stay? Yes/No

If Yes to Download:
How did you hear about the Babble app?

1. Hospital Staff
2. Personal Search
3. Friends or family
4. Other (please specify):

Have you used the Babble app? Yes/No

Next Page: Is there anything else you would like us to know about your neonatal experience?

Thank you for completing my study! We are also interested in understanding more about how the other parent/mātua of your baby/pēpi has found this experience. If they are interested in taking part, please invite them through the below link. Thank you!

**If they selected MidCentral:** Thank you for participating in this phase of my study! As you have/had an infant admitted to the Palmerston North Hospital NNU, we would be interested in hearing more about your experiences with the unit and the Babble App specifically. If you are interested in taking part in an interview to discuss your experience, please enter your email address and more information will be provided to you:

Thank you for your participation! The process of having an infant admitted to the neonatal unit can be stressful for parents but if any of these questions make you feel significantly distressed or upset, please reach out to your support systems be that family, friends, hospital support staff, kaumātua, GP or church. Alternatively, please speak with your neonatal nurse, doctor or ask to speak to the neonatal unit social work for more support within the unit if you are current admitted.

## 10.3 Extended Methodology

### *10.3.1 Control Variables*

The choices made concerning the confounding variables controlled for in tests for the first three hypotheses are explained below. The variables were selected as necessary to control for, given they were considered to be plausibly correlated with Babble use and may have affected the dependent variables of distress, parental self-efficacy and feeling informed, therefore indicating they have the characteristics of confounding variables (McNamee, 2003). To begin, each hypothesis will be outlined, followed by an overarching explanation as to why each variable has been controlled for across the three analyses. The same four controls were used across each hypothesis.

*Hypothesis 1*. Parents of infants in neonatal units who have used the Babble app will report lower levels of distress than parents who have not when controlling for level of unit, length of stay, parental age and parental role (mother/father).

*Hypothesis 2.* Parents of infants who have used the Babble app will report higher levels of self-efficacy compared to parents who have not when controlling for level of unit, length of stay, parental age and parental role (mother/father).

*Hypothesis 3.* Parents of infants who have used the Babble app will report a greater sense of feeling informed than parents who have not when controlling for level of unit, length of stay, parental age and parental role (mother/father).

**10.3.1.1 Level of Unit.** Parents of an infant admitted to a higher-level of unit (i.e., whose child is receiving significant medical care) may be more likely to utilise Babble due to a likely desire for greater information in response to the increased medicalisation of the process and medical fragility of the infant. Additionally, given that various factors associated with higher level of unit (e.g., a sicker infant, a longer stay) are associated with distress and self-efficacy, it was considered important to control for this factor (Donoghue, 2004; Dudek-Shriber, 2004).

**10.3.1.2 Length of Stay.** Research suggests that the greater amount of time spent in a neonatal unit, the less distress experienced (Miles et al., 2002). Parents who are in the unit for longer might be more likely to seek out additional information, such as that provided by the Babble app. More specifically, they may be more likely to have the time and interest to explore the app, potentially influencing how app use interacts with the outcome variables. Additionally, due to evidenced effects of habituation to the environment, it was considered that how long a parent is in the unit would increase knowledge independently (Miles et al., 2002). Thus, this was determined an important control variable to ensure that any results were indicative of the role of the app, rather than habituation or general knowledge acquisition.

**10.3.1.3 Parental Age.** Research suggests that age has an impact on the degree of distress experienced by parents, therefore it was considered an important factor to control for (Carter et al., 2007; Leigh & Milgrom, 2008; Meyer et al., 1995). Furthermore, when considering pregnancy app use, those who utilised apps the most, were more likely to be younger (Wallwiener et al., 2016), indicating it is likely that younger parents will utilise the Babble app more so, than older parents. Thus, indicating it as an important variable to control for.

**10.3.1.4 Parental Role.** Mothers and fathers are reported to experience distress differently, therefore this factor was considered important to control for (Baía et al., 2016; Dudek-Shriber, 2004). Mothers and fathers are also reported to have differential experiences of self-efficacy in the neonatal unit, indicating it necessary to control for in the analysis addressing hypothesis two (Salonen et al., 2009). Finally, research demonstrates there are gender differences between how knowledgeable parents feel they are about the neonatal experience as well as general information seeking behaviours (Hudson et al., 2003; Ybarra & Suman, 2008). There are additionally gender differences in technology use that may impact Babble use. Males typically have more positive attitudes towards technology use compared to females and are seen as more likely to utilise the Internet to gather information and seek out social support than females (Morris et al., 1999). Thus, it was considered important to control for any impact parental role may have in the findings of the analyses.

### 10.4 Scoring the PSS:NICU

The PSS:NICU has two recognised approaches to scoring. As described in Miles, et al. (1993) one such approach (Metric 1) measures perceived stress across only situations the parent identifies as having experienced (Miles et al., 1993). Alternatively, the other approach (Metric 2) measures overall stress, including situations that the parent may not have reported experiencing (not applicable is rated as no stress experienced). More specifically, any item reported as 'NA – not applicable' was thus, rated as 1 (*not stressful at all*), in order to measure overall stress, inclusive of situations that parents may not have reported experiencing (Miles et al., 1993). Metric 2 is recommended if the primary research aims focus on the parents' stress levels and was therefore used in the study in accordance with those guidelines (Miles, et al., 1993).

### 10.5 Developing a Unique Parental Self-Efficacy Measure

Other measures of parental self-efficacy (e.g., Parenting Sense of Competency; Gilbaud-Wallston &Wandersman, 1978) have typically focused on parental confidence around completing tasks related to caring for their infant, activities many parents in neonatal units are often unable to take part in. Using such measures with this population would have likely resulted in a bias towards a lower score of self-efficacy. To avoid this, as well as undue distress at a possible inability to engage in caring tasks, a more general statement was developed by the researcher. Research suggests that a single-item self-efficacy question can offer a shorter, more user-friendly measure of self-efficacy comparable to larger, multiple-item scales (Hoeppner et al., 2011). A novel, single-item, 5- point Likert scale of agreement ranging from 1 (*strongly disagree*) to 5 (*strongly agree*) with the statement: 'I felt confident in my roles and abilities as a parent during the admission period', was therefore utilised in the present study.

## 10.6 Deviations from the Pre-Registration – Necessary Variable Alterations

Several unexpected issues in variable management presented themselves subsequent to the submission of the pre-registration. These variations from the pre-registration are outlined below, inclusive of justification and action taken in response.

### *10.6.1 Birthweight*

Despite the question around infant birthweight only allowing for numerical values to be entered and clear guidelines to enter in grams, there were several values within the dataset that were considered implausible (e.g., reported birthweights of 1.2 grams). It was hypothesised that these parents may have entered infant weights in kilograms instead, but to avoid making excessive assumptions, it was considered important to exclude weight values beyond the realms of possibility. It was determined that the lightest baby to have ever survived was 230 grams and the heaviest baby to have ever been born was 10000 grams (Guinness World Records, 2020; Jacobo, 2019). Considering this, values beyond these constraints (e.g., below 280 grams and above 10000 grams) were converted to NA (missing) to remove the impossible outliers, in the interests of calculating accurate demographics. Weight was not an outcome or control variable included in the main analyses addressing the hypotheses, and as such, the responses provided by the participant to other components of the survey were considered valuable and important data to include. Hence, the decision to convert impossible weights to NA and not exclude these participants from the entire sample.

### *10.6.2 Parental Age*

Through descriptive analyses, it became clear that one parent had entered their age as 0.2. Once again, to avoid making assumptions it was considered important to create a function that would lead to any value beyond the realm of possibility to return NA (as was done for birthweight values). Research indicated that the youngest parent in New Zealand became a parent at age 11 (Gadd, 2013; Statistics New Zealand, 2019). It was considered important to only include values that were considered 'possible' and thus, values below 11 were converted to NA with single imputation performed, so as to not exclude them from analyses, as their response to the remainder of the survey was considered important and essential to include.

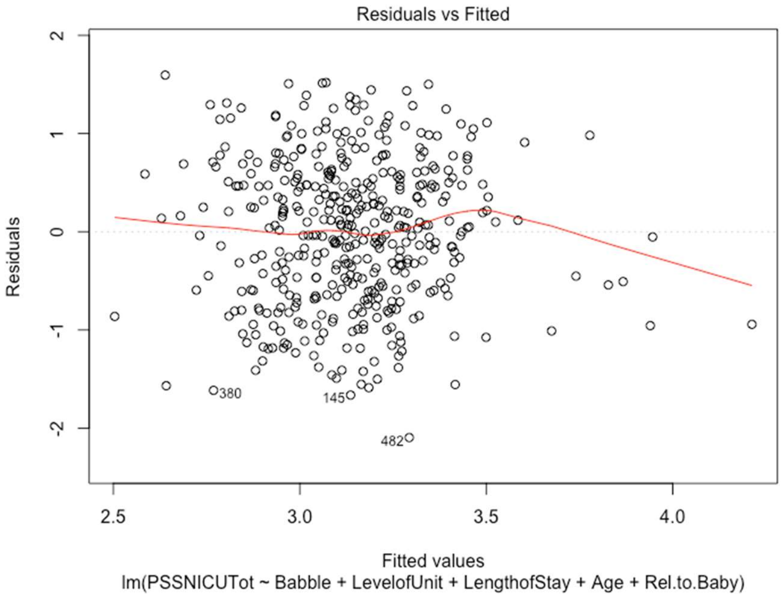
### *10.6.3 Length of Stay*

An unforeseen difficulty presented itself with regard to the measurement of length of stay. Participants were required to report their admission date, whether they were still admitted to the unit and, if not, their discharge date. The pre-registration stated that length of stay would be calculated by subtracting the discharge date from the admittance date, providing a numeric value in days (length of stay). It quickly became apparent that given that some participants were still admitted to the unit when they completed the survey and thus when they selected the option of being currently admitted, they were not provided with the option to include a discharge date due to survey design, and therefore, the discharge date value was left blank. It was decided the survey completion date would be used as the 'discharge date' for this calculation for this specific group who were currently admitted at the time of their survey completion, as it was concluded that their answers would be representative of the parents' experiences to that date. Similar to the management of the birthweight and parental age variables, some parents provided responses that were beyond the realms of possibility (e.g., negative values or several years of admittance). It was considered important to only include values that were considered possible and thus, values below 0 and beyond 12 months were converted to NA with single imputation performed, so as to not exclude them from analyses, as the response, in general, was considered important and essential to include. Those reportedly admitted beyond 12 months were excluded in response to clinical guidance provided that admittance beyond a year was highly uncommon. Additionally, the researcher could find no evidence in the literature of any individual infant being admitted beyond 12 months.

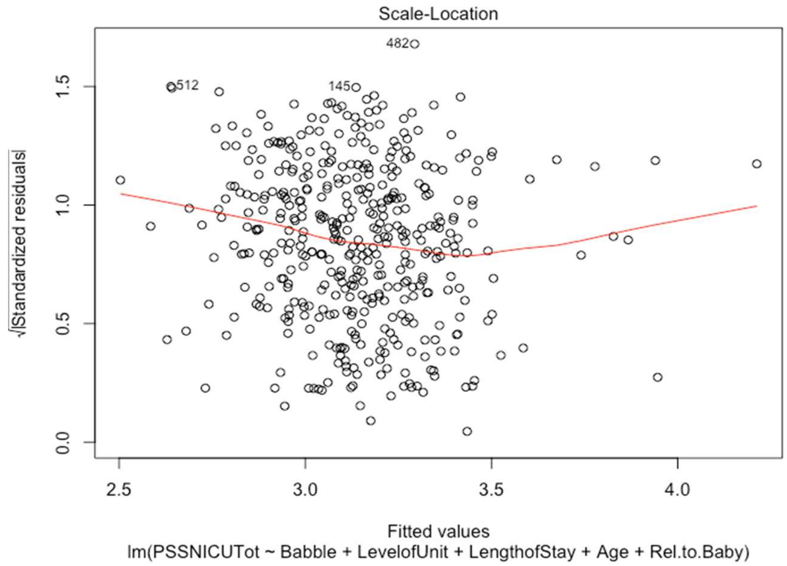
### 10.7 Assumption Testing (Field et al., 2012; Gelman & Hill, 2007)

The three main hypotheses as to the role of Babble across the outcome variables, parental distress, parental self-efficacy and sense of feeling informed, were tested with multiple hierarchical regression models, estimated using ordinary least squares. Assumptions were tested through the plot() function on R. Multiple hierarchical regression assumes linearity, meaning that the relationship between independent and dependent variables is linear. Secondly, normality of residuals variance was tested, whereby the residual errors are assumed to be normally distributed. The assumption of normality of errors is a relatively less important assumption of the regression model, and the large sample size of this study means that any assumption breaches of this nature are unlikely to have distorted the risk of Type 1 error (Gelman & Hill, 2007; Lumley et al., 2002). Regressions additionally assume the homogeneity of residuals variance, meaning that the residuals are assumed to have constant variance (homoscedasticity). The presence of outliers was measured via Cook's Distance, a method of indicating the influence of each observation on the regression coefficients. Although regression does not specifically assume an absence of outliers (Williams et al., 2019), it is nevertheless useful to check whether the results are especially strongly influenced by particular outlying cases.

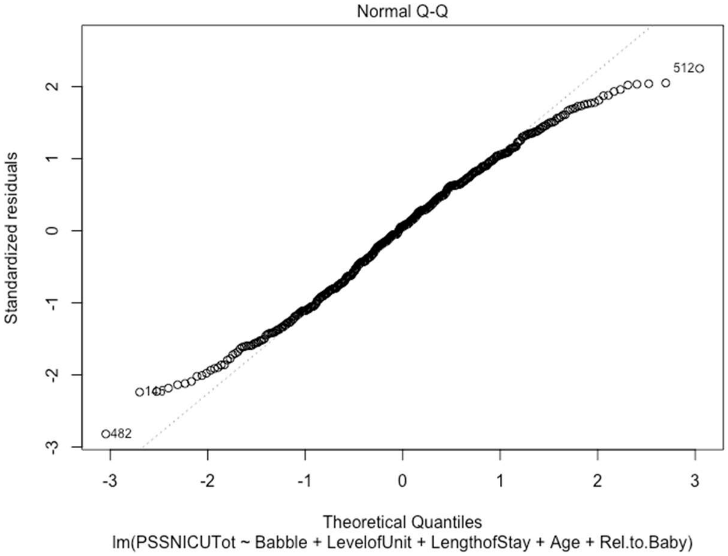
### *10.7.1 Hypothesis One*



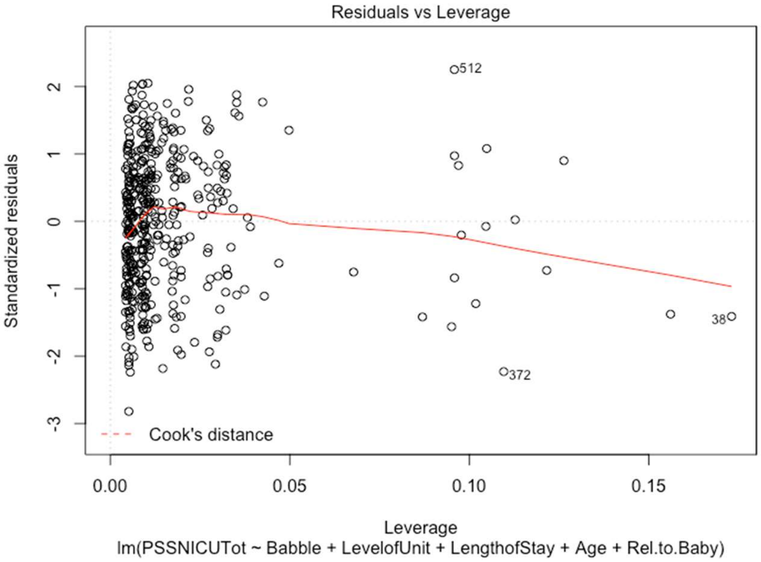
The assumptions of linearity and homogeneity of variance were tested using a plot of residuals against fitted values. The plot shows no fitted pattern, indicating that we can assume a linear relationship between predictors and the outcome variables.



The homogeneity of variance assumption is visualised through the scale-location plot. It can be seen that the residuals do not demonstrate any discernible pattern, indicative of homoscedasticity.

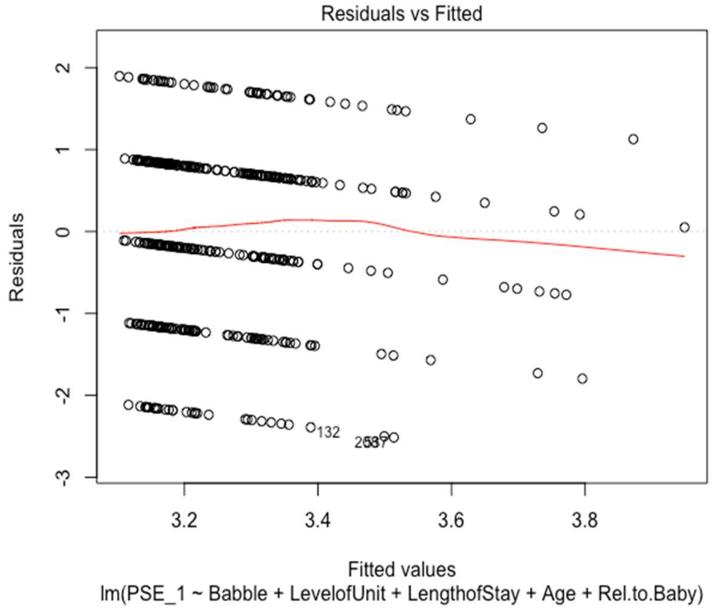


The assumption of normality is visualised through the Q-Q plot. The residuals in the graph are aligned in somewhat of a straight line, indicating that the assumption of normality is well approximated for this model.

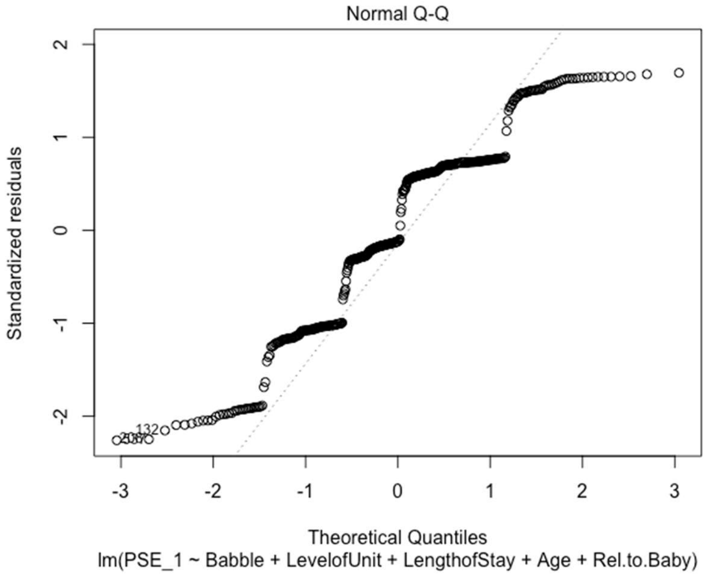


The residuals vs leverage graph outlines the presence of any points that have greater influence over others. There is limited evidence of any influential outliers as indicated by no values beyond Cook's distance.

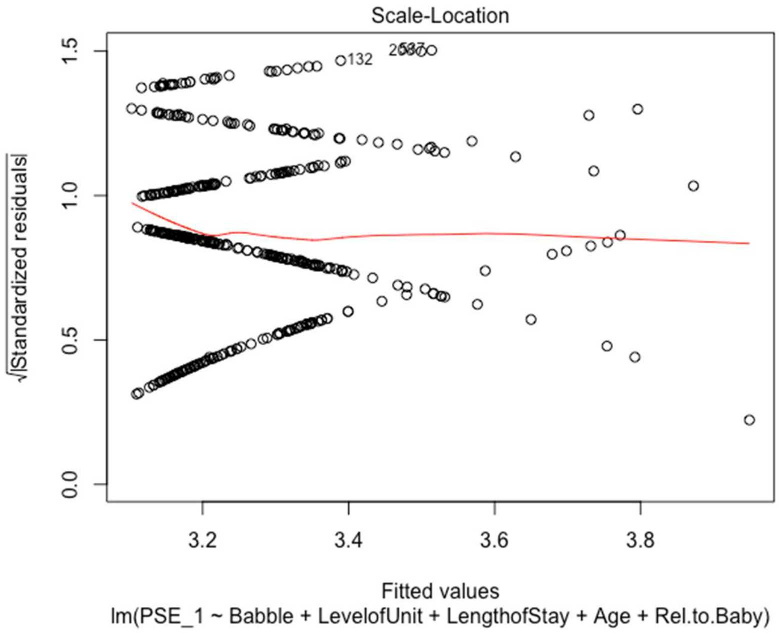
### *10.7.2 Hypothesis Two*



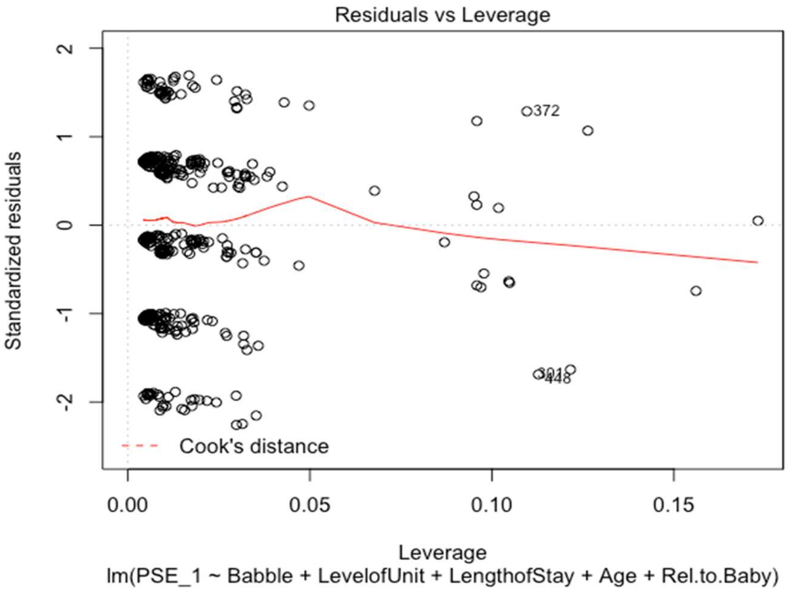
The residual plot is somewhat suggestive of mild non-linearity in the relationship between fitted values and residuals. Results should therefore be considered with this violation in mind.



The assumption of normality is visualised through the Q-Q plot. The residuals in this model indicate that the assumption of normality is violated, likely due to the discrete nature of the dependent variable as it has just five response options.

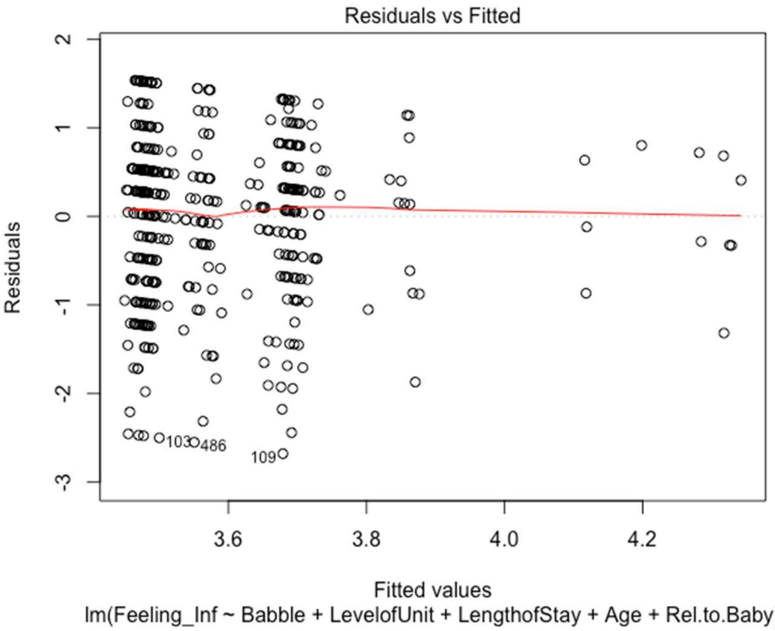


The homogeneity of variance assumption is visualised through the scale-location plot. It can be seen that the variability of the residual points decreases with the value of the fitted outcome variable, indicative of heteroskedasticity. Results should be considered with this violation in mind.

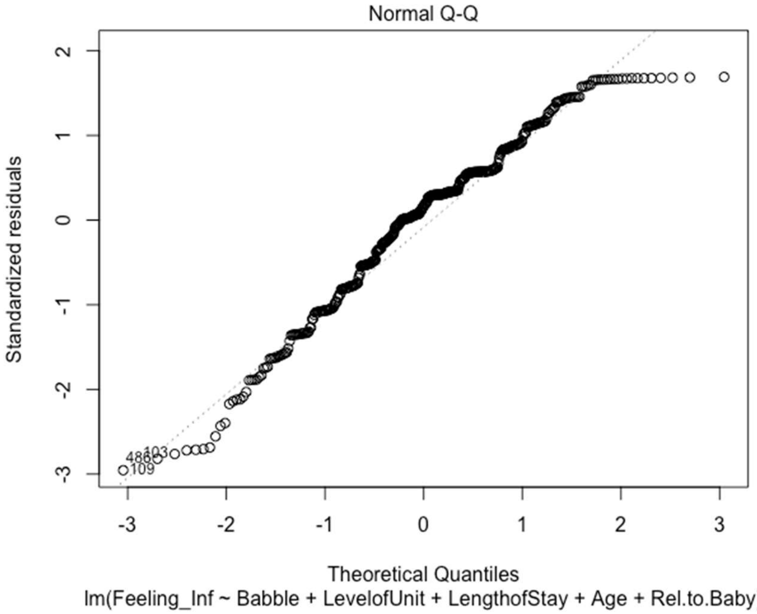


The residuals vs leverage graph outlines the presence of any points that have greater influence over others. There is no evidence of any influential outliers.

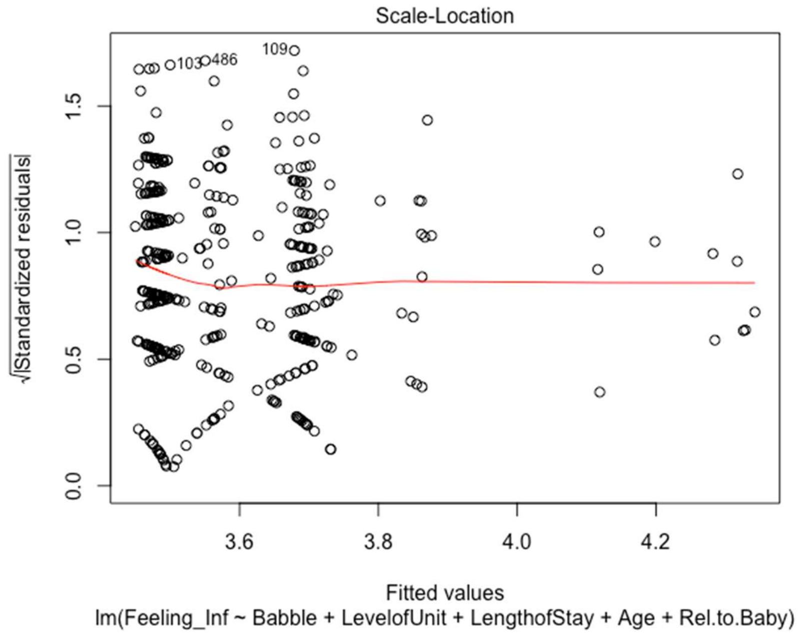
### *10.7.3 Hypothesis Three*



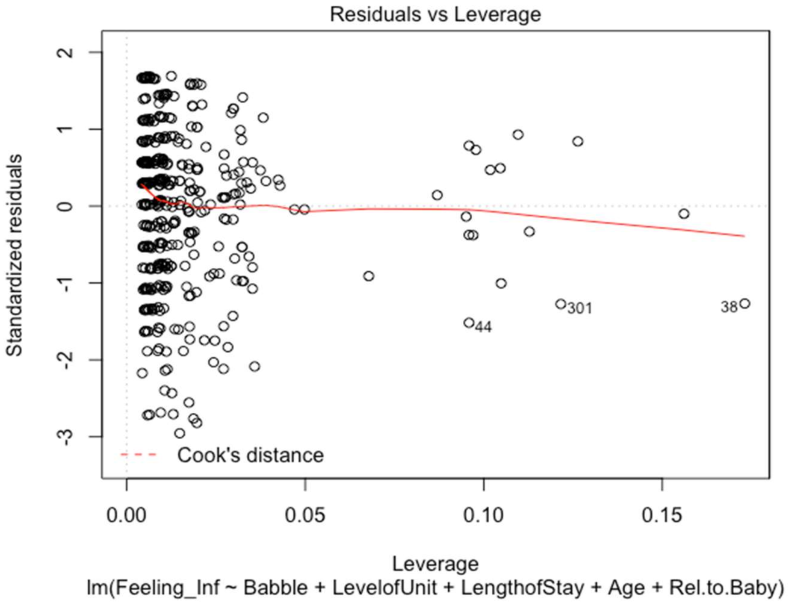
As the red line indicates, there is a smoothed local line of best fit, close to a straight line, ultimately, suggestive of a close to linear relationship between predictors and the outcome variables.



The assumption of normality is visualised through the Q-Q plot. The residuals in the graph are aligned in somewhat of a straight line, however there are clear deviations at each end. The assumption of normality is moderately well approximated for this model.



The homogeneity of variance assumption is visualised through the scale-location plot. It can be seen that the variability of the residual points decreases with the value of the fitted outcome variable, indicative of heteroskedasticity. Results should be considered with this violation in mind.



The residuals vs leverage graph outlines the presence of any points that have greater influence over others. There is no evidence of any influential outliers.

## 10.8 Extended Results

### Table 6

*Demographic and Neonatal Admission Characteristics of Sample.*

| **Parent Details** | M(SD) | N(%) |
|---|---|---|
| Age | 31 (5.27) | |
| *Gender* | | |
| Female | | 438 (98) |
| Male | | 11 (2) |
| *Ethnicity* | | |
| Pākehā/New Zealand European | | 348 (78) |
| Māori | | 7 (1.6) |
| Asian | | 7 (1.6) |
| Southeast Asian | | 6 (1.3) |
| Pacific Peoples | | 3 (0.7) |
| Other | | 26 (5.8) |
| Multiple Ethnicities | | 52 (11) |
| *Marital Status* | | |
| Single (never married) | | 21 (5) |
| Married or De Facto | | 368 (82) |
| Relationship | | 55 (12) |
| Divorced or Separated | | 5 (1.1) |
| Widowed | | 0 |
| *Living Arrangements* | | |
| Living with partner or spouse, and children | | 368 (82) |
| Living with partner or spouse, with no children | | 44 (9.8) |
| Solo adult with children | | 15 (3.3) |
| Living alone | | 2 (0.4) |
| Living with other adults (e.g., relatives, friends) | | 11 (2.5) |
| Other | | 8 (1.8) |
| *Employment Status* | | |
| Employed full time | | 63 (14) |
| Employed part time | | 45 (10) |
| Unemployed | | 82 (18) |
| Retired | | 0 (0) |
| Student | | 11 (2.4) |
| Maternity/Paternity Leave | | 238 (53) |
| A sickness benefit | | 10 (2.2) |
| *Level of Education* | | |
| Primary School | | 1 (0.2) |
| Intermediate School | | 6 (1.3) |
| Secondary School | | 111 (25) |
| Technical or Trade Certificate | | 51 (11) |
| University or Polytechnic Diploma | | 70 (16) |
| University Degree | | 209 (47) |
| *Relationship to Infant* | | |
| Mother | | 438 (98) |
| Father | | 11 (2) |
| *Multiple* | | |
| Yes | | 51 (11) |
| No | | 397 (89) |
| *Other Children in Household* | | |
| 0 | | 215 (48) |
| 1 | | 137 (31) |

| | | |
|---|---|---|
| 2 | | 60 (13) |
| 3 | | 23 (5.1) |
| 4+ | | 14 (3.1) |
| *Other Children Requiring Admission* | | |
| Yes | | 72 (31) |
| No | | 157 (69) |
| **Features of Neonatal Admission** | | |
| *Level of Unit Admitted To* | | |
| Level I | | - |
| Level II | | 128 (29) |
| Level II+ | | 66 (15) |
| Level III | | 255 (57) |
| Length of Time Admitted | 25.6 days | |
| Infant Birthweight | 2612 grams | |
| *Reasons for Admission* | | |
| Prematurity | | 217 (48) |
| Small for Gestational Age | | 35 (7.8) |
| Illness | | 93 (20) |
| Other (e.g., heart condition) | | 103 (22) |
| *Aware of Need for Admission* | | |
| Yes | | 170 (38) |
| No | | 279 (62) |
| *Infant Requiring Transfer* | | |
| Yes | | 125 (28) |
| No | | 324 (72) |
| *Travelled Away from Home* | | |
| Yes | | 172 (38) |
| No | | 277 (62) |
| **Babble App Use** | | |
| Yes | | 44 (10) |
| No | | 405 (90) |
| **Babble App Interest** | | |
| Yes | | 370 (92) |
| No | | 34 (8) |

### *10.8.1 Information-Seeking Behaviours*

Parents were asked to report their information-access behaviours, e.g., where and when they sought out information. Research suggests that parents in the neonatal unit spend up to twenty hours information-gathering a week, but little research has explored their preferences and when this takes place (Orr et al., 2017). Thus, including questions around this area was considered important to better understand parents informational needs and information-seeking behaviours. What sources of information parents’ primarily accessed, and across what time windows, are displayed in the two figures below.

**Figure 8**

*Information Sources Accessed by New Zealand Neonatal Parents, Organised in Descending Order of Popularity.*

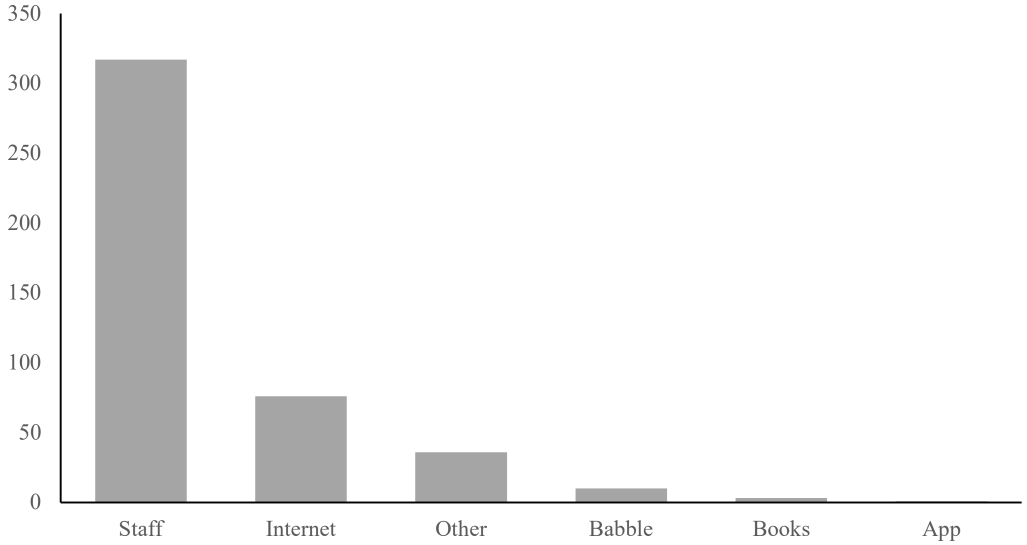
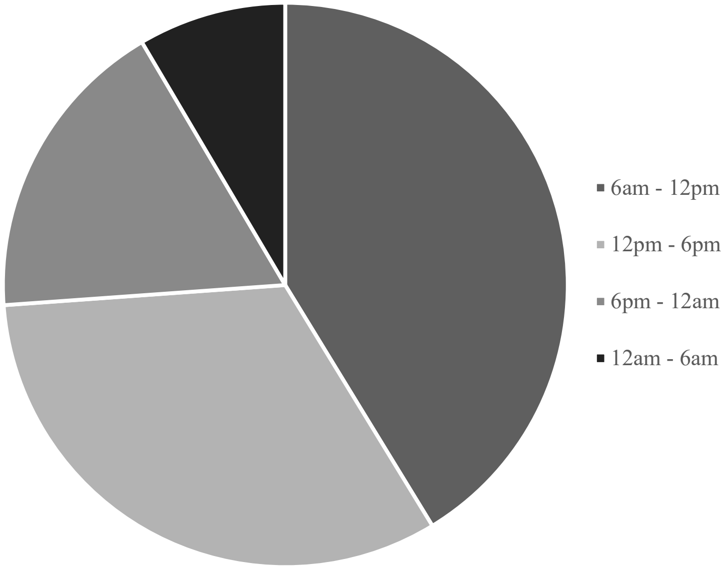


**Figure 9**

*Pie Chart Displaying the Windows of Time When New Zealand Neonatal Parents Most Commonly Accessed Information.*

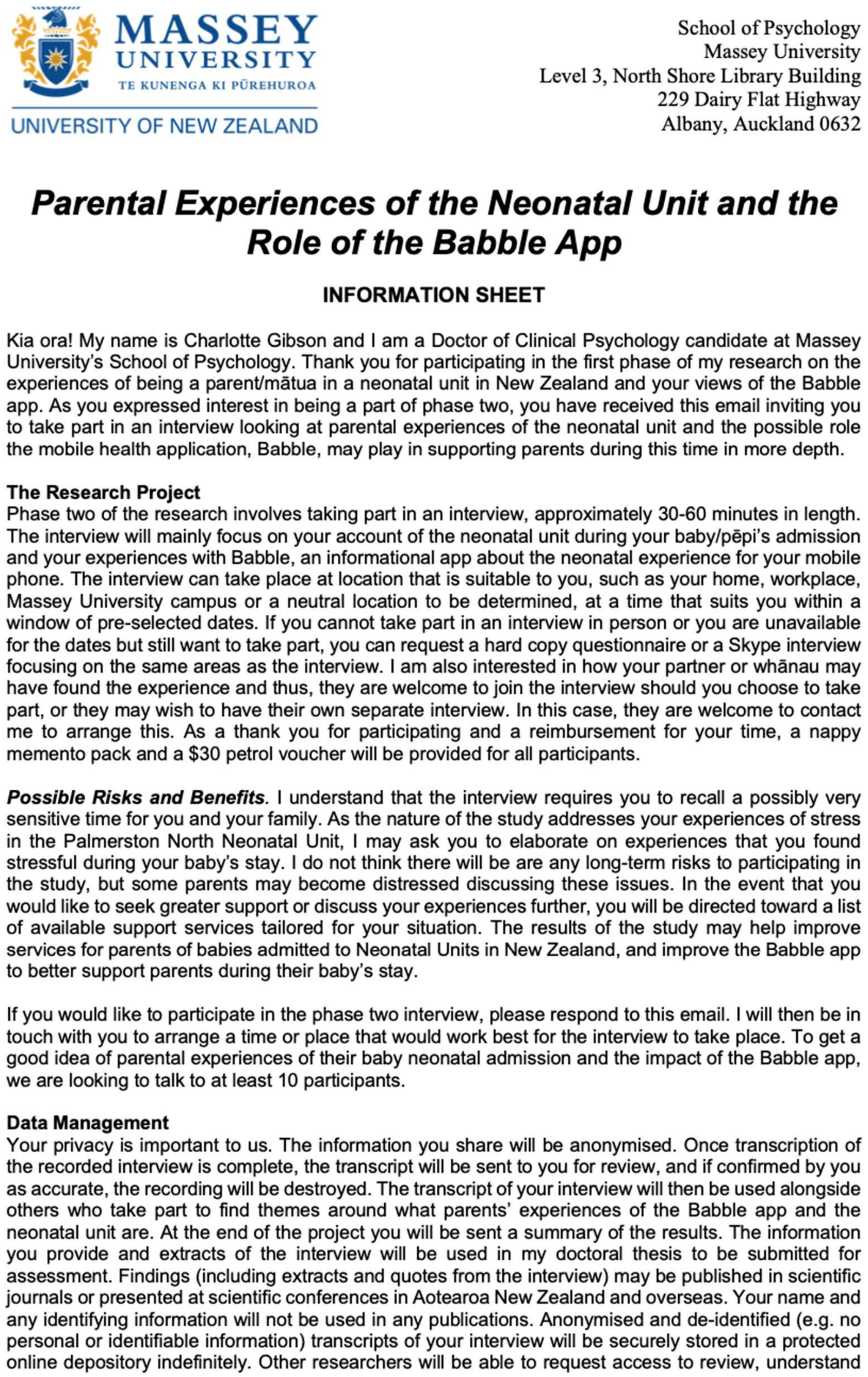


# 11. Appendix D: Supplementary Information for Article Two

Due to limitations in word count and to fit the purposes of a Doctor of Clinical Psychology thesis, additional information pertaining to additional methodological considerations for Study Two were included in this Appendix. References cited in this Appendix can be found in the consolidated reference list above.

## 11.1 Extended Methodology

### *11.1.1 Participant Information Sheet for Study Two*



MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

School of Psychology
Massey University
Level 3, North Shore Library Building
229 Dairy Flat Highway
Albany, Auckland 0632

# *Parental Experiences of the Neonatal Unit and the Role of the Babble App*

## INFORMATION SHEET

Kia ora! My name is Charlotte Gibson and I am a Doctor of Clinical Psychology candidate at Massey University's School of Psychology. Thank you for participating in the first phase of my research on the experiences of being a parent/mātua in a neonatal unit in New Zealand and your views of the Babble app. As you expressed interest in being a part of phase two, you have received this email inviting you to take part in an interview looking at parental experiences of the neonatal unit and the possible role the mobile health application, Babble, may play in supporting parents during this time in more depth.

**The Research Project**
Phase two of the research involves taking part in an interview, approximately 30-60 minutes in length. The interview will mainly focus on your account of the neonatal unit during your baby/pēpi's admission and your experiences with Babble, an informational app about the neonatal experience for your mobile phone. The interview can take place at location that is suitable to you, such as your home, workplace, Massey University campus or a neutral location to be determined, at a time that suits you within a window of pre-selected dates. If you cannot take part in an interview in person or you are unavailable for the dates but still want to take part, you can request a hard copy questionnaire or a Skype interview focusing on the same areas as the interview. I am also interested in how your partner or whānau may have found the experience and thus, they are welcome to join the interview should you choose to take part, or they may wish to have their own separate interview. In this case, they are welcome to contact me to arrange this. As a thank you for participating and a reimbursement for your time, a nappy memento pack and a $30 petrol voucher will be provided for all participants.

***Possible Risks and Benefits***. I understand that the interview requires you to recall a possibly very sensitive time for you and your family. As the nature of the study addresses your experiences of stress in the Palmerston North Neonatal Unit, I may ask you to elaborate on experiences that you found stressful during your baby's stay. I do not think there will be are any long-term risks to participating in the study, but some parents may become distressed discussing these issues. In the event that you would like to seek greater support or discuss your experiences further, you will be directed toward a list of available support services tailored for your situation. The results of the study may help improve services for parents of babies admitted to Neonatal Units in New Zealand, and improve the Babble app to better support parents during their baby's stay.

If you would like to participate in the phase two interview, please respond to this email. I will then be in touch with you to arrange a time or place that would work best for the interview to take place. To get a good idea of parental experiences of their baby neonatal admission and the impact of the Babble app, we are looking to talk to at least 10 participants.

**Data Management**
Your privacy is important to us. The information you share will be anonymised. Once transcription of the recorded interview is complete, the transcript will be sent to you for review, and if confirmed by you as accurate, the recording will be destroyed. The transcript of your interview will then be used alongside others who take part to find themes around what parents' experiences of the Babble app and the neonatal unit are. At the end of the project you will be sent a summary of the results. The information you provide and extracts of the interview will be used in my doctoral thesis to be submitted for assessment. Findings (including extracts and quotes from the interview) may be published in scientific journals or presented at scientific conferences in Aotearoa New Zealand and overseas. Your name and any identifying information will not be used in any publications. Anonymised and de-identified (e.g. no personal or identifiable information) transcripts of your interview will be securely stored in a protected online depository indefinitely. Other researchers will be able to request access to review, understand

and explore the transcripts themselves within this repository, but access will be at the discretion of the researcher.

**Your Rights**
You are under no obligation to accept this invitation. If you decide to participate, you have the right to:
- refuse to answer any particular question;
- withdraw from the study at any time until you confirm your transcript;
- ask any questions about the study at any time during participation;
- provide information on the understanding that your name will not be used;
- be given access to a summary of the project findings when it is concluded;
- ask for the recorder to be turned off at any time during the interview.

Thank you for your time.

Ngā mihi nui,

Charlotte Gibson.

**Project Contacts**
If you have any queries about phase two of the research project, please do not hesitate to contact me, or my supervisors; Dr Kirsty Ross and Dr Matt Williams:

Charlotte Gibson
thebabblestudy@gmail.com

Dr Kirsty Ross
k.j.ross@massey.ac.nz

Dr Matt Williams
m.n.williams@massey.ac.nz

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 18/64. If you have any concerns about the conduct of this research, please contact Dr Lesley Batten, Chair, Massey University Human Ethics Committee: Southern A, telephone 06 356 9099 x 85094, email humanethicsoutha@massey.ac.nz.

### *11.1.2 Interview Schedule for Study Two*

*denotes possible follow-up questions

**Tell me about….** Yourself and your family (e.g., partner, family of origin, children)?

Demographics: Age:

Location:

Role:

Education:

Career history:

Present job:

Culture:

## General Experience:

***Opening Question**:* I would like to learn more about your experience in the neonatal unit. I'm going to ask you a few questions to help guide our talk, but I'm very interested in hearing about your experiences as a whole so please feel free to mention anything else you think could be important. To start us off, why was your baby admitted?

*Before Admission:*

What were the events leading to the neonatal admission?

*Were you aware of the need for admission?

*How was your/the mother's pregnancy and birth experience?

What was life like before the admission?

*Admission*:

What was the experience of having your infant admitted to the neonatal unit like for you?

What did you find most difficult about the experience?

*How did you manage in these difficult moments?

Can you tell me about any positive memories you may have from the experience?

What forms of support did you seek throughout your infant's admission, if any?

*What would you say was the most helpful for you?

*What sort of coping strategies did you use to get through the time she/he was admitted?

How did the experience impact your relationships? (If applicable: With the infant? Your other children? Your partner? Your parents?)

*Information*:

How did you learn about your infant and the care he/she was provided?

*Did you feel informed and involved throughout the experience?

*Where did this information come from? Staff? Own research?

What could have improved your experience?

*The Babble App:*

Did you use the Babble app during your neonatal stay?

How did you find the app to use?

Did you particularly enjoy any components?

Did you find any components less helpful or useful than others?

How did the app fit with the other support you were provided?

*Did it meet any of your needs in particular?

Do you have any comments for improvement?

*Looking Forward:*

How have you been since discharge?

How was the discharge process for you?

How has it been settling in at home? How is your baby doing now?

## **Closing Questions:**

Is there anything else you would like me to know about your experience?

How have you found talking to me today?

*Thank you very much for taking the time to speak with me today. I appreciate you taking part in my study and sharing your experiences with me. Do you have any questions for me or is there anything else you'd like to share?*

**Support Services.**

Thank you for your participation! The process of having an infant admitted to the neonatal unit can be stressful for parents but if any of these questions make you feel significantly distressed or upset, please reach out to your support systems, be that family, friends, hospital support staff, kaumātua, GP or church. Alternatively, please speak with your neonatal nurse, doctor or ask to speak to the neonatal unit social worker for more support within the unit if you are current admitted. For more general support, here is a list of resources may be useful to help support you and your family during this process:

| Service | Contact Details |
|---|---|
| **The Nationwide Neonatal Trust**<br>*Provide information packs, support networks and some financial support e.g., petrol voucher/accommodation* | https://www.neonataltrust.org.nz/support-resources/how-we-help-nicu |
| **Plunket Palmerston North**<br>*Free home visits and support for parents of children under five* | 06 356 7248<br>https://www.plunket.org.nz/plunket/show/palmerston-north-family-centre |
| **Plunketline**<br>*Free parent helpline and advice service* | 0800 933 922 |
| **Birthright New Zealand**<br>*Support for single-parent families* | 06 357 3509<br>http://www.birthright.org.nz/region/palmerston-north |
| **Parent to Parent Manawatu**<br>*Information and support for parents of children with disabilities, health difficulties etc* | 06 355 0787<br>https://parent2parent.org.nz |

| | |
|---|---|
| **Mokopuna Ora**<br>*A kaupapa Māori approach providing information around pregnancy and parenting, incorporating tikanga and te reo* | https://mokopunaora.nz |
| **Te Waka Huia a Manawatu Trust**<br>*Māori community health service providing whānau and tamariki support (e.g., well child service)* | 06 357 3400 |
| **Anglican, Catholic & Community Social Service (ACROSS) Palmerston North**<br>*Parenting support and programmes* | 0800 227 677 |
| **Tapuaki**<br>*Information about pregnancy and parenting for Pacific families* | http://www.tapuaki.org.nz |
| **Parent Help**<br>*Free parenting support service* | 0800 568 856 |
| **Barnados Parent Help Line**<br>*Free parenting support service* | 0800 472 7368 |
| **Mothers Matter**<br>*Online postnatal depression information and support* | https://www.mothersmatter.co.nz |
| **Lifeline**<br>*Free counselling service* | 0800 543 354 |
| **Depression Line**<br>*Free depression counselling and advice* | 0800 111 757<br>Free text 4202 |
| **Anxiety Line**<br>*Free anxiety management and support* | 0800 269 4389 |
| **Healthline**<br>*Free health information* | 0800 611 116 |
| **Samaritans**<br>*Free counselling and support* | 0800 726 666 |
| **Family Services 211 Line**<br>*Information around community based health and social support services* | 0800 211 211 |

### *11.1.3 Thematic Analysis*

Qualitative thematic analysis methodology was chosen to support the investigation into parents' experiences of the neonatal unit and the role of the Babble app. This decision was made due to the accessible and flexible framework it offers (Braun & Clarke, 2006), and the prevalence of its usage within this area of research (Arnold et al., 2013; Hagen et al., 2016; Mäkelä et al., 2018; Russell et al., 2014; Stacey et al., 2015; Treherne et al., 2017; Turner et al., 2015; Whittingham et al., 2014). Thematic analysis as a research methodology accommodates diverse and varied perspectives and allows for an independence from theory, leading to wider application across settings (Braun & Clarke, 2006). For the present work, an inductive thematic analysis at the semantic level was considered appropriate.  Such an inductive approach of semantic information allowed the researcher to explore 'bottom-up' themes free of any preconceived concepts or theoretical bias. Rather than seeking views on topics informed by evidence base, an advantage of an inductive approach is that is open to participants' experiences and is built off participant responses, limiting the assumptions and biases perpetuated in the literature. Given the vulnerability of the mothers who participated, it was considered important to empower their stories and utilise a methodology that spoke to this.

In this study, retrospective interviews were utilised to allow the mothers time from the stressful setting of the neonatal unit and to give them time to adjust to their new role as a parent of a newborn. Although the use of retrospective interviews presents issues relating to their reliability, it was considered that as the event of neonatal admission is considered particularly salient for the individual, it would be easily recalled by participants (Blane, 1996; Wereszczak et al., 1997).

Thematic analysis allows for the consideration of a large amount of data from multiple participants to be synthesised into a meaningful account (Boyatzis, 1998). Braun and

Clarke’s (2006) approach to thematic analysis was utilised, providing a structured methodology to identify key themes within the data set.

Commonly transcription is considered the first stage of data analysis due to the necessary interpretive decisions about how to represent conversations between the interviewer and participants (Braun & Clarke, 2006). Not only does transcription by the researcher allow for greater familiarity with the literature but also enhances early thematic coding as this familiarity grows. Transcription for the present study was completed as soon as possible subsequent to each interview. Transcripts included verbatim interactions between the interviewer and participants, inclusive of laughs, tears, wavering, pauses and false starts. Minimal encouragers by the interviewer such as ‘mm’, ‘OK’ and ‘right’ were removed so as to limit the disruption of the flow of participant’s responses. Participants were provided with a copy of their completed transcript for review and any changes or additional comments were included. Upon the integration of any participant comments, transcripts were finalised and reviewed multiple times to increase familiarisation, and initial concepts were formulated.

As per Braun and Clarke’s (2006) approach to thematic analysis, the next step was to develop initial codes from the raw data. Accordingly, raw data was then organised into as many or as few meaningful groups as needed. Inclusive codes were used to allow for ideas to fit as many codes as appropriate, enabling a deeper understanding of the data and a more realistic representation of the human experience where ideas commonly overlap.

Once identified, the initial codes were then grouped together with other codes that were similar to create potential themes (Braun & Clarke, 2006). These themes were reviewed to provide a rich and in-depth description of the data set. Themes were reviewed repeatedly to refine them and ensure they were consistent across all participants, supported by the responses and quotes provided throughout the interviews. The themes were then defined and named through a reflective process where the researcher explored questions such as ‘What is this theme about?' 'Is this identified theme consistent with the data?' 'Are there any sub-themes?' (Braun & Clarke, 2006). A detailed written analysis explaining each individual theme was completed, informed by this process reflection and refinement (Braun & Clarke, 2006).

### *11.1.4 Ethical Considerations*

Possible distress caused by the discussion topic was identified as an ethical issue. Due to the sensitive information discussed in the interview, including topics relating to being separated from the infant and possibly traumatic births, it was possible that participants may become distressed during the interview. To mitigate this risk, the researcher's supervisor, a Clinical Psychologist, made herself available for supervision to ensure any presentations of acute distress were navigated appropriately and support was provided as needed. Interview questions were reviewed by this supervisor and deemed appropriate for the researcher to utilise. The researcher herself also has considerable psychological training and experience in clinical interview settings as a Clinical Psychology student. During the interview, participants were made aware of their right to stop or take a break at any stage. As the interviews took place subsequent to the neonatal stay, there was considered to be a lower risk of emotional distress than had the interview taken place during the admission period.

Another identified ethical issue was the balance of confidentiality and ensuring data was openly accessible to other researchers. To preserve confidentiality, the researcher used codes instead of names on transcriptions of audio-recordings. All electronic data was password protected, and all paper data was stored in a locked cabinet, intended to remain there for at least five years, as per university policy, before it is destroyed. In the interest of open science, transcription data has been stored indefinitely in a durable, online, password protected file through the Open Science Framework. Only the researcher has direct access to this data, but other researchers are able to contact the researcher and request access if they have legitimate reasons to do so. The researcher can then decide whether to provide other researchers with access through a password. Participants were informed of the process for storing data both verbally, and in the information sheet and consent form. No participants expressed concerns about the use and storage of their information, either during or after data collection.

Other considerations included that due to the small community of the Manawatū region, specific or unique experiences that may have enabled the identity of participants to be revealed was considered and avoided. All published excerpts from the interview transcripts were made anonymous and did not contain any identifiable information.

# 12. Appendix E: Conference Presentation

This appendix includes information pertaining to a presentation that was given at the Paediatric Society of New Zealand Conference: 71st Annual Scientific Meeting 2019.

## 12.1 Abstract

### *12.1.1 Parents' Experiences of the Neonatal Unit And the Role of the Babble App*

**Charlotte Gibson**[*1], Kirsty Ross[2] , Matt Williams[1], and Nathalie de Vries[3]

[1] *School of Psychology, Massey University, Auckland, New Zealand*

[2] *School of Psychology, Massey University, Palmerston North, New Zealand*

[3] *Child Health, MidCentral Health, Palmerston North, New Zealand*

### *12.1.2 Background*

Neonatal unit admission is typically a distressing and difficult time for parents, during which parents may experience lower confidence, predisposing them to significant mental health difficulties. The present study aimed to explore the role of the informational support app, Babble, on distress, self-efficacy and how informed parents feel.

### *12.1.3 Methods*

Using a preregistered nationwide, anonymous, online survey for parents with an infant admitted to any neonatal unit in New Zealand within the last year, participants responded to a variety of questions, including their levels of distress as measured by the Parental Stressor Scale: Neonatal Intensive Care Unit, how informed they felt and how confident they felt in their parental role. Parents were also asked to report whether they had used the Babble app or not.

### *12.1.4 Results*

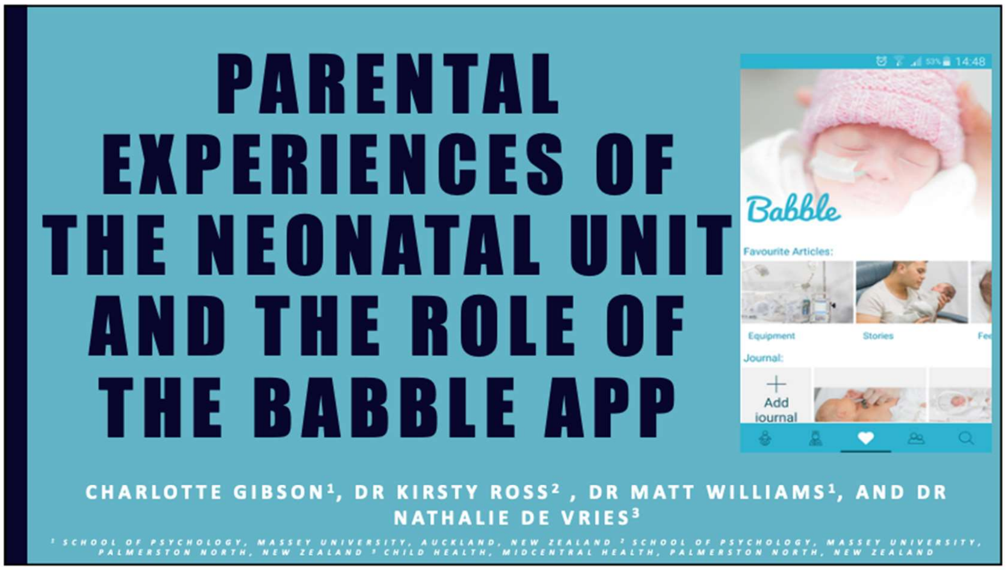
Four hundred and forty-nine parents who completed the survey were included in the analysis. 44 of these parents reported using the Babble app. No significant effects of Babble app use on parental distress, how informed parents felt or parental self-efficacy were

identified. Greater reported distress was significantly predicted by parents being younger, having an infant admitted to a higher level of unit, and for a longer period of time. Parents admitted to a Level III unit were significantly more likely to report feeling less informed than other units, and, mothers reported feeling significantly more informed than fathers. Mediational analyses indicated that the more informed parents felt, their distress was reduced, partially mediated by enhanced parental self-efficacy.

### *12.1.5 Conclusion*

Although the results did not indicate a significant effect of Babble on the variables of interest, the more informed parents were, the greater their self-efficacy and the less distress they reported experiencing. Future interventions targeted at increasing how informed parents feel may be effective in improving self-efficacy, thus, reducing parents' experiences of distress.

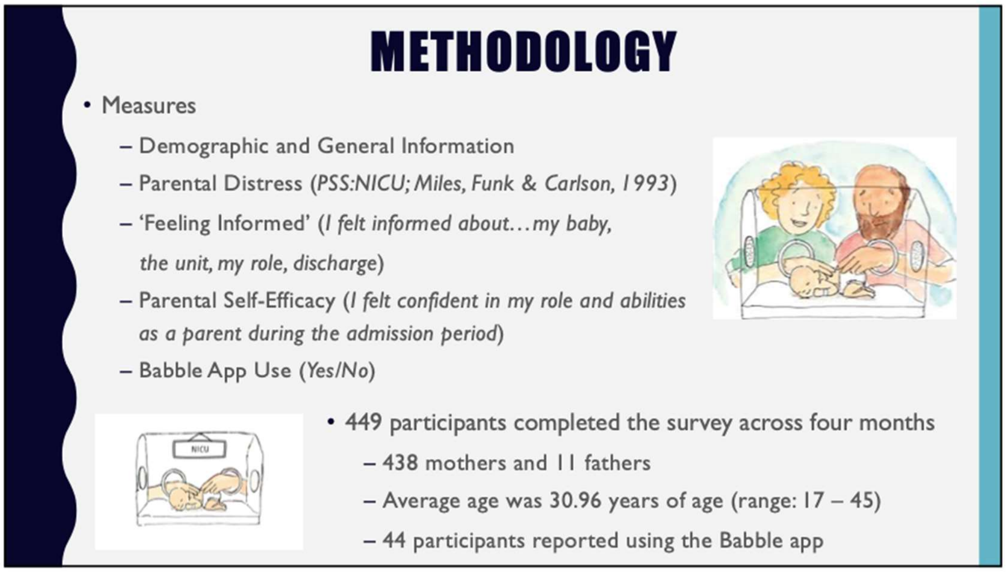
## 12.2 Presentation



# PARENTAL EXPERIENCES OF THE NEONATAL UNIT AND THE ROLE OF THE BABBLE APP

CHARLOTTE GIBSON[1], DR KIRSTY ROSS[2] , DR MATT WILLIAMS[1], AND DR NATHALIE DE VRIES[3]

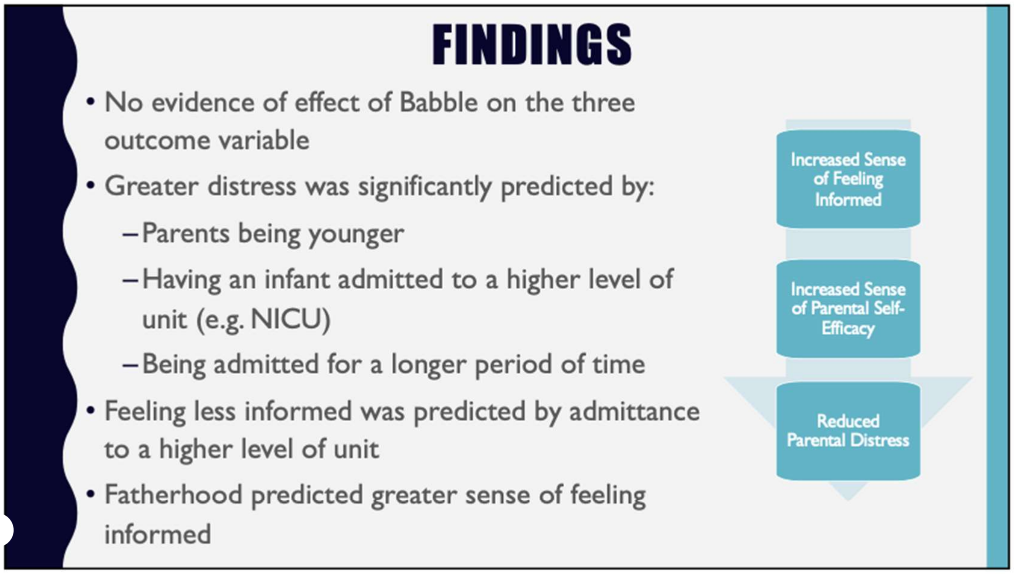
[1] SCHOOL OF PSYCHOLOGY, MASSEY UNIVERSITY, AUCKLAND, NEW ZEALAND [2] SCHOOL OF PSYCHOLOGY, MASSEY UNIVERSITY, PALMERSTON NORTH, NEW ZEALAND [3] CHILD HEALTH, MIDCENTRAL HEALTH, PALMERSTON NORTH, NEW ZEALAND



# METHODOLOGY

- Measures
  - – Demographic and General Information
  - – Parental Distress (*PSS:NICU; Miles, Funk & Carlson, 1993*)
  - – 'Feeling Informed' (*I felt informed about…my baby, the unit, my role, discharge*)
  - – Parental Self-Efficacy (*I felt confident in my role and abilities as a parent during the admission period*)
  - – Babble App Use (*Yes/No*)

- 449 participants completed the survey across four months
  - – 438 mothers and 11 fathers
  - – Average age was 30.96 years of age (range: 17 – 45)
  - – 44 participants reported using the Babble app



# FINDINGS

- No evidence of effect of Babble on the three outcome variable
- Greater distress was significantly predicted by:
  - Parents being younger
  - Having an infant admitted to a higher level of unit (e.g. NICU)
  - Being admitted for a longer period of time
- Feeling less informed was predicted by admittance to a higher level of unit
- Fatherhood predicted greater sense of feeling informed

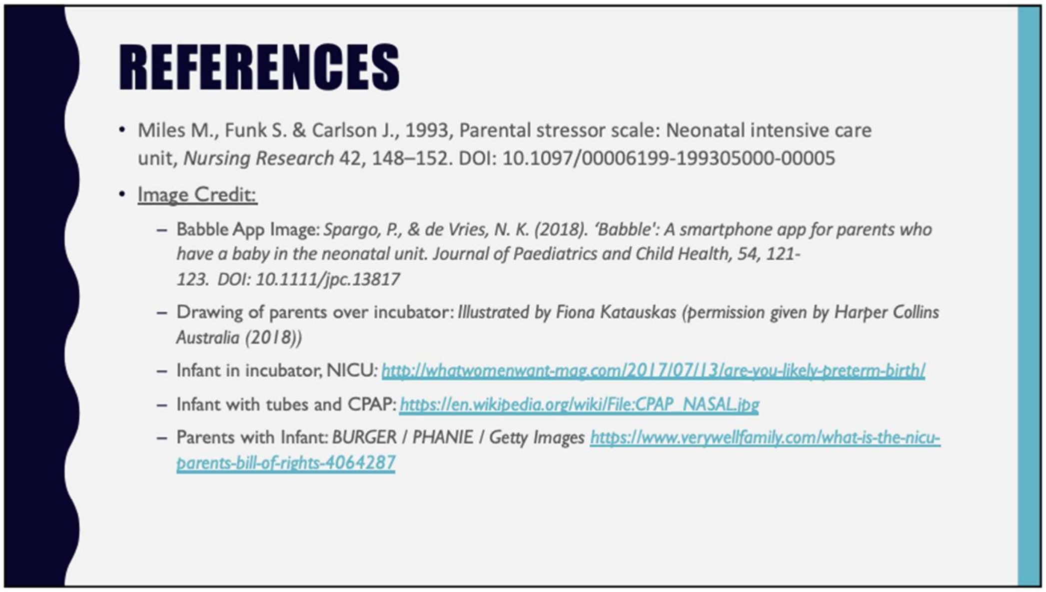
Increased Sense of Feeling Informed

Increased Sense of Parental Self-Efficacy

Reduced Parental Distress

# THANK YOU FOR LISTENING

ANY QUESTIONS?



# REFERENCES

- Miles M., Funk S. & Carlson J., 1993, Parental stressor scale: Neonatal intensive care unit, *Nursing Research* 42, 148–152. DOI: 10.1097/00006199-199305000-00005
- Image Credit:
  - Babble App Image: *Spargo, P., & de Vries, N. K. (2018). 'Babble': A smartphone app for parents who have a baby in the neonatal unit. Journal of Paediatrics and Child Health, 54, 121-123. DOI: 10.1111/jpc.13817*
  - Drawing of parents over incubator: *Illustrated by Fiona Katauskas (permission given by Harper Collins Australia (2018))*
  - Infant in incubator, NICU*:* *http://whatwomenwant-mag.com/2017/07/13/are-you-likely-preterm-birth/*
  - Infant with tubes and CPAP: *https://en.wikipedia.org/wiki/File:CPAP_NASAL.jpg*
  - Parents with Infant: *BURGER / PHANIE / Getty Images* *https://www.verywellfamily.com/what-is-the-nicu-parents-bill-of-rights-4064287*

# 13. Appendix F: Thesis Case Study

As part of a Doctor of Clinical Psychology thesis, candidates are required to include a 'Thesis Case Study' which is examined as part of the clinical component of the doctorate. The case study speaks to the learnings the candidate has taken from the research conducted, and how these learnings have contributed to their clinical internship. The case study is included below.

Massey University
Clinical Psychology

# CASE STUDY [*RESEARCH #1*]

# ‘The Power of Little Things’: How my Doctoral Research Contributed to my Clinical Practice during my Internship with the Department of Corrections

Candidate : Charlotte Gibson
Clinical Psychology Programme Massey University
Student ID : 15281227
Setting : Counties Manukau Community at Department of Corrections
Supervisor : Jacques Taylor and Kalpana Govind

This case study represents the work of Charlotte Gibson during her research from 2018 to 2019 and reflections as an Intern Psychologist in 2020.

---

| | |
|---|---|
| **Supervisor** | **Student** |
| **Kirsty Ross** | **Charlotte Gibson** |
| **Senior Clinical Psychologist & Senior Lecturer** | **15281227** |
| **Massey University Palmerston North Clinical Programme Campus Coordinator** | |
| KRoss | |

Date : 23 June 2020

## 13.1 Abstract

The present work outlines learnings I have taken from my experiences with my doctoral research and how they apply to my work as an intern psychologist at the Department of Corrections, specifically, with the Counties Manukau Corrections team which services Auckland Region Women's Correctional Facility (ARWCF), Korowai Manaaki (Youth Justice Residence) and Probation sites across the Manukau region. The case study opens with an overview of my doctoral research, which focuses on the experiences of parents with an infant admitted to a neonatal unit within New Zealand, and their perspective of an informational support app, Babble. Attention is then paid to how my experience designing, conducting and analysing my doctoral research has informed and enhanced my work as an intern psychologist within a forensic setting. Such reflections include the refining of interviewing skills, building relationships with those of different backgrounds or experiences, the importance of information, working within institutions of power, and the need to acknowledge power imbalances within a therapeutic space.

### *13.1.2 Keywords*

Self-reflection; neonatal units; offender; information; empathy; power.

## 13.2 Doctoral Research Overview

My doctoral research focuses on understanding the experiences of parents with an infant admitted to a neonatal unit. Neonatal units are facilities located throughout New Zealand hospitals built to care for infants who are born premature, sick or small. The study had a secondary aim of assessing the feasibility and usefulness of an app, Babble, targeted to support and improve the experiences of parents of neonates. The following section will provide an overview of the study background, rationale, aims, methodology and results. By providing information about the research conducted, it is hoped that the reflections around my role as an intern psychologist will be contextualised.

### *13.2.1 Study Beginnings*

Dr Kirsty Ross, my supervisor, has strong ties with MidCentral District Health Board, as she has done significant work with families of children with cancer and other serious health conditions through their services. In 2017, she was approached by Dr Nathalie de Vries who had recently developed and implemented the Babble app within the neonatal unit at Palmerston North Hospital. Dr de Vries was aware of the need to empirically validate the effects of the app before implementing the app into other units across New Zealand, and so spoke about the possibility of conducting such a study with Dr Ross. The proposed study planned to look at the Babble app and its role within the Palmerston North neonatal unit (unique in its level of care[6]). It was assumed that such a focused, centralised approach would provide the greatest insight into the impact of the app. I approached Dr Ross in 2017 for potential supervision. Given my interest in developmental and family psychology,

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[6] Level II+ unit, meaning it is able to care for infants born as early as 28 weeks. Typically, infants born at 32 weeks' gestation or younger are required to be admitted to Level III or neonatal intensive care units. On the other hand, Level II units have facilities to care for infants beyond 32 weeks gestation. Level II+ units appear unique to the New Zealand context and bridge some of the care provided between Level II and Level III.

accompanied with my previous experience in conducting research with infants, it was agreed it would become my doctoral research project.

Initially, the study intended to focus exclusively on the role of the Babble app on parental experiences, looking to determine if the app had any impact of their reported distress, self-esteem and how informed they felt. However, when the initial literature search was performed in early 2018, it became clear that very little attention had been paid to the experiences of New Zealand parents with infants admitted to neonatal units, with the most recent New Zealand based literature being performed around 15 years ago (Carter et al., 2005; Carter et al., 2007; Carter et al., 2007). Additionally, as time had passed since the initial conceptualisation, it became clear that Babble was being used by units aside from the Palmerston North unit where the initial project was centred. Thus, the research expanded into a nationwide exploration of parental experiences of the neonatal unit and their use of the Babble app.

### *13.2.2 Study Rationale and Aims*

The admittance of an infant to a neonatal unit has commonly been associated with significant emotional distress (Ballantyne et al., 2017). Parents of neonates are seen to have significantly higher rates of mental health difficulties and general distress, compared to parents of full-term infants (Carter et al., 2005; Holditch-Davis et al., 2015). Moreover, there is evidence to suggest that neonatal admission impacts parental self-efficacy, which ultimately affects parental resilience and adaptive coping abilities moving forward (Reid, 2000). Research shows that mothers with lower self-efficacy are more likely to become easily overwhelmed and report lower parenting effectiveness, an insecure bond with their infant and increased susceptibility to helplessness (Coleman & Karraker, 1998). These experiences of distress and impacted self-efficacy have been shown to influence a parent's ability to parent effectively. For example, the literature suggests that neonatal infants are at a greater risk of neglect and child abuse, in part due to greater rates of stressed and overwhelmed parents (Puls et al., 2019; Spencer et al., 2006). Thus, it is understandably in the best interests of the parent, infant and wider community to provide support to parents with infants admitted to neonatal units to prevent negative long-term outcomes for the family as a whole.

Given the significant and varied negative impacts of neonatal admission on parents, international literature has explored ways to best support parents throughout the process. Parents of admitted infants commonly report a need for consistent and reliable information during their neonatal stay, citing information as a tool that helps build their confidence and manage their distress (Cleveland, 2008; De Rouck & Leys, 2009; Lantz, 2017). As such, several informational or education-orientated interventions have demonstrated reductions in parental stress and improvements in overall wellbeing and confidence (Bracht et al., 2013; Melnyk et al., 2006). Recent New Zealand literature demonstrated that parents felt positively towards such informational support being provided through a smartphone application, alongside traditional formats (Williams et al., 2020). Other research indicates that information provided to parents through apps, during the postpartum period, meets parental informational needs and enhances their parenting self-efficacy (Danbjørg et al., 2015; Garfield et al., 2016; Shorey et al., 2017). Ultimately, no research has been performed on exploring the role of an app targeted directly at neonatal parents to provide them with informational support during their neonatal admission, hence the need for an investigation into the feasibility and usefulness of the Babble app. The Babble app is a freely available, portable and accessible tool, which provides general information about the neonatal unit, medical equipment, unit processes and health of the infant.

The aim of this project was to explore the experiences of New Zealand parents with an infant admitted to any of the 23 neonatal units in New Zealand. Additionally, the project looked to explore the role of the Babble app within these experiences, specifically across the measures of general distress, parental self-efficacy and how informed parents feel about their infant and the care they received. This project was designed to develop and contribute to neonatal parent literature, both internationally and within a New Zealand context. Furthermore, it looked to better understand the feasibility and usefulness of a smartphone application intervention, namely the Babble app.

## 13.3 Methodology

A mixed-method approach was taken to address the study aims through both survey data and qualitative interviews. The following section is divided, for ease of understanding, into Study One, which utilised a nationwide survey obtaining qualitative data, and Study Two, qualitative interviews analysed through thematic analysis. Study One was pre-registered[7].

### *13.3.1 Participants*

**13.3.1.1 Study One.** Four hundred and forty-nine parents with an infant admitted to any neonatal unit in New Zealand from March 2018 to June 2019, participated in this study. Primarily mothers took part and 44 of these participants were Babble users. Participants were invited to participate if they had an infant admitted to any neonatal unit, for any reason and for any length of time, within New Zealand in the last 12 months.

**13.3.1.2 Study Two.** Participants with an infant who had been admitted to the Palmerston North neonatal unit within the last 12 months were invited to participate. Eight mothers were interviewed by way of semi-structured, qualitative interviews lasting around 53 minutes on average. Of the eight mothers, five reported using the Babble app.

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[7] The pre-registration document is viewable at https://osf.io/28sn6?view_only=55f68c3550534a858ac7cfdc5b7c79f6

### *13.3.2 Procedure*

**13.3.2.1 Study One.** Recruitment ran for four months and through a variety of mediums. Primarily recruitment occurred through social media sites (such as Facebook, infant support groups and neonatal support organisations) and posters across the Palmerston North neonatal unit (in an attempt to target Babble users specifically). A link to the survey was also placed in versions of the Babble app available to nationwide users, aside from the version available to Counties Manukau District Health Board users. Information about the survey and the link to the survey was available through these avenues.

Participants completed an online, anonymous survey designed by the researcher and hosted on a Qualtrics survey system. The survey included questions focusing on participants' demographic information, the admission experience, parental needs, distress (as measured by the Parental Stressor Scale: Neonatal Intensive Care Unit; Miles et al., 1993), self-efficacy, feeling informed, and the Babble app. Median survey completion time was 13 minutes. As a thank you for participating, participants went into a draw to win 1 of 10 $75 GiftPay vouchers. 10 participants were selected and provided with their voucher.

**13.3.2.2 Study Two.** Recruitment occurred through the same avenues as Study One. Upon completion of the online survey, parents who had selected 'Palmerston North Hospital' as where their infant had been admitted to, were given the opportunity to select if they were interested in taking part in an interview. Interviews were held in a location of participants' choosing; six participants opted to have the interview in their home, with one participant offering to host herself and another participant. Two of the eight interviews were completed over Skype. Interviews were audio-recorded and the interviewer took additional field notes. Recordings were then transcribed verbatim and identifying information removed. Transcripts were sent to participants for review and amendments were made as requested. As a thank you for participating, parents were provided with a $30 petrol voucher and a nappy memento pack.

A semi-structured interview schedule was used consisting of five topics, encompassing 29 open-ended questions. Questions focused on parents' experiences of the birth (e.g., how was your pregnancy and birth experience?), the admission (e.g., what was the experience of neonatal admission like for you?), information access (e.g., how did you learn about your baby and the care they were provided?), the Babble app (e.g., how did you find the app to use?) and the discharge process (e.g., how was the discharge process for you?). General socio-demographic information was obtained at the beginning of the interview and data about the infant's health and wellbeing was obtained through questions spread throughout the interview.

### *13.3.3 Data Analysis*

**13.3.3.1 Study One.** Data analysis was completed using R version 3.5.1 (R Core Team, 2019). The three main hypotheses around Babble app use were addressed through regression analysis. These hypotheses were as follows:

> *Hypothesis One.* Parents of infants in neonatal units who have used the Babble app will report lower levels of distress than parents who have not, controlling for level of unit, length of stay, parental age and parental role.
>
> *Hypothesis Two.* Parents of infants who have used the Babble app will report higher levels of self-efficacy compared to parents who have not, controlling for level of unit, length of stay, parental age and parental role.
>
> *Hypothesis Three.* Parents of infants who have used the Babble app will report a higher sense of feeling informed than parents who have not, controlling for level of unit, length of stay, parental age and parental role.

Additional exploratory analyses were conducted to answer a variety of research questions pertaining to the overarching study aims.

**13.3.3.2 Study Two.** Inductive thematic analysis, as per Braun and Clarke's (2006) guidelines, was used to carry out the qualitative analysis of the interview transcripts. Braun and Clarke (2006) suggest that thematic analysis offers an accessible, systematic and theoretically flexible approach to analysing qualitative data; thus, it was considered an appropriate method for the present work. In addition, thematic analysis has been used widely to investigate parents' experiences in the NICU, further indicating it to be an appropriate methodology (Whittingham et al., 2014; Turner et al., 2015; Treherne et al., 2017).

An inductive approach was utilised to avoid potential assumptions and biases and to ensure the findings were grounded in participant responses. In line with the Braun and Clarke's (2006) thematic analysis method, transcripts were firstly read and then re-read, to allow for familiarisation with the data. Initial codes of interest were then generated based on commonality and saliency of responses across the data. These initial codes were organised into potential themes and were reviewed and refined, ensuring consistency across the entire dataset. Finally, themes were named and defined with a written analysis completed to accompany each theme identified.

### *13.3.4 Ethics*

Ethics approval for both components of the study was granted by the Massey University's Ethics Committee Southern A (Application 18/64, 05/11/18). MidCentral District Health Board approved advertising on the 28th of February 2019.

## 13.4 Results

### *13.4.1 Study One*

Primarily, parents reported finding the experience of neonatal admission moderately distressing, reporting they viewed the overall experience relatively positively. There was no effect of the Babble app on parental distress levels, how informed parents felt, or how confident they felt in their parental role. There was a negative relationship between self-efficacy and parental distress, which was partially mediated by how informed parents felt. These findings suggest that with the provision of information, parents feel more confident which in turn, reduces their distress. Thus, the importance of information in supporting and enhancing parental experiences was evidenced.

#### *13.4.2 Study Two*

Three key themes were identified pertaining to maternal experiences of the neonatal unit and their perspectives on their use of the Babble app. These themes were: 1) adjusting to neonatal motherhood; 2) relationships; and 3) the power of information. Becoming a mother of a neonate was seen to encompass a variety of reported experiences, but primarily focused on difficulty in establishing maternal identity, a need to manage expectations, an adjustment in how they connected with their infant and the importance of embracing the parental role. Negative emotions were common and, for several of the mothers interviewed, coloured the entire experience. Mothers also identified significant and varied impacts on relationships with their partner, extended family and other children. They reported that the relationships built with staff were essential to their experience, holding sway over whether the experience was positive or negative. Finally, all mothers identified the power that information held, and their need for clear and consistent information, in an effort to manage their feelings of anxiety and the experience as a whole. Those who utilised the Babble app acknowledged its role in providing clear and comprehensive information necessary in helping them adjust to the neonatal experience.

### 13.5 Clinical Psychology Internship

My internship began in February 2020 with the Counties Manukau Community Corrections team, at the Department of Corrections. I had previously completed a 120-hour placement with the service and so had some familiarity with the team, and service as a whole, upon beginning my internship. The Manukau Psychologists Office works across all the community probation sites within the Counties Manukau area as well as with Korowai Manaaki (a Youth Justice Residence), and Auckland Region Women's Prison (ARWCF). My internship has been primarily based in the women's prison and thus, the observations made below are representative of my work with this population. They include reflections on general interviewing skills and building rapport, engaging with those whose experiences differ from my own, the power of information and difficulties associated with working within systems of power. In the following, my clients are referred to at times, as wāhine, people in our care, paihere, or offenders, as is the common protocol within the Department of Corrections.

### *13.5.1 Interviewing Skills*

I began my research interviews in early 2019, prior to any of my community placements and experience of face-to-face clinical interviewing, aside from role plays and other jobs I had done prior to commencing my clinical training. Before my first research interview, I felt incredibly anxious and as I conducted more interviews, I found it difficult to establish the balance between a research interview and a therapeutic interview. The research interviews I conducted were powerful in honing my clinical skills without the pressure of being 'perfect' or feeling a need to utilise a variety of therapeutic tools or techniques. Skills like building rapport, reflective listening, sitting with distress and traumatic experiences, as well as general questioning skills, were all developed through my research interviews. Research interviews, as I understand it, are primarily utilised to gather information in a supportive way, but within my research, there was not the same demand to understand a presenting problem and identify treatment needs as there is likely to be in a clinical interview. Rather, I considered indicating that I would be able to support them in a clinical sense to be unethical, given the purpose of me meeting them. However, I did find similarities between a clinical and research interview in the need for participants to understand the process, the importance of open-ended questions and taking a non-judgmental and empathetic approach. My listening and rapport-building skills were all needed in the research context also to support participants to feel comfortable in being honest with me. These experiences allowed me to improve on, and practice these important clinical skills, which have been essential in the context of my internship. As the interviews progressed, it became easier to define my role and purpose, and thus, I was able to focus on developing rapport and understanding the participants' narrative, in a way that I hope was supportive and positive for them.

My first experiences of having another person lean into their vulnerability in front of me occurred within the context of the research interviews. I am thankful to those mothers who were so vulnerable with me. Not only because of the information they gave me to support my research and hopefully improve experiences for other families, but also because of the exposure they gave me to raw vulnerability and pain, and the learnings I took from this. Within my internship, several of my clients have spoken of various traumatic experiences and have become emotionally distressed when recounting these. Due to the experiences of discussing traumatic events within research interviews and having the valuable time to learn how best to hold the space, I have found myself able to sit with clients when trauma has presented itself throughout my internship. These moments have become significant to me as a clinician, in part because I was able to see how impactful these moments can be through my research interviews. Within a Corrections setting, holding the space, by staying silent or providing validation, when discussing trauma is essential to help the client process their own experiences. Holding this space additionally enhances the therapeutic relationship and helps clients develop trust in me, which is highly relevant within my population as trust is not always easily established.

### *13.5.2 Experiences that Differ from My Own*

During the design and implementation phases of my research, people were often intrigued or surprised to find that I was not a mother myself. Within the first few interviews, it became clear that some participants would, at times, dismiss me as 'not understanding' the bond between themselves and their child, as indicated by statements such as 'you'll get it one day'. At times, these comments were hard to hear, and I resisted the urge to reassure or justify my position. As the interviews progressed it became clear that the best way of managing this was to explore why the participants felt this way or reflect that, as I was not a mother and I could not imagine the connection they felt with their infant and the impact their infant's absence would have had. Such strategies appeared to effectively build trust and validate the experiences of the mothers. Ultimately, I concluded that when I was challenged around differing backgrounds or experiences, it was essential to respect, validate and empathise the person's experiences, rather than become defensive or righteous.

Such learnings were highly valuable for my work within the prison context as I am a Pākehā, young, middle-class female who has never been incarcerated. At times throughout my internship, I have felt out of my depth in terms of relating to the backgrounds, behaviours and actions taken by my clients. I have become acutely aware of my naivety in terms of illegal or illicit activities. Additionally, there is a cultural component at play, whereby predominantly my clients are of Māori descent, whereas I am not. At times, I have been challenged by wāhine about how I could possibly understand their perspectives.

On a personal level, I am incredibly open to learning about different experiences and fundamentally believe that each client is the expert in their own life, but it is my job to be responsive to their experiences. In particular, I have spent significant time developing my cultural competency and understanding Te Ao Māori and tikanga, in order to support my clients appropriately. As with my research, I have become aware of the importance of being knowledgeable about the experiences of my clients/participants, yet not overshadowing or making assumptions about their lived experience. However, keeping in mind my experiences with the interview participants, I have approached being challenged with honesty, reflection, validation and empathy. Thus far, I have not had an incident of this damaging or inhibiting the therapeutic process. Without my research experience, I doubt I would be as mindful of the importance of rapport or how it may be for clients to work with someone who has not had a similar set of life circumstances. Thus, I believe by selecting a research topic that is vastly different from my own experiences, I was able to prepare and educate myself on how best to manage similar circumstances, in ways that enhance the therapeutic process.

### *13.5.3 The Power of Information*

My research findings indicate that the more informed parents feel, the greater reductions they experience in their emotional distress. Parents in interviews often spoke about the importance of feeling included and informed about the care of their infant in managing their anxiety and improving their general experience. However, findings also suggested that information provision needed to be tailored to individual needs and that this was essential to manage parental anxiety/distress. Reflecting on these results was essential for my internship. The population I currently work with often present as paranoid, suspicious and mistrusting of professionals. At times, they may present aggressively, but often underlying that aggression is significant anxiety. In light of my research findings, I have tried to lead every session by providing as much appropriate and tailored information as I can to reduce anxiety, being open and responsive to questions, and being honest and transparent when I don’t know the answer or what is going to happen.

The power of information was evidenced as significantly changing the direction of an assessment with a female offender who had been previously labelled as ‘difficult to engage’. Upon meeting her, I began to go through the consent process. As I did so, she continuously interrupted me asking ‘why’ in an aggressive tone and requested I presented an argument as to why she should engage. Rather than react defensively or persuasively, I decided that it was important to provide her with all the information she needed to make her decision, and thus, I would be able to defuse her underlying anxiety. Through this process, she appeared to develop greater trust in me, and I could visibly see her anxiety dissipate. It culminated with her expressing vulnerability and requesting that I would see her regularly, indicative of the relationship we were beginning to build. Without the important lesson of the power of information in defusing and managing negative emotions that I obtained first-hand from my doctoral research, I doubt we would have reached such a positive ending. As such, it was a really valuable moment for me as a developing clinician.

#### *13.5.4 Working within Institutions and the Power Imbalance*

As aforementioned, my research focuses on parental experiences of neonatal units, facilities which exist within hospitals. Conversely, my internship exists primarily within a prison. On first consideration, these two settings may appear to exist at the opposite ends of the institutional spectrum; a hospital, designed for healing and supporting people, and a prison, designed for punishment (and rehabilitation). When considered as such, it becomes obvious they are both places of ‘getting better’, yet in very different ways. Both prisons and hospitals can also be considered institutions of power. They hold power over those in their care and power over decisions made for these people. For example, neonatal units create policies around visitation and care regimes for the best interests of the infants admitted, with a sentiment of exclusion expressed often by parents as a result of these policies. Prisons also create such regimes and rules that offenders exist within, often rules that don’t make sense to the wāhine or are not explained clearly by staff. At times, parents during my research interviews referred to the neonatal unit as a prison, labelling the nurses as prison guards. Recognising my role within these institutions of power, and ultimately, the innate power I carry into sessions by being aligned with an institution was an important reflection I had during my research, which has carried into my internship. Within my internship setting, the expectation is that, as a Corrections Psychologist, I am to hold my clients accountable for misconducts and negative file notes. At times, I am required to side with the Corrections Officers, even if I feel that my clients have been acting appropriately. Additionally, I am required to disclose any risk-related information to Corrections. Carrying this responsibility and this role of power has weighed heavily on me, but over time I have begun to see the necessity and importance of the power dynamic. However, I also recognise the need to build rapport and develop engagement to a greater degree than perhaps would be required in other settings, due to this dynamic. I have additionally relied heavily on supervision to unpack some of these experiences and understand how best to proceed with clients. I believe my research and experiences with parents viewing me as having a strong relationship with the hospital, an institution they often believed had not supported them, has helped me understand the power dynamics inherent in my internship setting.

In the research interviews and my initial sessions as an intern psychologist, I was naïve to the role I played and the power I carried with me. As someone who struggles to see themselves as an authority figure, I was often surprised and shocked to see parents in my research, and clients in my internship, defer to me for expertise. Reflecting on my role and expertise has been a challenging process as it requires me to be honest with myself and express confidence in my skills. Such a process has made me significantly more mindful of the way that clients can view me, some seeking reassurance in me as an ‘expert’, and others responding with defiance to the perceived ‘authority’. Ultimately, recognising and acknowledging the power imbalance inherent in psychologist-client relationships is imperative to my future practice and ensuring I can be sensitive to individual needs. Being aware of such individual needs and my position within systems will be essential to developing good therapeutic relationships as I go forward.

### 13.6 Summary

Despite initial appearances, I consider that my doctoral research has heavily informed and contributed to the development of my skills as an intern psychologist. The time spent with the mothers who willingly shared their stories with me was invaluable in providing a platform for my skills to be consolidated through my internship. Such skills include building rapport and connecting with those of a different background or whose experiences I do not share. The settings of my research and internship may appear to be very different. However, through time spent reflecting, it has become clear to me that there is significant overlap. For example, invaluable learnings during my research around power imbalances and the importance of information were carried through into my internship and have informed the way in which I have worked to build therapeutic alliances with clients. Ultimately, the journey of learning is never over, but I believe that the research I have performed, and internship I am completing, have provided an excellent starting point from which I can continue to reflect, grow and develop as a clinician.

# 14. Appendix G: Statements of Contribution for Publications

Massey University requires that a Statement of Contribution (form DRC 16) is included for each publication included in a doctoral thesis. A copy of this form is provided below for each of the two publications contained in this thesis. Information about the contributions of my supervisors and I included can be found in the Preface at the beginning of the thesis.

DRC 16

MASSEY UNIVERSITY
GRADUATE RESEARCH SCHOOL

# STATEMENT OF CONTRIBUTION
# DOCTORATE WITH PUBLICATIONS/MANUSCRIPTS

We, the candidate and the candidate's Primary Supervisor, certify that all co-authors have consented to their work being included in the thesis and they have accepted the candidate's contribution as indicated below in the *Statement of Originality*.

| | |
|---|---|
| Name of candidate: | Charlotte Gibson |
| Name/title of Primary Supervisor: | Dr Kirsty Ross |
| Name of Research Output and full reference: | |
| Distress, Self-Efficacy, Feeling Informed and the Babble App:A NZ Parent Sample | |
| In which Chapter is the Manuscript /Published work: | Chapter Four |
| Please indicate: | |
| • The percentage of the manuscript/Published Work that was contributed by the candidate: | 87.5% |
| and | |
| • Describe the contribution that the candidate has made to the Manuscript/Published Work: | |
| Charlotte took the primary role in research design, data collection and analysis, and independently wrote the manuscript. All supervisors proof-reads the manuscript and provided editing advice. | |
| **For manuscripts intended for publication please indicate target journal:** | |
| Infant Mental Health | |
| Candidate's Signature: | Charlotte Gibson Digitally signed by Charlotte Gibson<br>Date: 2020.11.04 18:17:26 +13'00' |
| Date: | 4 November 2020 |
| Primary Supervisor's Signature: | Dr Kirsty Ross Digitally signed by Dr Kirsty Ross<br>DN: cn=Dr Kirsty Ross, c=NZ, o=Massey University, ou=School of Psychology, email=K.J.Ross@massey.ac.nz<br>Reason: I am approving this document<br>Location: Massey University, Palmerston North, NZ<br>Date: 2020.11.06 17:05:39 +13'00' |
| Date: | 6 November 2020 |

(This form should appear at the end of each thesis chapter/section/appendix submitted as a manuscript/ publication or collected as an appendix at the end of the thesis)

DRC 16

MASSEY UNIVERSITY
GRADUATE RESEARCH SCHOOL

# STATEMENT OF CONTRIBUTION
# DOCTORATE WITH PUBLICATIONS/MANUSCRIPTS

We, the candidate and the candidate's Primary Supervisor, certify that all co-authors have consented to their work being included in the thesis and they have accepted the candidate's contribution as indicated below in the *Statement of Originality*.

| | |
|---|---|
| Name of candidate: | Charlotte Gibson |
| Name/title of Primary Supervisor: | Dr Kirsty Ross |
| Name of Research Output and full reference: | |
| The Experiences of Mothers in the Neonatal Unit and Their Use of the Babble App | |
| In which Chapter is the Manuscript /Published work: | Chapter Five |
| Please indicate: | |
| • The percentage of the manuscript/Published Work that was contributed by the candidate: | 87.5% |
| and | |
| • Describe the contribution that the candidate has made to the Manuscript/Published Work: | |
| Charlotte took the primary role in research design, data collection and analysis, and independently wrote the manuscript. All supervisors proof-read the manuscript and provided editing advice. | |
| For manuscripts intended for publication please indicate target journal: | |
| SAGE Open | |
| Candidate's Signature: | Charlotte Gibson Digitally signed by Charlotte Gibson<br>Date: 2020.11.04 18:17:26 +13'00' |
| Date: | 4 November 2020 |
| Primary Supervisor's Signature: | Dr Kirsty Ross Digitally signed by Dr Kirsty Ross<br>DN: cn=Dr Kirsty Ross, c=NZ, o=Massey University, ou=School of Psychology, email=K.J.Ross@massey.ac.nz<br>Reason: I am approving this document<br>Location: Massey University, Palmerston North, NZ<br>Date: 2020.11.06 17:05:05 +13'00' |
| Date: | 6 November 2020 |

(This form should appear at the end of each thesis chapter/section/appendix submitted as a manuscript/ publication or collected as an appendix at the end of the thesis)