

Parental Stress Following the Birth of a Very Preterm Infant Admitted to a Neonatal Intensive Care Unit:

Maternal, Paternal and Staff Perceptions of Stress

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“Don't be afraid to go where you've never gone and do what you've never done because both are necessary to have what you've never had and be who you've never been”.

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List of Abbreviations

CPAP	Continuous Positive Airways Pressure
ELBW	Extremely Low Birth Weight
EPT	Extremely Preterm
ESS	External Stressors Scale
IUGR	Intrauterine Growth Restriction
NICU	Neonatal Intensive Care Unit
PDA	Patent Ductus Arteriosus
PSS: NICU	Parental Stressors Scale: NICU
VLBW	Very Low Birth Weight
VPT	Very Preterm

Glossary of Terms

Birth Asphyxia (also known as Intrauterine Hypoxia)

A symptom of late toxemia (toxins in the blood) in pregnancy and can lead to perinatal death.

Coagulopathy

A disorder in which the blood is either too slow or too quick to coagulate (clot).

Continuous Positive Airways Pressure (CPAP)

CPAP is administered by a ventilation device which blows a gentle stream of air into the nose during sleep to keep the airway open.

Delayed Transition Post Delivery

Failure of ductal closure and sustained elevated right circulatory pressures.

Electrolyte Imbalance

Raised or lowered sodium, potassium, calcium or magnesium levels.

Enteral Feeding

Where infants are fed by gastric tube when oral feeding is not possible.

Extremely Low Birth Weight (ELBW)

Infants born weighing less than 1000g are classified as being ELBW.

Extremely Preterm (EPT)

Infants born earlier than 28 weeks' gestation are considered to be EPT.

Hyperglycaemia

An abnormally large amount of sugar in the blood.

Hypoglycaemia

An abnormally low blood-sugar level.

Hypothermia

Abnormally low body temperatures.

Intrauterine Growth Restriction (IUGR)

IUGR is a condition where infants' growth in the womb is restricted.

Jaundice

A condition where a baby's skin and the whites of the eyes are discoloured yellow due to an increased level of bile pigments in the blood resulting from liver disease.

Nosocomial Infection

An infection acquired after 72 hours or longer of being hospitalized

Oxygen Therapy

Nasal prong oxygen is usually the first step for bigger babies who have good respiratory effort.

Patent Ductus Arteriosus (PDA)

PDA is a heart defect that occurs when the ductus arteriosus does not close at birth.

Phototherapy

Treatment for severe or chronic jaundice. Provided by row of lights that shine directly on an undressed infant.

Pulmonary Hypertension

This is a rare lung disorder characterized by an increased pressure in the pulmonary artery.

Respiratory Distress

A condition in which infants with lung disease are not able to get enough oxygen.

Retinopathy of Prematurity

Vascular changes in the retina of very preterm infants identified when they reach 34-38 weeks' gestation. This is associated with raised oxygen blood levels.

Sepsis

Sepsis refers to a bacterial infection in the bloodstream or body tissues.

Surfactant Deficiency

Premature lung disease and respiratory distress secondary to immature or insufficient lung surfactant production.

Systemic Hypotension

Abnormally low blood pressure often associated with shock.

Very Low Birth Weight (VLBW)

Infants born weighing less than 1500g are considered to be VLBW.

Very Preterm (VPT)

Infants born before 32 weeks' gestation are classed as VPT.

Abstract

Many parents experience high levels of stress after the birth of a premature infant admitted to a neonatal intensive care unit (NICU) given the often fragile status of their infant and the numerous medical interventions necessary to stabilize the infant. Previous research has found that parents of very preterm (VPT; <32 weeks' gestation) infants often experience high levels of stress, particularly in relation to feelings of having lost their parental role. Of particular concern are findings which suggest that such symptoms may last beyond the immediate hospitalization period to have an adverse effect on the parental ability to provide quality infant care-giving at home. However, little is known about the paternal NICU stress response, the role of stressors external to the NICU environment and the perceptions of NICU staff. Against this background, aims of this thesis were: 1) to describe and compare sources of NICU stress for mothers and fathers of VPT infants, 2) to identify key predictors of parental NICU stress, 3) to describe staff perceptions of parental NICU stress, and 4) to identify parental stressors external to the NICU.

Two cohorts of parents of VPT infants were studied: 11 mothers and 10 fathers of VPT infants (<32 weeks' gestation) admitted to a level III NICU, Christchurch Women's Hospital; and 68 mothers and 68 fathers of VPT infants (<30 weeks' gestation) who participated in the Victorian Infant Brain Studies, admitted to the Royal Women's Hospital NICU, Melbourne. Twenty-three NICU nurses from Christchurch Women's Hospital, level III NICU were also interviewed. The Parental Stressors Scale: NICU (PSS: NICU) determined sources of stress among parents. NICU nurses completed an adapted version of the PSS: NICU that measured nursing staffs' perceptions of parental NICU stress. Parents also completed the Life Events Scale on upsetting life events from the previous 12 months. An external stressors scale which measured stress relating to finances, transport and childcare was developed and completed by parents and staff. Familial demographic and infant clinical information was collected from birth records and hospital databases.

Results showed across both cohorts studied that mothers reported significantly higher levels of NICU stress than fathers on the “sights and sounds”, “infant appearance”, and “loss of parental role” subscales on the PSS: NICU ($p < .05$). The number of upsetting life events ($\beta = .33, p = .01$) and paternal level of NICU stress predicted maternal NICU stress ($\beta = .23, p = .03$). Maternal NICU stress also predicted paternal NICU stress ($\beta = .37, p = .01$). Staff consistently overestimated parental stress levels ($p < .05$). The most stressful item on the external stressors scale reported by parents and staff was “fitting in everything else I have to do”.

Findings emphasize the need for increased awareness of NICU-specific and NICU-external factors contributing to parental stress. Research into the extent to which staff perceptions of parent experiences may affect the quality of staff-parent relations in the NICU is also warranted. These findings contribute to our understanding of the parental experience of having a preterm infant in the NICU and implications for practice and future research are discussed.

Chapter 1 Premature Birth and the Neonatal Intensive Care Unit

1.1. Introduction

It has been well documented that the premature birth and on-going care of an infant in a neonatal intensive care unit (NICU) is a stressful experience for parents (Miles & Holditch-Davis, 1997; Franck, Cox, Allen & Winter, 2005; Shields-Poe & Pinelli, 1997; Meyer, Coll, Seifer, Ramos, Kilis & Oh, 1995). Parents must come to terms with the early arrival of their infant, the medical complications common to premature infants and adjust to parenting an infant in a hospital environment. Researchers who have examined the parental stress response to having a premature infant have identified some common themes. These include parental stress relating to the loss of a normative parental role; and the infant's illness, treatment and appearance (Holditch-Davis & Miles, 2000). The parental stress response is unsurprising given that premature infants are often born fragile and dependent on medical staff for survival.

With survival rates of infants born prematurely on the incline in recent decades owing to advances in maternal-fetal medicine and neonatology (Doyle, 2004; Hack & Faraonoff, 1999), there is an increased need to support parents involved. There has been significant progress in understanding the factors contributing to preterm birth and improved survival rates; however, there has not been similar progress in reducing the prevalence of preterm birth itself or associated morbidities (Goldenberg, Culhane, Iams & Romero, 2008). Family impact is even less studied. Premature birth now accounts for approximately 10% of all live births (Moutquin, 2003) making research on the parental stress response both relevant and necessary to better understand how parents of preterm infants may be best supported.

Preterm birth refers to infants born earlier than 37 weeks' gestation irrespective of birth weight. Very preterm (VPT) birth refers to infants born earlier than 32 weeks' gestational age (Moutquin, 2003). VPT infants now make up approximately 1- 2% of all live births (Ewald, 2006), and have a survival rate that exceeds 85% (Horbar et al., 2002). Infants born earlier than

28 weeks' gestational age are referred to as extremely preterm (EPT) and have a survival rate that can range from 10% to 70% depending on gestational age (Fellman et al., 2009).

Much of the research on infants admitted to a NICU has focused on infants born with a very low birth weight (VLBW), categorised as weighing less than 1500g at birth. This is due to the unavailability of ultrasound technology pre 1990s which has since enabled more accurate indications of gestational age (Lawn et al., 2010). As a result of the availability of ultrasound technology, birth weight is no longer used as the primary indicator of prematurity, but instead gestational age is used. Although there may be significant overlap between VPT and VLBW infant populations, these populations do not always fully overlap. For example, in some cases VLBW is the result of Intrauterine Growth Restriction (IUGR) rather than prematurity. IUGR is a condition where infants' growth in the womb is restricted, where one-third of birth weight variations for infants with IUGR are due to genetic factors and two-thirds due to environmental factors (Bryan & Hindmarsh, 2006). Parents of VPT infants may be considered to be at a higher risk of psychological distress than parents of VLBW infants because of infants' low birth weight plus the added impact of giving birth to a baby unexpectedly early. Accordingly, the present research focuses primarily on the effects of prematurity (as defined by gestational age) on parental experiences, particularly within the NICU environment.

The NICU is designed to care for infants at risk, with infants born prematurely, infants requiring surgery or those born with congenital abnormalities who are typically admitted. NICU sites are equipped with specialized medical equipment and personnel that include doctors, nurses and allied health professionals. Typically, NICU sites include a team of health professionals (i.e., developmental physiotherapists, pharmacists, dietitians, neonatologists, paediatricians, paediatric surgeons, registered nurses, neonatal nurse specialists, midwives, enrolled nurses, obstetric nurses, karitanees, radiologists, radiographers, social workers, hospital chaplains, research nursing team and lactation consultants). In New Zealand, NICU sites often also contain a Kaiawhina Whaea me nga Peepi or a Maori Health Worker. Extremely sick or unwell babies are usually

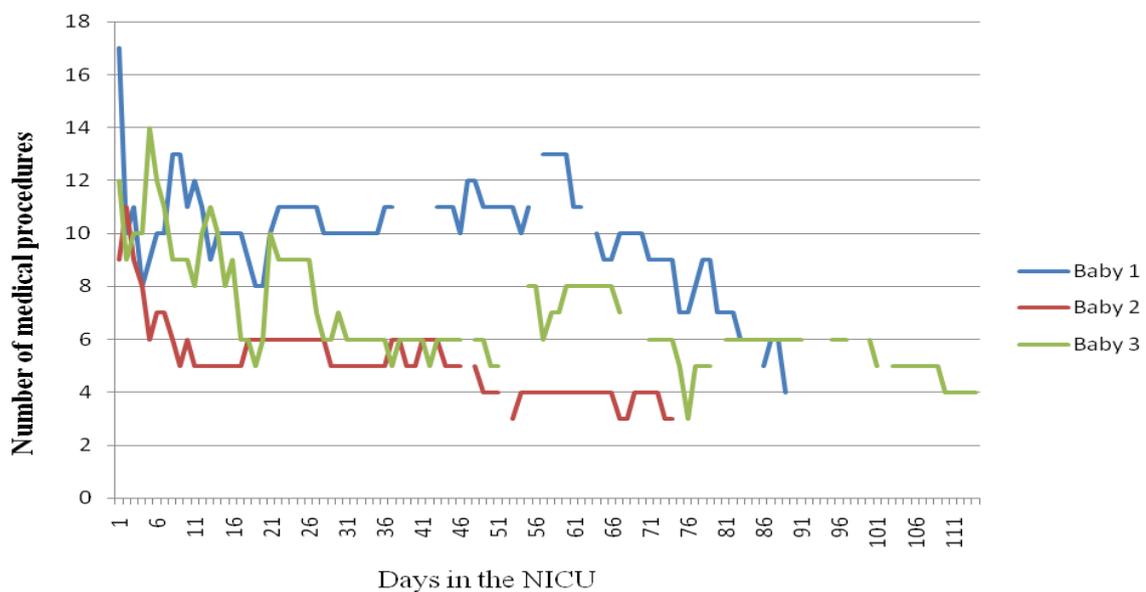
cared for by one nurse who is able to focus solely on the needs of the baby and family (Healthfirst Christchurch Women's Hospital, n.d.).

1.2. VPT Infants in the NICU: Medical Interventions and Care

In order for the present research to fully document the parental experience of having a VPT infant in the NICU, the next section outlines some of the medical procedures and treatments that these infants are subject to. The medical journey for an infant born prematurely can often be complex. Once born, a VPT infant may face medical challenges and be subjected to one or more medical procedures each day of their stay in the NICU. Typically, the medical complications for VPT infants are largely due to anatomic and physiological immaturity. Common complications (see Glossary of Terms, p. x for further definition of the following terms) include birth asphyxia (when the infant does not receive adequate oxygen before, during or after birth); hypothermia in the first few days or weeks of life (due to heat losses that occur during resuscitation; Loughhead, Loughhead & Reinhart, 1997); respiratory distress caused by a delay in alveolar clearance of water; and surfactant deficiency (Ewald, 2006). Other examples are delayed circulatory adaptation after birth with pulmonary hypertension (high blood pressure in the arteries to the lungs); systemic hypotension (abnormally low blood pressure often associated with shock); and delay in the closure of shunts in fetal circulation such as the ductus arteriosus (Ewald, 2006). Further complications associated with VPT birth include hypo- and hyperglycaemia, electrolyte imbalance, jaundice, coagulopathy, retinopathy, sepsis and increased likelihood of developing nosocomial infections (Ewald, 2006).

To illustrate the extent of medical interventions common to VPT infants, Figure 1.1 (p. 4) shows the number of daily medical treatments for three randomly selected infants from the

current research over the course of their stay in the NICU of Christchurch Women's Hospital.¹ The medical procedures these infants were subject to included respiratory interventions such as continuous positive airways pressure (CPAP) and oxygen treatments, the insertion and maintenance of arterial and venous lines, tube feeding, transfusions and injection of medicines (Appendix A provides further details on which medical procedures were included in the daily tally). As shown, these infants could undergo as many as 17 medical procedures or treatments in one day. The gradual downward trend in the number of medical procedures per day that is shown in the graph indicates a general decrease in the rate of treatments as the infant matures.



Note. Discontinuous lines represent missing data

Figure 1.1. Number of daily medical procedures of three infants in the NICU, Christchurch Women's Hospital

In caring for VPT infants and to optimise their outcome, NICU staff follow a number of procedures which are dependent on the infant's condition. For instance, to minimise the amount of heat loss an infant experiences, VPT infants are given thermal protection and the room temperature in the NICU is kept stable at 26°C. For medically stable babies weighing more than 1200g, immediate skin-to-skin contact and kangaroo mother care can be effective in stabilising

¹ This medical data was collected from the hospital records of infants residing in the NICU of Christchurch Women's Hospital and thus their information was from the same database as the infants who participated in the current research.

body temperature, while babies born extremely preterm tend to require incubator care (Ewald, 2006). Depending on the medical stability of the infant, breast feeding or the intake of expressed breast milk is encouraged. However, if oral feeding is not possible, the infant may be fed via a gastric tube (known as enteral feeding; Ewald, 2006). For infants with respiratory distress, oxygen therapy can be delivered by nasal prongs, or if respiratory insufficiency develops, CPAP is often used. Infants who have delayed closure of the ductus arteriosus may require treatment through pharmacological or surgical means as they are at an increased risk of pulmonary symptoms and even cardiac failure (Ewald, 2006). The ductus arteriosus allows significant blood to flow from the right ventricle of the heart and bypass the fetus's lungs; the failure of an infant's ductus arteriosus to close after birth results in a condition termed Patent Ductus Ateriosus (PDA). In essence, VPT infants are commonly wired up to machines and subjected to many medical procedures during their stay in the NICU.

Given the breadth of medical complications and medical procedures common to VPT infants, it is not surprising that VPT infants are at an increased risk for poor outcomes. Research has shown these to include poor outcomes relating to neurocognitive; respiratory; and behavioural and emotional disorders (McCormick, Workman-Daniels & Brooks-Gunn, 1996; Peterson et al., 2000; Schothorst & van Engeland, 1996; Wood et al., 2000). It is also not surprising then that parents of VPT infants often experience distress about concern for their infant's development but also stress relating to the NICU experience itself. Previous research on the psychosocial adjustment of mothers with an infant in the NICU has shown that the unique sights and sounds of a NICU as well as the infant's fragile appearance may all be sources of parental stress (Carter, Mulder & Darlow, 2007). Research has also consistently found that many mothers of VPT infants experience high levels of stress in relation to the loss of a normative parental role (Carter, et al., 2007; Montgomery-Hönger, Pritchard, Clark & Woodward, 2010; Franck, et al., 2005). Therefore, in order to ensure VPT infants have the best possible start in life,

further understanding is needed of the nature of the relationship between preterm infants and parental stress.

1.3. Transactional Model of Development

As discussed, VPT infants require special medical attention and parents often experience stress after the birth of a VPT infant. VPT infants are at risk of developmental delay, including in one study it was found that VPT infants showed cognitive delay, language delay and emotional/behavioural adjustment problems at four years of age (Woodward et al., 2009). In another study, difficulties were found in math, written language, language comprehension, handwriting, spelling and physical education at age six (Pritchard et al., 2009). These delays are compounded by the risk that parents of VPT infants are often highly stressed which may result in poorer parenting and adverse infant outcomes. To understand this relation, the Transactional Model of Development originally proposed by Sameroff in the 1970s, offers a useful framework for understanding how parental stress and infant medical status may work together to influence later child development. This model holds that children's developmental outcomes are a function of the interplay between nature and nurture. For example, Sameroff (2009) conceptualises development as a result of this interplay between the child and the ways of behaving influenced by their personality, as well as family experiences and the family's economic and social resources. Therefore, it has been argued that child outcomes are neither a result of the individual or their context alone, but both.

The Transactional Model of Development is a useful framework to conceptualise the relationship between VPT infants' development and parental stress. For instance, a recent study of 231 mother-infant dyads showed support for the Transactional Model (Pesonen et al., 2008) in accounting for later adverse outcomes. The researchers examined the directional links between maternal stress and infant temperament development over a five-year period starting in infancy. Results showed that higher negative emotionality and lower positive affectivity in infants as measured on the Infant Behaviour Questionnaire (a standard measurement tool for infant

temperament) contributed to increased maternal stress levels. On the other hand, results also showed that higher maternal stress contributed to increased child negative affectivity and decreased positive affectivity and self-regulation. This second finding was stronger than the first, suggesting that maternal stress plays an influential role in child development. Although this sample of mothers and infants excluded infants born prematurely, these findings imply that the Transactional Model of Development could be valuable in understanding the transactions between premature infants admitted to a NICU and their parents.

The pathway between infant development and maternal stress in a VLBW sample is highlighted in two studies. Having an infant hospitalized in the NICU is known to be stressful for parents not only immediately after birth but also after the hospitalization period (Singer et al., 1992; Cronin, Shapiro, Casiro & Cheang, 1995). For instance, Singer et al. (1999) compared rates of parenting stress in a longitudinal study of 122 mothers of high-risk VLBW infants and comparison groups of 84 mothers of low-risk VLBW infants and 123 mothers of term infants (i.e. 40 weeks' gestation). At the 1 year and 3 year follow ups, results showed that mothers of high-risk infants had significantly higher parenting stress than mothers of low-risk infants. This is consistent with other research findings, such as in a study of parents of 96 VLBW infants who reported higher stress levels five years after the birth of their infant compared to parents of full-term infants (Cronin et al., 1995). Furthermore, mothers of high-risk infants reported their children to be more distractible, hyperactive and demanding than low-risk or full-term infants (Singer et al., 1999). It would appear from these studies that the level of care and supportive parenting these high-risk infants require can lead to higher parental stress persisting over time. This is in contrast to parenting lower-risk infants who are unlikely to need the same extent of supportive parenting to thrive. Therefore, there is evidence that parents experience a unique degree of stress relating to having an infant who requires NICU care that lasts beyond the hospital period and raises questions as to what extent this impacts on parents' ability to provide the sensitive and quality care-giving that preterm infants may need.

The literature on parental stress following the birth of a preterm infant has also made some links between high-risk infants, parental stress and poorer parenting. For instance, Muller-Nix et al. (2004) found that at infant age 6 months, mothers of high-risk premature infants and mothers who were highly stressed in the perinatal period (as measured on the Perinatal Posttraumatic Stress Disorder Questionnaire; DeMier, Hynan, Harris & Manniello, 1996) were less sensitive and more controlling than mothers of low-risk premature infants or full-term comparison mothers. This was measured while mothers and infants were interacting during a play task and included 47 preterm infant-mother dyads and 25 full-term infant-mother dyads. It is of note that the highly stressed mothers displayed lower levels of sensitivity and were more controlling, despite no differences between preterm and full-term infants in their interactive behaviours at that stage. This suggests that maternal stress of mothers of preterm infants not only persists beyond the hospitalisation period but also that stress levels may continue to impair the ability to parent over the first few years of life even when preterm infants are interacting in an age-appropriate manner.

Parental stress levels and parenting behaviour have also been found to influence children's later cognitive outcomes. For example, Grunau et al. (2009) studied 137 VPT infants and 74 full-term control infants and their parents. Data were collected on the number of skin-breaking procedures that occurred during infants' stay in the NICU as a measure of neonatal pain. Parental stress was also measured at 8 and 18 months corrected infant age using the Parenting Stress Index (Abidin, 1995). Results showed that lower parental stress modulated the effects of neonatal pain on child cognitive outcomes (as measured on the Mental Development Index of the Bayley Scales of Infant Development; Bayley, 1993) at 18 months corrected age. This demonstrates, that just as high parental stress can impact negatively on later infant outcomes, low parental stress can allow for more positive infant outcomes. In another study, the way parents interacted with their VPT infants was shown to have an impact on children's early development. In the study of 152 VPT infants at age two corrected age and their parents,

Treyvaud et al. (2009) had parents complete a semi-structured task that assessed parent-infant synchrony and parenting behaviour. A key finding in this study was that greater parent-child synchrony predicted cognitive development and was associated with greater social-emotional competence at age two. Findings such as these show that parenting has a specific influence on early development and suggests that environmental factors such as parenting may be modifiable and thus infant outcomes can be improved. However, just as parenting can support positive cognitive development, parents under great stress may be impaired in their ability to provide quality parenting which may place VPT infants at high risk of poorer developmental outcomes and impairments.

Taken together, children born VPT may be considered to be doubly disadvantaged. Because these infants are born with physiological immaturity, they are at risk of developmental delay. Parents of VPT infants may be experiencing high levels of stress relating to the NICU environment, their infant's illness status and concerns about any developmental difficulties that may emerge following discharge. Due to these high levels of stress, parents of VPT infants may be impaired in their ability to provide the degree of sensitive care-giving needed to ensure the best chance of positive child developmental outcomes. Therefore, children born VPT are not only disadvantaged due to being born early but also because of possible poorer parenting as a result of parental stress. Therefore, it is vital that highly stressed parents of VPT infants are identified early and interventions are targeted at reducing this parental stress. Although it is not possible to change the physiological effects that being born prematurely has on infants, it may be possible to reduce the degree of stress that parents experience. The Transactional Model of Development provides the over-arching framework for conceptualising the interplay between infant development and parental stress over time and highlights the importance of early intervention for parents of VPT infants experiencing stress. In order to lower parental stress, it is important first to understand the key sources of stress from having a VPT infant in the NICU.

1.4. Model of Parental Distress in the NICU

Many factors cause stress for parents of premature infants after the early and often unexpected delivery of their baby. Not only must they come to terms with their infant's fragile health but they must also negotiate the unfamiliar and machine-dominated environment of the NICU. For example, studies have shown that parents may find many aspects of the NICU environment highly stressful: the continuous beeps and drones of life support and monitoring equipment; bright lights overhead; the sight of several other ill infants; and the many medical personnel surrounding each infant (Franck et al., 2005). However, other research suggests that the relation between preterm birth and parental distress may be much more complex, extending beyond purely environmental factors.

To identify major contributing factors, Holditch-Davis and Miles (2000) asked mothers of medically fragile VPT infants to narrate stories about their experiences in the NICU. These stories were then analysed within the framework of the Preterm Parental Distress Model (Figure 1.2, p.11), a model that was initially developed for parents of children in the paediatric intensive care unit (Holditch-Davis & Miles, 2000). The model was developed based on findings from over 20 years of literature on parental stress following a preterm birth (Holditch-Davis & Miles, 2000). In this model, "loss of parental role", "infant illness, treatments, and appearance" and "concerns about outcome" were identified as the three main contributors to parental distress (Holditch-Davis & Miles, 2000). The authors propose that three additional key factors influence the extent of parents' distress response: "the pre-existing and concurrent personal and family factors"; "prenatal and perinatal experiences"; and "health care providers."

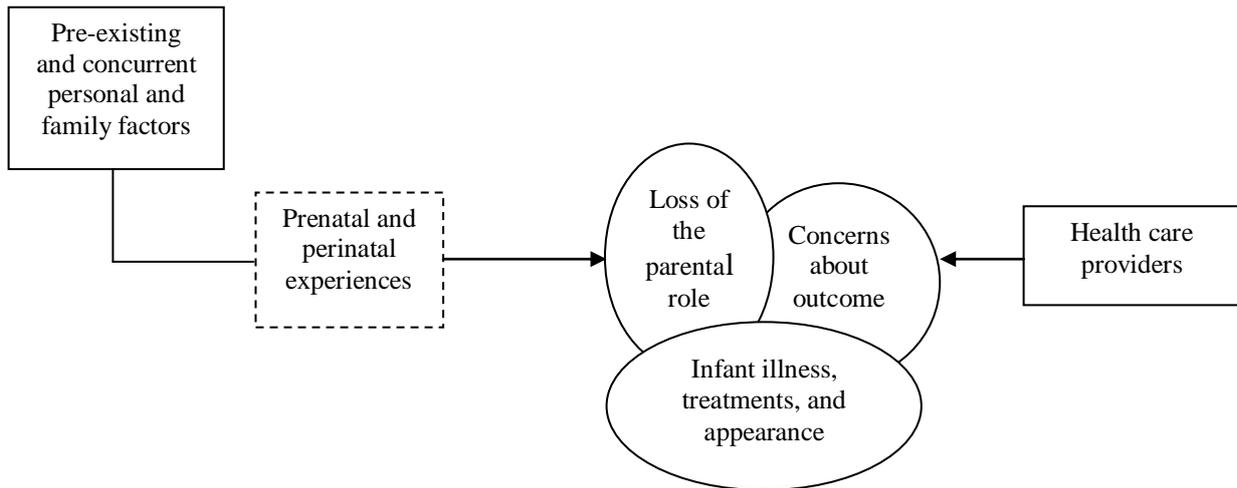


Figure 1.2. The Preterm Parental Distress Model

All six stress components of the model, either in combination or individually may play a part in parents' overall distress level. With respect to the "loss of parental role" component of the model, because parents with a baby in the NICU are likely to experience a parental role that differs from any preconceived ideas, they are likely to feel a sense of loss (Franck et al., 2005). For instance, parents of VPT infants often cannot engage in their expected or anticipated parenting tasks, such as feeding or changing, or even holding their infant. This can lead to feelings of helplessness or distress about not being able to care for their infant or protect their infant from pain (Miles, Funk & Kasper, 1992) or loss of control. Having an infant whose physical appearance is wrinkled or jaundiced, or seeing their infant make jerky or restless movements may also be distressing for parents and further exacerbate stress levels (as seen in the "infant illness, treatment and appearance" component of the model). Added to these issues are concerns about the infant's developmental outcomes, for instance, the potential impact of prematurity and medical complications on an infant's later development. As mentioned above, these can include poor outcomes for VPT infants such as the development of: neurocognitive; respiratory; and behavioural and emotional disorders (McCormick et al., 1996; Peterson et al., 2000; Schothorst & van Engeland, 1996; Wood et al., 2000). These three components in the model are considered to be interrelated.

Pre-existing and concurrent personal and family factors are also likely to play a role in parent's stress response. Such factors might include the parental financial situation, job stress, previous experiences with illness and childcare arrangements for other children. In terms of the "prenatal and perinatal experiences", this may include pregnancy experiences relating to this infant or to previous pregnancies. For instance, this component of the model includes factors such as previous perinatal or infant death, problematic labour and/or delivery, and parental perceptions of premature delivery, all of which are considered to influence parents' emotional response to having a premature infant in the NICU. Finally, the model shows that the quality of interactions with health care providers may also influence parental stress in the NICU. For instance, one study found that the quality of verbal interactions with nursing staff influenced a mother's confidence, sense of control and feelings of connectedness to her infant (Fenwick, Barclay & Schmied, 2001). Therefore, research shows support for this model and accordingly it forms the foundation on which the current research on parental experiences in the NICU is based.

1.5. Measuring Parental Stress in the NICU

In order to document quantitatively the specific aspects of the NICU experiences that parents find most stressful, Miles, Funk, & Carlson (1993) developed the Parental Stressors Scale (PSS: NICU). The PSS: NICU has been widely used in studies of parents' response to VPT birth to document stress associated with having an infant in the NICU. Other studies that have quantitatively documented parental NICU stress tended not to have used validated measures. The PSS: NICU consists of 47 items of potentially stressful aspects of the NICU environment. The scale is divided into four key dimensions of the NICU environment; a) sights and sounds, b) infant appearance, c) loss of parental role, and d) staff behaviours and communication. Parent response to items are rated on a 5-point Likert scale, with scores ranging from 1 = *not at all stressful* to 5 = *extremely stressful*. Although the four subscales of the PSS: NICU do not map

directly on to the three aspects of NICU-specific distress described in the Preterm Parental Distress Model (Figure 1.2, p.11), they encompass the elements of each dimension with the exception of parental concern about infant outcome, as the scale was developed prior to the model (Holditch-Davis & Miles, 2000). The psychometric properties and scoring procedures of the PSS: NICU are described in detail in Chapter 2 (Method, p.37).

1.6. Research Issues

There is relatively less research on the experiences of parents with a premature infant in the NICU than research focussing on the infant. For instance, a search of key words such as “preterm” and “infant” in the PsycINFO Database produced 1100 results compared with a cumulative total of 307 results for keywords “parent”, “mother”, “father”, combined with “preterm” and “infant”. Given that parents are the primary caregivers of their infant, further research is needed in this area to ensure that parents are empowered. The first step towards parental empowerment is to document their experiences of having a fragile infant in the NICU and identify any areas of need. When NICU stressors are better understood, interventions can be developed to mitigate their negative effects on the parental NICU experience. To date, however, few studies have compared sources of parental stress across different NICU sites or identified which infant clinical or sociofamilial factors may be most predictive of parental distress. The current research examines parental NICU stress across two different NICU sites and investigates key NICU-specific and parental stressors external to the NICU environment. Staff perceptions of parental stress are also investigated.

1.7. Outline of the Chapters to Follow

This thesis is arranged into four chapters and presents findings from two studies. Chapter 2 examines research findings on the maternal and paternal sources of NICU stress. The existing

research on parental experiences of the NICU environment is then reviewed to find common themes amongst studies of the most stressful aspects of the NICU experience and to identify key factors associated with NICU stress. Limitations in the research to date are discussed. The research aims, methods, results and discussion of Study 1 are presented. The key aims for Study 1 are to describe sources of NICU stress for mothers and fathers, across two different NICU sites and to identify predictors of NICU stress.

To describe the broader picture of the stress response of parents of VPT infants, part 1 of Chapter 3 examines the existing research on how NICU staff view the NICU experience for parents, while part 2 of Chapter 3 concentrates on identifying factors outside of the NICU environment that may contribute to parental stress. Important research issues identified in the literature form the impetus for study 2. The key aims of study 2 are to describe perceptions of sources of NICU parental stress among NICU staff, to identify potential stressors external to the NICU environment among parents and to validate the External Stressors Scale as a measure of external stress for parents with an infant in the NICU.

Chapter 4 provides a general discussion of the current research. This includes, outlining the overall strengths and limitations of the studies. How study findings support the Preterm Parental Distress Model is also discussed. Implications for NICU nursing staff are considered as well as the need for follow-up research, which is discussed within the context of the Transactional Model of Development. Speculations are made on how future research in this area could contribute towards lowering parental NICU stress.

Chapter 2

Parents of VPT Infants: A Study of Maternal and Paternal Stress Relating to the NICU

2.1. Introduction

As outlined in Chapter 1, parents of premature infants have much to come to terms with following their infant's admission to the NICU. In this chapter, the literature on parental stress in the NICU was reviewed in order to determine which specific aspects of the NICU environment parents find most stressful, whether mothers and fathers differ in levels of NICU stress and to identify personal, family and infant clinical factors that are associated with parental NICU stress, and to identify any gaps in the literature. The methodological strengths and weaknesses of the reviewed studies were also examined. The review formed much of the rationale for Study 1.

2.1.1. Sources of parental stress in the NICU. Over the years, researchers have been concerned with understanding which specific aspects of the NICU experience parents find most stressful. To date, the PSS: NICU is the measure most commonly used to document the NICU experiences of parents of VPT infants (see Table 2.1, p. 17, for a summary of the studies using this measure). A consistent finding among studies using the PSS: NICU has been that parents report highest levels of stress on the "loss of parental role" subscale (Carter, et al., 2007; Akbarbegloo & Valizadeh, 2009; Montgomery-Hönger et al., 2010; Franck, et al. 2005; Miles et al., 1992). These studies have shown that stress relating to "loss of parental role" results from experiences such as "being separated from my baby" and "feeling helpless to protect my baby from pain". One example is the study by Franck et al. (2005). They studied 184 mothers and 73 fathers of infants admitted to NICU sites in the United Kingdom (UK) and United States (US). Parents reported more stress relating to "loss of parental role" than to any other aspects of having an infant in the NICU. In the UK and the US samples, the mean scores for the "loss of parental role" subscale were 2.98 and 2.75 respectively (on the scale of 1-5 as described above). The next most stressful aspect of having an infant in the NICU recorded by Franck et al. (2005) was "infant's appearance" (UK $M = 2.46$ and US

$M = 2.28$ respectively), followed by “sights and sounds” (UK $M = 2.29$; US $M = 2.25$) and “staff behaviour and communication” (UK $M = 1.63$; US $M = 1.68$). This pattern of results was similar for both mothers and fathers in the study.

These findings are supported by New Zealand-based research. For instance, Carter et al. (2007) studied 172 randomly selected couples who had an infant admitted to the NICU in Christchurch Women’s Hospital, New Zealand. Results from that study showed “loss of parental role” to be the highest source of stress for both mothers and fathers. The next most stressful dimension was “sights and sounds”, followed by “infant appearance” and “staff behaviour and communication”. Similar findings were reported by Montgomery-Hönger et al. (2010) in their study of 133 Christchurch-based mothers of VPT infants. In this study, mothers rated “loss of parental role” to be most stressful, particularly “being separated from my baby” (an item on the “loss of parental role” subscale) as the most stressful component of being in the NICU. Therefore, it would appear that, of the studies using the PSS: NICU, stress relating to “loss of parental role” stress has been found to be most characteristic of the parents of VPT infants.

Table 2.1.
Literature Review: Studies Documenting Parental Stress in the NICU: Years 1992-2010

Author/s	Study Design	Sample	Interview Timing	Main Construct	Measures	Findings	Strengths	Limitations
Montgomery-Hönger, Pritchard, Clark & Woodward (2010) NEW ZEALAND	Cross-sectional study	133 mothers of infants born VPT or <1500g	Interviewed when infants reached term equivalent age.	Maternal NICU stress (PSS: NICU)	Depression (EPDS), stressful life events (Life Events Scale), maternal wellbeing (Mother and Baby Scale-MABS)	Over 75% of mothers perceived being in the NICU to be moderately to extremely stressful. “Loss of parental role” most stressful, followed by “infant appearance”, “sights and sounds” and then “staff behaviour and communication”. “Being separated from my baby” was the single most stressful item on the PSS: NICU. Nearly 25% of mothers reported mental health problems during pregnancy and after giving birth. Depression at term, number of life events, singleton birth and NZ European were key predictors of overall perceived stress. Depression, maternal education, life events, days of CPAP and birth weight were key predictors of ‘loss of parental role’ stress.	+ Good sample size. + Good focus on ‘loss of parental role’ stress as little research has focussed on this to date.	- Did not include fathers therefore results cannot be generalised to fathers.
Carter, Mulder & Darlow (2007) NEW ZEALAND	Cross-sectional	172 couples: parents of infants born <34 wks, <1800g, infant illness admitted to level 3 NICU between February 2001-2002	Within 3 weeks of admission to NICU	NICU stress (PSS: NICU)	Personality (TCI), Trait Anxiety (STAI) and Early Parenting (PBI)	Mothers reported higher stress levels than fathers. Loss of parental role subscale most stressful. Personality (high self-transcendence, high harm avoidance, high novelty seeking, high cooperativeness) & trait anxiety most common predictors of NICU stress. For mothers, high stress was associated with low income, de facto relationship, abnormal pregnancy scan, no previous NICU experience. For fathers, key associations were transfer of the pregnant mother due to complications and paternal history of drug/alcohol abuse and dependence.	+ Included fathers. + Recruited from large catchment area, therefore diverse SES. + Recruitment rate of 82%. + Good sample size.	- Some of independent variables assessed retrospectively-possible recall bias.

Table 2.1.

Literature Review: Studies Documenting Parental Stress in the NICU: Years 1992-2010

Author/s	Study Design	Sample	Interview Timing	Main Construct	Measures	Findings	Strengths	Limitations
Franck, Cox, Allen & Winter (2005)	Cross-sectional	Mothers = 184, fathers = 73 from 9 NICUs in UK and 2 comparison NICUs in US over 12 month period.	1 week after admission to NICU	NICU stress (PSS: NICU)	Trait Anxiety (STAI)	Similar PSS: NICU scores in US and UK samples, high internal consistency in the scale. Parents in UK sample had higher state anxiety than parents in US Mothers had higher mean score than fathers in UK but not in US In both UK and US samples parents consistently reported “loss of parental role” as most stressful followed by “infant appearance”	+ Included fathers + Good sample size. + Captures initial stress response.	- US sample was homogenous and there was lesser severity of infant illness - May be geographical bias as most NICUs were based in southern UK - interviewed soon after admission, therefore did not capture on-going stress response
Reid & Bramwell (2003)	Cross-sectional. Validation study	40 mothers of moderate risk preterm infants. <u>Inclusion criteria:</u> ventilated < 24 hours, < 51% oxygen requirements at 48 hrs, singleton birth, APGAR score 7 or more at 5 mins, <34 wks gestation, no history of maternal substance abuse, no congenital abnormality	PSS: NICU completed within 48-96 hours of delivery.	Maternal NICU stress (PSS: NICU)	Background demographic variables	- The “appearance and behaviour”, “sights and sounds” and “parental role” subscales found to be internally reliable. - Mothers of relatively well infants still found to report stress levels similar to mothers of critically ill infants. - Younger mothers and those of lower SES, experienced higher stress on “sights and sounds”, while younger mothers had significantly greater scores on “parental role” scale. - Low birth weight and gestation did not correlate significantly with any PSS: NICU subscale. - Stress scores did not differ between mothers with other children and mothers for whom this was their first child. - No significant difference found on subscales between different modes of delivery.	+ Captures initial reaction of NICU. + Fair sample size.	- Staff behaviours and communication might not have been fully established yet in such short time – therefore timing may be important when examining sources of stress. - Did not ask about other stressors e.g. Familial, support, time or financial strains. - May not have detected relationships between infant/maternal factors and stressors

Table 2.1.

Literature Review: Studies Documenting Parental Stress in the NICU: Years 1992-2010

Author/s	Study Design	Sample	Interview Timing	Main Construct	Measures	Findings	Strengths	Limitations
Shields-Poe & Pinelli (1997) CANADA	Cross-sectional study	122 mothers and 90 fathers of infants admitted to a NICU. Stratified sample of infants (varying weight groups and illness severity)	Within 3 weeks of admission.	NICU parental stress (PSS: NICU)	STAI, Life Events Scale, demographic and background information	For mothers: trait anxiety, age, where first saw baby, perceived morbidity, marital status, whether pregnancy wanted: all significantly correlated to PSS: NICU subscale scores. For fathers: perceived morbidity, frequency of attendance at religious services, trait anxiety, when first saw baby, speaking with social worker, whether pregnancy was wanted and time of interview. Overall, perception of baby's illness severity was most strongly associated with stress scores.	+ Good sample size, which exceeded minimum sample sized calculated to have 80% power. + Fathers included.	- Time of interview varied from 2 to 21 days after birth, therefore could account for some variation in reported stress levels
Meyer, Coll, Seifer, Ramos, Kilis & Oh (1995) UNITED STATES	Cross-sectional study	142 mothers of preterm infants admitted to the NICU.	Recruited when infants were medically stable and being fed by tube	Mothers psychological distress	Stress (PSS: NICU), psychological distress (Symptom Checklist 90-R), demographic information	PSS: NICU and Symptom Checklist correlated significantly. 28% of mothers met clinically significant levels of distress. Useful to separate psychological distress into: 1) NICU-specific stress (predicted by infant's greater need for ventilator support and lower gestational age with maternal variables covaried) and 2) general psychological distress (predicted by younger maternal age with infant variables covaried).	+ Good sample size.	- Only examined mothers, therefore results may not generalise to fathers. - Mothers of infants born earlier than 37 weeks

Table 2.1.

Literature Review: Studies Documenting Parental Stress in the NICU: Years 1992-2010

Author/s	Study Design	Sample	Interview Timing	Main Construct	Measures	Findings	Strengths	Limitations
Miles, Funk & Kasper (1992)	Prospective longitudinal	23 mothers and fathers (couples) who had premature infants admitted to the NICU	1. within 1 week of admission 2. 1 week later	NICU stress (PSS: NICU)	Parent Perception of Uncertainty Scale & STAI	Loss of parental role subscale most stressful, with mothers reporting significantly higher levels of stress than fathers in this area. Stress on “loss of parental role”, “infant appearance” subscales, and general uncertainty decreased significantly after a week in the NICU. There were no significant differences between mothers and fathers in levels of anxiety.	+ Included fathers.	- Relatively small sample size

2.1.2. Comparison of stress levels in the NICU between mothers and fathers. Of the few studies on parental stress in the NICU that have included paternal responses, most have shown that mothers tend to report higher levels of NICU-specific stress than fathers. For instance, in the study by Carter et al. (2007), mothers reported significantly higher levels of stress than fathers across all four subscales of the PSS: NICU and a higher overall stress score. In addition, while Franck et al. (2005) did not find a gender difference for their US sample in terms of stress levels, mothers in their UK sample reported significantly higher stress levels than fathers across all four subscales of the PSS: NICU. Outside the literature on premature birth, Shields-Poe and Pinelli (1997) studied 122 mothers and 90 fathers of high-risk infants admitted to a NICU. They also found that mothers reported significantly higher levels of stress than fathers. However, these were restricted to the PSS: NICU “loss of parental role” and “sights and sounds” subscales only. Likewise, in a study of 23 couples with preterm infants, Miles et al. (1992) also found that mothers reported significantly higher stress relating to “loss of parental role” than fathers.

Although the findings from the aforementioned studies suggest a gender difference in terms of degree of NICU stress experienced, which aspects of the NICU mothers find more stressful than fathers remains ambiguous. It may also be possible that mothers and fathers differ in which personal, family and infant clinical characteristics contribute to their stress levels in the NICU, an issue largely neglected by current research. This may account for some of the ambiguity in research findings. Given that many studies to date have been limited to maternal experiences in the NICU, further research is warranted to determine more exactly how mothers and fathers differ by their experience. A further endeavour should be to determine the relevance of personal, family and infant clinical characteristics in any explanation of gender differences.

2.1.3. Factors associated with parental stress in the NICU. Previous studies have examined factors associated with parental stress in the NICU. This thesis will focus on two key components of the Preterm Parental Distress Model (Figure 1.2, p.11; Holditch-Davis & Miles,

2000) that can be linked to research findings on which factors are associated with parental NICU stress. These components are “pre-existing and concurrent personal and family factors” and “infant illness, treatments, and appearance” factors. The model is supported by previous findings on parental NICU stress.

2.1.3.1. Pre-existing and concurrent personal and family factors. Many researchers have found that factors that can be categorised within the “pre-existing and concurrent personal and family factors” component of the Preterm Parental Distress Model (Figure 1.2, p.11) are key contributors to parental stress in the NICU. For instance, across the studies reviewed, associations have been found between parental NICU stress and the following: personal and mental health factors such as parental age, ethnicity and post-natal depression, as well as a variety of family functioning and background factors such as family SES and income. For example, in one study of 40 mothers of moderate risk preterm infants (born earlier than 34 weeks’ gestation), mothers who were of lower SES were found to report higher stress on the “sights and sounds” subscale of the PSS: NICU (Reid & Bramwell, 2003). High stress on the PSS: NICU was also associated with low income in Carter et al.’s (2007) study. This suggests that financial resources may play an important role in the degree of NICU stress that mothers experience. Financial concerns may place extra strain on parents with an infant in the NICU, thus increasing their NICU stress levels.

Younger maternal age has also been linked to higher NICU stress scores. For instance, younger mothers were found to have significantly higher scores on the “sights and sounds” subscale as well as the “loss of parental role” stress subscale than older mothers (Reid & Bramwell, 2003). In another example, Shields-Poe and Pinelli (1997) conducted a study which included 122 mothers and 90 fathers of infants admitted to a NICU in Canada. Results showed that younger maternal age was significantly correlated with higher maternal PSS: NICU scores on all subscales. Possible explanations could include that younger mothers may have less social support after giving birth, they may have fewer financial resources to draw from which may in turn exacerbate their stress levels, or

they may have fewer life skills that would aid their coping. Therefore, if younger mothers are at an increased risk of experiencing higher stress levels in the NICU, further research may be warranted in order to determine why this is the case.

Other pre-existing and concurrent personal and family factors have been found to predict NICU stress, further supporting the Preterm Parental Distress Model (Figure 1.2, p.11). For instance, ethnicity and the number of upsetting life events have been found to be key predictors of higher stress ratings on the PSS: NICU (Montgomery-Hönger et al., 2010). Furthermore, in the same study, results showed that low maternal education and the number of upsetting life events were key predictors of higher maternal stress scores on the “loss of parental role” subscale. Other research has identified additional key sociofamilial background characteristics that were significantly correlated with all PSS: NICU subscale scores. For mothers of infants in the NICU, these included marital status (Shields-Poe & Pinelli, 1997; Carter et al., 2007), whether the pregnancy was wanted (Shields-Poe & Pinelli, 1997), an abnormal pregnancy scan and no previous NICU experience (Carter et al., 2007). For fathers, the key characteristics associated with NICU stress were frequency of attendance at religious services (where fathers who never attended religious services had lowest stress scores, whereas those who attended never or occasionally had the highest stress scores), speaking with a social worker, whether their partner’s pregnancy was wanted, the timing of the PSS: NICU interview (Shields-Poe & Pinelli, 1997), transfer of their pregnant partner due to medical complications and paternal history of drug/alcohol abuse or dependence (Carter et al., 2007). As shown, there is a wide range of personal and family factors found to contribute to NICU stress.

Parental personality factors have also been found to predict NICU stress. For example, high self-transcendence, high harm avoidance and high novelty seeking have been shown to predict higher parental stress levels (Carter et al., 2007). Interestingly, parents who scored highly on the cooperativeness scale of the Temperament and Character Inventory (Cloninger, Prybeck, Svakic, & Wetzel, 1994, cited in Carter et al., 2007) reported high scores on the “loss of parental role” subscale

on the PSS: NICU (Carter et al., 2007). Parents who are highly cooperative are likely to be particularly tolerant, empathetic, compassionate and helpful toward others. Although these personality traits would normally be considered adaptive, these parents may be placing higher importance on their parental role. Thus, when their parental role is disrupted, as is predictable when having an infant in the NICU, highly cooperative parents may find this particularly stressful.

NICU stress has been found to be related to a number of parental mental health variables. In particular, trait anxiety (a predisposition to be anxious) is linked to stress scores on the PSS: NICU for mothers and fathers (Shields-Poe & Pinelli, 1997; Carter et al., 2007). Other studies using the PSS: NICU have identified that mothers who experienced stress pertaining to alterations to their parental role were more likely to exhibit depressive symptoms, not only immediately after the birth of their premature infant (Montgomery-Hönger et al., 2010), but also during their infant's first year (Miles et al., 2007). Maternal depression at term was also found to predict higher overall maternal stress on the PSS: NICU (Montgomery-Hönger et al., 2010). Furthermore, in the same study when focussing only on the "loss of parental role" subscale, results showed that maternal depression was a key predictor of higher maternal stress on the "loss of parental role" subscale. NICU-related stress among mothers has also been associated with more general psychological distress. In a study of 142 mothers of preterm infants admitted to the NICU, Meyer et al. (1995) found that NICU specific stress was significantly correlated with maternal psychological distress as measured on the Symptom Checklist 90-R; 28% of mothers met clinically significant levels of distress. It would appear from these results that the NICU experience predicts parental mental health outcomes. Therefore, early identification and interventions for parents experiencing high levels of NICU stress could alleviate the impact this stress has on the development of poorer mental health for parents and may prevent negative outcomes for the parent-infant relationship. Therefore, further research into the parental NICU experience is essential in order to ensure further understanding on how best to support parents during this time.

2.1.3.2. Infant illness, treatment and appearance factors. As shown in the Preterm Parental Distress Model (Figure 1.2, p.11), “infant illness, treatment, and appearance” is considered to be a key component of parental NICU stress. Studies have identified a number of specific infant clinical variables that are associated with NICU stress. For instance, Meyer et al. (1995) found that the preterm infant’s greater need for ventilator support and low gestational age were associated with maternal NICU stress levels. Consistent with this link between infant variables and maternal stress are results from another study that showed the number of days of CPAP and low birth weight were key predictors of higher maternal stress on the “loss of parental role” subscale (Montgomery-Hönger et al., 2010). These findings suggest that mothers of sicker infants experience higher NICU stress than mothers of infants whose medical status is not as compromised. Other research, however, found low infant birth weight and gestation did not correlate significantly with any PSS: NICU subscale for parents (Reid & Bramwell, 2003). This suggests that the relationship between infant illness and parental stress may not be straight forward. This may be due to a number of methodological differences in the studies. For instance, the studies that found associations between infant illness and NICU stress (Meyer et al., 1995; Montgomery-Hönger et al., 2010) involved large sample sizes (142 and 133 mothers) compared to 40 mothers in Reid and Bramwell’s (2003) study. Mothers were also interviewed when their infant was medically stable rather than being interviewed within 4 days of birth (which was the case in Reid & Bramwell, 2003). Thus research is needed to further examine how infant clinical variables are related to parental stress in studies with different sized samples and at different time points across the NICU stay.

Another infant clinical characteristic found to be related to parental NICU stress includes parental perception of how ill their infant is. For example, associations were found for parents between the perceived morbidity of their baby and their level of NICU stress (Shields-Poe & Pinelli, 1997). Overall, perception of infant’s illness severity was strongly associated with NICU stress scores for mothers and fathers (Shields-Poe & Pinelli, 1997). This finding is consistent with findings

listed above regarding parents of sicker infants reporting higher stress levels (Meyer et al., 1995; Montgomery-Hönger et al., 2010). This finding implies that it is not just the infant's objective illness status (for example an infant born low birth weight or very early) but also the *perception* of illness severity that determines the level of stress parents experience (Reid & Bramwell, 2003).

The evidence from literature on how personal, family and infant characteristics are associated with parental NICU stress suggests that many factors contribute to the parental NICU experience. These associations may point to potential parental risk factors for experiencing high NICU-related stress and once identified, this information can be used to inform how best to support parents. As there are relatively few studies that have documented these associations, there are some limitations with respect to the generalizability of these findings.

2.1.4. Limitations in the current literature. Whilst studies on parental stress in the NICU have been informative, it is important to note that many of these are characterized by a number of methodological limitations. Of the studies using the PSS: NICU, there has been significant variation in the timing of when the PSS: NICU interview was administered. For instance, researchers have conducted the PSS: NICU at the following time points: 48 hours after infant NICU admission (Reid & Bramwell, 2003), 1 week after NICU admission (Miles et al., 1992; Franck et al., 2005), within 3 weeks of NICU admission (Shields-Poe & Pinelli, 1997; Carter et al., 2007), and at infant term equivalent (40 weeks'; Montgomery-Hönger et al., 2010). In another study, interview timing was not specified, except that the PSS: NICU was conducted when infants were deemed medically stable and being fed by tube (Meyer et al., 1995). One concern that arises when examining findings from studies that have conducted the PSS: NICU interview across different time points is the potential for parents to experience a recall bias with respect to how stressful they remember their infant's stay in the NICU to have been.

Recall bias is a common limitation of studies reliant on self-report questionnaires (Brink, Bandell-Hoekstra & Abu-Saad, 2001) whereby recall may differ depending on the timing of the

interview. A number of factors related to recall errors (Brink et al., 2001) are relevant to the studies using the PSS: NICU questionnaire. These include the length of time that had elapsed since infants were first admitted to the NICU, the salience of the stressors in the NICU environment itself and parental psychological state at the time of completing the PSS: NICU. This highlights how parental reports of current stress levels can be influenced by many factors which are likely to be unconscious for parents. As discussed by Carter et al. (2007), recall bias can occur when responses are assessed retrospectively or not during the time of most stress. Reid and Bramwell (2003) also assert that the time when parental stress measures are administered may be critical given that different stressors may be more relevant at different stages of a parent's NICU experience. Studies that have conducted the PSS: NICU at different time points may be capturing different stress responses. Therefore, it is important to consider this when comparing results across studies. As the body of literature on NICU stress grows, future research could examine the relationship between timing of interviews and the degree and type of NICU stress experienced.

The variation in timing of the PSS: NICU interview may also account for some of the discrepancies evident in the results of studies that have examined gender differences in the amount of NICU stress experienced. For instance, mothers and fathers may not experience the same stress symptoms as each other during the same stages of their NICU experience. Therefore, it may be important to take interview timing into account when comparing maternal vs. paternal results across studies. However, despite the large variation in interview timing, it is of note that "loss of parental role" is consistently reported across studies as being the most stressful NICU-related experience for mothers and fathers.

The literature on parental NICU stress is also limited in that, for the most part, researchers are unable to randomly select participants (with the exception of the study by Carter et al., 2007). Therefore, selection bias may occur because the participants interviewed may not provide an accurate representation of the general population of parents with infants in the NICU (e.g., parents

who consent to participate may be those who are coping better with their infant's medical status than those who do not consent). This limitation is also noted in Cronin et al.'s (1995) study where the authors outlined that most parents in the study were well educated, employed and married thus suggesting a possible selection bias.

Another issue is that the cohorts used in previous studies may potentially not be relevant today. For instance, the recruitment period for several of the key studies in the literature on parental NICU stress took place between 1991 and 1997 (Miles et al., 1992; Meyer et al., 1995; Shields-Poe & Pinelli, 1997). Since then, infants are now surviving from as early as 23 weeks' gestation. This has been aided by advances in technology, such as the effective early use of CPAP for extremely preterm infants needing support with breathing (Alallah, 2012). As a result, there is a new population of parents dealing with extremely premature infants. There have also been advances in the care practices in NICU sites themselves, and the impact this has had on parental NICU stress levels may not have been documented in earlier studies. The degree of stress experienced by parents of infants born extremely prematurely may not be fully captured in the literature pre-2000; therefore studies that include this group of parents are essential.

Although these limitations found in previous literature on NICU stress could not be completely eradicated, the current study aimed to minimise these limitations in the following ways. To minimise possible recall bias, parents were interviewed as early as was deemed ethically appropriate (i.e., when their infant was medically stable at 34 weeks' gestation in the Christchurch cohort and at 40 weeks' gestation for the Melbourne cohort). In order to account for the different timing that the PSS: NICU was administered across studies, care was taken when comparing current study results with those of previous studies. To address the selection bias found in some studies, the current researchers invited all eligible parents to participate. In terms of presenting findings that reflect the parental experience of having an infant admitted to a modern NICU, the current study recruited participants between 2001 and 2011. The present research aims to provide information

relating to NICU-specific stressors for a more contemporary sample of parents with VPT infants born earlier than 32 weeks' gestation. In addition, because many studies use US- and UK-based samples, the extent to which findings from these studies are generalizable to an Australasian population is questionable. To address this, the current research uses data from Christchurch and Melbourne NICU sites.

2.1.5. Summary of studies concerning parental stressors in the NICU. The parental NICU stress literature reviewed thus far highlights that having an infant admitted to the NICU can be highly stressful for parents of VPT infants. The extent to which there are gender differences in the sources and degree of stress experienced relating to the NICU environment, however, remains unclear. Furthermore, a large number of personal, family and infant characteristics have been identified as being associated with parental NICU stress. Despite the methodological limitations listed above, existing studies have highlighted that “loss of parental role” is the most prominent stressor for parents. Further research is needed to clarify the most stressful aspects of having an infant in the NICU, to what degree mothers and fathers differ in terms of their NICU experience, and which are the key factors associated with parental NICU stress.

2.1.6. The current study objectives. The current research aims to contribute to the body of knowledge on parental experiences in the NICU relating to VPT birth. To this end, Study 1 involved a cross-sectional examination of NICU-specific stressors for parents of VPT infants in Christchurch and Melbourne. The aims of the current study were as follows:

Aim 1. To describe the most stressful aspects of the NICU environment for Christchurch and Melbourne parents.

Hypothesis. It was predicted that parents at both sites would report “loss of parental role” to be the most stressful aspect of being in the NICU.

Aim 2. To compare sources of NICU stress between mothers and fathers of VPT infants in the NICU.

Hypothesis. It was predicted that mothers would report higher levels of NICU stress than fathers and that there would be differences in which aspects mothers and fathers find most stressful.

Aim 3. To identify key personal, family and infant clinical predictors of parental stress in the NICU.

Hypothesis. It was predicted that several factors spanning personal, family and infant clinical factors would be identified as being predictive of parental NICU stress, particularly the number of upsetting life events.

2.2. Method

2.2.1. Sample: Christchurch cohort. The sample consisted of 11 mothers and 10 fathers of 13 infants born VPT (< 32 weeks' gestation) who were admitted to a regional level III NICU at Christchurch Women's Hospital (New Zealand) between June 2010 and February 2011. The region covered by the NICU at Christchurch Women's Hospital extends to Timaru in the South, Greymouth in the West and Kaikoura in the North (approximately 20,000 square kilometres). All newborn babies requiring surgery in the South Island, which is approximately 50,000 square kilometres (excluding the Nelson region), are also cared for within this service. Exclusion criteria for the study included infants with congenital abnormalities, non-English speaking families and families who did not live within the greater Canterbury region. Ethical approval was obtained for this study from the Upper South Regional Ethics Committee, New Zealand (see Appendix B for Ethics Approval Letter and Appendices C, D and E for a copy of the Maternal Invitation Letter, Information Letter and Consent forms).

2.2.1.1. Infant clinical and medical characteristics. Infant clinical and medical data were collated from clinical notes and hospital databases. Table 2.2 (p. 32) describes the infant clinical characteristics for infants in the Christchurch and Melbourne cohorts. The table also shows comparisons between the cohorts on the variables shared across the groups of infants. As shown, in the Christchurch cohort, 77% of infants were male, they had a mean birth weight of 1227 grams and on average were born at 28 weeks' gestation (range: 26-30 weeks' gestation). Two of the infants were twins. In terms of infants' medical characteristics, 54% of infants had PDA (indicative of a heart defect); the mean number of days on CPAP (for treatment of respiratory insufficiency) was 32 days. On average, infants needed 42 days on oxygen (for the treatment of respiratory distress). Just fewer than half the infants still required oxygen at 36 weeks (indicative of chronic lung disease). Twenty-three percent of infants had sepsis, none underwent surgery while hospitalised in the NICU

and on average infants were re-admitted less than once post-discharge. The total number of days spent in the NICU for infants in this sample was on average 76 days or close to 11 weeks.

Table 2.2.
Infant Clinical Characteristics of Infants Born Very Preterm in Christchurch and Melbourne

Infant Clinical Characteristics	Christchurch Cohort (N=13 infants)	Melbourne Cohort (N=97 infants)	χ^2/t	<i>p</i>
% (<i>n</i>) Male gender	76.92 (10)	58.76 (57)	0.92	.34
<i>M (SD)</i> Birth weight (grams)	1222.08 (343.58)	1012.60 (230.66)	-2.03	.08
<i>M (SD)</i> Gestation (wks)	27.75 (1.36)	27.74 (1.76)	-0.02	.98
% (<i>n</i>) Patent Ductus Arteriosus (PDA)	53.85 (7)	a		
<i>M (SD)</i> Days of Continuous Positive Airway Pressure (CPAP)	31.85 (20.34)	a		
<i>M (SD)</i> Total Days of oxygen	41.62 (28.79)	a		
% (<i>n</i>) Oxygen at 36 wks	46.15 (6)	a		
% (<i>n</i>) Home on oxygen	0.00 (0)	a		
% (<i>n</i>) Proven sepsis in infant	23.08 (3)	a		
% (<i>n</i>) Surgery while in NICU	0.00 (0)	a		
<i>M (SD)</i> Number of admissions post discharge	0.69 (0.85)	a		
<i>M (SD)</i> Total number of days in hospital	76.38 (19.52)	a		

Note. Data presented in this table is consistent with data available. For example, birth weight was only available for 1 infant per mother (therefore twin or triplet birth weight is not included in this analysis).

df = 12 for Christchurch cohort. *df* = 96 for Melbourne cohort.

^aData not available.

2.2.1.2. Personal and family factors. Table 2.3 (p. 35) provides a description of personal and family factors of the parents of VPT infants as collated from parent interviews at term. As shown, mothers had a mean age of 29.8 years while fathers had an average age of 35.7 years. Of the 11 mothers, 1 was living alone. One mother also gave birth to twins. Half the families had 1 or more

children living at home. No parents in the sample indicated that they left school between 13-16 years of age. Nine of the mothers were NZ European and 10 of the fathers were also NZ European.

Socioeconomic status (SES) scores as defined by Elly and Irving (2003) were measured for both mothers and fathers. To gauge family's overall SES, the best score was taken from those of mothers and fathers and is shown in Table 2.3 (p. 35) along with other personal and family factors. Those families with SES scores of 1 or 2 were considered to fall in the professional/managerial group (4 families), those with scores of 3 or 4 considered to be skilled (7 families) and those with scores of 5 or 6 to be unskilled (1 family). In terms of total household income, 8 families reported to have an income of \$50, 000 a year or less. The mean number of upsetting "Life Events" over the past 12 months as measured on the Life Events Scale (Holmes & Rahe, 1967) was 2.5 for mothers and 2.4 for fathers.

2.2.2. Procedure: Christchurch cohort. Study parents were recruited when their infant was 32 weeks' old. Parents completed a questionnaire on NICU stress (PSS: NICU) when their infant was 34 weeks' old. Interviews were conducted at this time because infants were considered to be medically stable at this age. The PSS: NICU was delivered verbally to allow any participants who were illiterate to be able to participate. Information on maternal and infant medical history was collected from hospital records. Study mothers also completed a maternal interview which obtained information on demographic and socio-familial characteristics. Of the 25 mothers and fathers approached to participate, five potential participants declined to take part in the study (20%) stating reasons such as "too stressed to do anything else" and "not enough time".

Because of a 6.3 magnitude earthquake in Christchurch on 22 February 2011, recruitment of the Christchurch sample had to be terminated early. Only the parents of 13 infants had participated in the study up to 22nd February 2011. This event was declared a New Zealand-wide State of Emergency and had a death toll of 185 people. Data collection was therefore cancelled primarily so as not to breach ethical concerns about asking participants to discuss their stress in the NICU while

they were also dealing with distress relating to the earthquake. In addition, if data collection had been continued earthquake stress was considered to be too large a confounding variable when measuring stress pertaining to the NICU experience. Due to the cancellation of data collection and in order to examine whether the results found in the Christchurch sample were in fact representative of a larger population, permission was sought and obtained from the Victorian Infant Brain Study (VIBeS) research group to source their data. Permission was granted to use data collected in Melbourne for a sample of parents in Melbourne who had VPT infants in the NICU.

Table 2.3.
Personal and Family Factors of Parents of Infants Born Very Preterm in Christchurch and Melbourne

	Christchurch Cohort (N=11 mothers, 10 fathers)	Melbourne Cohort (N=68 mothers, 68 fathers)	χ^2/t	<i>p</i>
<i>M (SD)</i> Maternal age at birth of VPT infant	29.82 (7.24)	30.86 (5.70)	1.09	.28
<i>M (SD)</i> Paternal age at birth of VPT infant	35.70 (7.44)	a		
% (N) Single parent family	9.09 (1)	7.35 (5)	0.00	1.00
% (<i>n</i>) Mothers who had multiple births	8.33 (1)	39.71 (27)	3.14	.06
Other children living at home				
% (<i>n</i>) 1 or more	50.00 (6)^	35.30 (24)	0.37	.54
Maternal education				
% (<i>n</i>) Low education (left school between 13-16 years)	0.00 (0)	11.76 (8)	0.45	.50
Paternal education				
% (<i>n</i>) Low education (left school between 13-16 years)	0.00 (0)	20.60 (14)	1.56	.21
Maternal ethnicity				
% (<i>n</i>) NZ/Australian European	81.81 (9)	85.29 (58)	0.00	1.00
Paternal ethnicity				
% (<i>n</i>) NZ/Australian European	100 (10)	82.4 (56)	1.12	.29
Family SES ^b				
% (<i>n</i>) Unskilled	8.30 (1)	7.40 (5)	0.36	.55
Total Household Income				
% (<i>n</i>) Income below \$50, 000 per year	38.10 (8)	a		
<i>M (SD)</i> Maternal # upsetting life events in past 12 months	2.45 (2.46)	3.24 (2.94)	-0.83	.41
<i>M (SD)</i> Paternal # upsetting life events in past 12 months	2.40 (1.96)	a		

Note. ^aData not available.

^bSocioeconomic status (SES) as defined by Elly & Irving (2003).

2.2.3. Sample: Melbourne cohort. The sample was recruited for this study as part of the Victorian Infant Brain Studies cohort between 2001 and 2004. The sample was made up of 68 mothers and 68 fathers of 97 VPT infants (<30 weeks' gestation or <1250g birth weight). Infants were born at or transferred shortly after birth to the Royal Women's Hospital, the largest of the three high-risk obstetric hospitals in Victoria State, Australia. Infants were excluded from the study if they had major congenital abnormalities associated with early mortality. Parents of infants who died after birth were excluded from analysis. The study was approved by the Research and Ethics Committee at the Royal Women's Hospital.

2.2.3.1. Infant clinical and medical characteristics. As shown in Table 2.2 (p. 32), just over half (59%) of the infants in this sample were male and had a mean birth weight of 1010 grams. Infants were on average born at 28 weeks' gestation (range: 22-31 weeks' gestation) and 30% were either born a twin or triplet. Comprehensive infant clinical and medical data were not available for infants in the Melbourne cohort (unlike the Christchurch cohort). To determine whether there were any differences between the two NICU sites relating to infant clinical variables, shared infant clinical variables were compared across the groups. There were no significant differences between the Christchurch and Melbourne cohorts on infant gender, birth weight or gestational age.

2.2.3.2. Socio-familial characteristics. Table 2.3 (p.35) shows that the mean age of mothers at the birth of their VPT infant was 30.9 years. Seven percent (5 mothers) were living without a partner, and classed as being a single parent family. Close to 40% of mothers in this sample gave birth to either twins or triplets. Of the 68 parents, just over a third (24) had 1 or more children living at home. In terms of level of education, 8 mothers and 14 fathers reported leaving school between 13-16 years. Mothers and fathers were predominantly Australian European (85% and 82% respectively). Seven percent of families were categorised as being unskilled in terms of the Elly & Irving (2003) SES categories described above. The mean number of upsetting "Life Events" over the past 12 months was 3.2 for mothers.

The results of the between-group comparisons in Table 2.3 (p. 35) showed that parents in the Christchurch and Melbourne cohorts did not differ significantly on any personal or family factors. This implies that the two cohorts had sufficient demographic similarities to allow for combining Christchurch and Melbourne mothers, and Christchurch and Melbourne fathers in analyses examining key predictors of maternal and paternal stress (described below).

2.2.4. Procedure: Melbourne cohort. Participants were interviewed when their infant was 40 weeks' gestational age or term equivalent (this was 6 weeks later than when participants in the Christchurch cohort were interviewed). Parents completed the PSS: NICU and the Life Events Scale as well as questions about their demographics. No information was available as to how many parents did not consent to participate in the study. Perinatal information was collected from hospital records.

2.2.5. Measures. A description of the parental NICU stress and upsetting life events measures used in Study 1 is provided below.

2.2.5.1. NICU-related stress. The Parental Stressor Scale: NICU (PSS: NICU; Miles et al., 1993) was used to measure parental perceptions of stressors in the physical and psychosocial environment of the NICU (Miles et al., 1993). The PSS: NICU consists of 47 items, where parents rate their level of stress pertaining to experiences in the NICU on a Likert scale ranging from 1 = *not at all stressful* through to 5 = *extremely stressful*. Example items from the PSS: NICU can be found in Table 2.4. The items on the PSS: NICU fall into four subscales indicating different aspects of NICU stress: "sights and sounds", "infant appearance", "loss of parental role", "staff behaviours and communication". Four composite subscale scores can then be calculated. In addition, parents are also asked to indicate on a single item how stressful they have found their NICU experience overall: termed "overall stressfulness".

Table 2.4.
Example Items from the PSS: NICU

PSS: NICU subscales	Example items from PSS: NICU subscales
Sights and Sounds	“The sudden noises of monitor alarms”, “The other sick babies in the room”
Infant Appearance	“Seeing my baby stop breathing”, “Bruises, cuts or incisions on my baby”
Loss of Parental Role	“Being separated from my baby”, “Feeling helpless and unable to protect my baby from pain and painful procedures”
Staff Behaviours and Communication	“Not feeling sure I will be called about changes in my baby’s condition”, “Staff acting as if they did not want parents around”
Overall Stressfulness	Single item: “Indicate how stressful, in general, the experience of having your baby hospitalised in the NICU has been for you.”

Note. Adapted from a similar table published in Carter et al. (2007).

The PSS: NICU can be scored in two main ways (Miles et al., 1993). The first of these (Metric I - Stress Occurrence Level) assesses the level of stress experienced in relation to a specific situation. Therefore, only participants experiencing stress relating to a specific item receive a score for that item, while those who did not, receive a score of zero. The second scoring method (Metric II - Overall Stress Level) assesses overall stress levels experienced in the NICU environment. For example, for those participants not reporting an experience relating to a specific item, a score of one is given rather than a zero to indicate that no stress was experienced. Because the present research was focussed on the parents’ overall stress levels during their stay in the NICU, it was decided to use Metric II.

The PSS: NICU has been found to have good validity and reliability in both US and UK samples (Franck et al., 2005). It has been found to correlate highly with state anxiety, a situationally-based temporary experience of anxiety (Miles et al., 1993). This relationship is expected to be found when studying stress levels in the NICU. Shields-Poe and Pinelli (1997) reported Cronbach’s alpha coefficients ranging from .73 to .92 for the subscales, and .89 to .94 for the overall stressfulness score. The authors also found the PSS: NICU to have adequate test-retest reliability ranging from .69 to .87. In the study by Meyer et al. (1995), internal consistency was found to be acceptable, with

alphas ranging from .67 to .92 for the subscales. Concurrent validity was also supported by significant correlations with the Spielberger State Anxiety Scale for each PSS: NICU subscale, except “staff behaviours and communication” (Meyer et al., 1995). In essence, the reliability and validity of the PSS: NICU is considered acceptable in the literature. (A copy of the interview is provided in Appendix F).

2.2.5.2. General life events external to the NICU. The Life Events Scale (Holmes & Rahe, 1967) is a measure that documents how many general life events participants experienced over a 12 month period and how upsetting they were found to be (a copy of the Life Events Scale can be found in Appendix G). With the PSS: NICU documenting NICU-specific stress, this instrument was used to determine the extent to which parents experienced other upsetting events over the past year leading up to the birth of their VPT infant. The severity of these events was thought to relate to the degree of NICU stress experienced. There were a total of 34 different life events listed in the scale. Included in this scale were items such as “miscarriage” or “loss of job”. Participants were required to rate how much upset they had experienced in relation to each event on a scale of 2 (not upset) to 5 (very upset). Items were coded 1 if participants had not experienced that event, allowing for scoring along two lines, a) number of events experienced, and b) number of upsetting events experienced. For the purposes of identifying associations with parental NICU stress, the second method of scoring was used. This scale has been found to have good reliability and validity in a sample of British university students, where higher life event scores correlated with responses on the General Health Questionnaire (Clements & Turpin, 1996).

2.2.6. Statistical analyses. Descriptive statistics (means and standard deviations) were calculated for PSS: NICU scores for Christchurch and Melbourne mothers and fathers. The means of each PSS: NICU subscale were visually inspected and the most stressful through to the least stressful subscales were determined. Means were also calculated for the overall stressfulness single item on the PSS: NICU and the mean level of stress across all items. The number of participants who

reported a score of 5 (equivalent to *extremely stressful* on the PSS: NICU rating scale) on the overall stressfulness single item was calculated and was reported as percentages. To determine whether statistically significant differences existed between the maternal and paternal groups, t-tests were conducted for the continuous variables to compare means while a Chi square test for independence was conducted for the categorical variables. Further descriptive statistics were determined by calculating the mean level of stress reported for each individual item of the PSS: NICU.

In order to determine which factors were correlated with maternal and paternal NICU stress levels (and to increase overall sample size), Christchurch and Melbourne maternal and paternal data were combined to comprise one maternal and one paternal group. This was possible because Christchurch and Melbourne parents did not differ significantly on any infant clinical variables (such as birth weight), parental demographics (such as parental age or education), or family variables (such as family SES or income; see Table 2.2, p.32 and Table 2.3, p. 35). All continuous variables were then entered into a correlation matrix to determine which variables correlated with mean NICU stress, while Chi-square tests were conducted for categorical variables. Following this, variables which correlated significantly with NICU stress were identified. These were for the maternal group: number of upsetting life events and paternal NICU stress; for the paternal group: number of other children at home and maternal NICU stress. In addition, variables that were tending towards significance, with a cut point of $r > 0.15$ were also included for analysis (for mothers: maternal age and maternal education; for fathers: infant gestational age and number of upsetting life events). These variables were entered simultaneously into a standard linear regression model and the significant predictors of parental NICU stress were presented.

2.3. Study 1 Results

2.3.1. Parental stress in the NICU. The first aim of Study 1 was to describe the most stressful aspects of the NICU environment for Christchurch and Melbourne parents. In order to address this aim, Table 2.5 (p. 43) describes sources of stress as measured on the subscales of the PSS: NICU for Christchurch and Melbourne parents of VPT infants respectively. Ratings of overall levels of stressfulness as measured on a single item on the PSS: NICU are also reported as well as the percentage of parents who rated this item to be *extremely stressful*. The mean level of stress across all items is also shown. To address the second aim of Study 1 and to compare sources of stress between the maternal and paternal groups, Table 2.5 (p. 43) shows t-tests comparing maternal and paternal levels of NICU stress and chi square tests to compare sex differences in the percentage of participants who rated overall stressfulness as *extremely stressful*.

2.3.2. Christchurch cohort

2.3.2.1. Sources of maternal stress in the NICU. As shown in Table 2.5 (p.43), mothers reported that aspects of the NICU experience measured on the “infant appearance” subscale were most stressful during their infant’s stay in the NICU ($M = 2.50$, $SD = 0.92$). This was followed by the stressful experiences relating to the “loss of parental role” subscale ($M = 2.45$, $SD = 1.16$), “sights and sounds” subscale ($M = 2.16$, $SD = 0.77$) and lastly “staff behaviours and communication” subscale ($M = 1.93$, $SD = 1.93$). With respect to overall stressfulness scores, mothers reported a mean of 3.82 ($SD = 1.47$), where a score of 3 reflects a response of *moderately stressful* on the PSS: NICU. This indicates that mothers found that overall their time in the NICU was a moderately stressful experience. In addition, a visual inspection of stress ratings on the overall stressfulness item revealed that 55% of mothers reported that their overall experience in the NICU was *extremely stressful* (a score of 5 on the Likert scale). In contrast, the mean level of stress across all responses was 2.31 ($SD = 0.88$), indicating this to be *a little stressful* or above for most mothers.

2.3.2.2. Sources of paternal stress in the NICU. The paternal group reported that aspects of the NICU captured by the “infant appearance” subscale was most stressful ($M = 1.60$, $SD = 0.31$). This was followed by “loss of parental role” ($M = 1.53$, $SD = 0.35$), “sights and sounds” ($M = 1.48$, $SD = 0.40$) and lastly “staff behaviours and communication” ($M = 1.93$, $SD = 0.96$). Fathers reported that overall they perceived their time in the NICU to be somewhere between *a little stressful* and *moderately stressful* on the Likert scale ($M = 2.60$, $SD = 0.84$). No fathers reported finding the NICU experience as a whole (as measured on the single item of overall stressfulness) to be *extremely stressful*. The mean level of paternal stress across all PSS: NICU items was 1.50 ($SD = 0.28$) or between the *not at all stressful* and *a little stressful* response options on the PSS: NICU.

2.3.2.3. Comparisons between maternal and paternal NICU stress. The second aim of Study 1 was to compare sources of maternal and paternal NICU stress. As shown in Table 2.5 (p. 43), mothers reported significantly higher levels of stress than fathers on all subscales ($p < .05$) except on the “staff behaviours and communication” subscale ($p = .07$). This can also be seen by mean maternal PSS: NICU subscale scores (with the exception of “staff behaviours and communication”) being above a 2, which equates to *a little stressful* on the PSS: NICU Likert scale, whereas, mean paternal subscale scores were all below a score of 2.

Both the maternal and paternal groups of parents consistently rated the subscales of the PSS: NICU in the same order of stressfulness. The mean for the maternal overall stressfulness item was significantly higher than the paternal overall stressfulness item mean ($M = 3.82$ vs. $M = 2.60$, $p < .05$). In addition, 55% of mothers compared to 0% of fathers reported the NICU to be *extremely stressful* on the overall stressfulness single item; this difference was significant ($\chi^2 (1) = 5.20$, $p < .05$). Similarly, the mean level of stress across all items was significantly higher in the maternal group than in the paternal group ($M = 2.31$ vs. $M = 1.50$, $p < .05$).

Table 2.5.

Maternal and Paternal PSS: NICU Scores of Christchurch and Melbourne Parents of VPT Infants

PSS: NICU Subscales		Maternal Group N=11 M (SD)	Paternal Group N=10 M (SD)	χ^2/t	p
Christchurch Cohort	Sights & sounds	2.16 (0.77)	1.48 (0.40)	2.50	.02
	Infant appearance	2.50 (0.92)	1.60 (0.31)	3.06	.01
	Loss of parental role	2.45 (1.16)	1.53 (0.35)	2.51	.03
	Staff behaviours & communication	1.93 (0.96)	1.29 (0.42)	2.00	.07
	Overall stressfulness single item	3.82 (1.47)	2.60 (0.84)	2.35	.03
	% (n) rated overall stressfulness single item <i>extremely stressful</i>	54.55 (6)	0.00 (0)	5.20	.02
	Mean level of stress across all items	2.31 (0.88)	1.50 (0.28)	2.91	.01
		Maternal Group N=68 M (SD)	Paternal Group N=41 M (SD)	χ^2/t	p
Melbourne Cohort	Sights & sounds	2.42 (0.85)	2.00 (0.70)	2.66	.01
	Infant appearance	2.63 (0.82)	2.20 (0.77)	2.71	.01
	Loss of parental role	2.99 (0.91)	2.11 (0.75)	5.29	.00
	Staff behaviours & communication	1.73 (0.73)	1.63 (0.59)	0.70	.49
	Overall stressfulness single item	3.96 (1.14)	3.12 (1.25)	3.57	.00
	% (n) rated overall stressfulness single item <i>extremely stressful</i>	34.33 (23)	17.07 (7)	2.96	.09
	Mean level of stress across all items	2.44 (0.65)	1.99 (0.55)	3.72	.00

2.3.3. Melbourne cohort

2.3.3.1. Sources of maternal stress in the NICU. As reported in Table 2.5 (p. 43), mothers in the Melbourne sample reported that the “loss of parental role” was the most stressful subscale ($M = 2.99$, $SD = 0.91$), followed by “infant appearance” ($M = 2.63$, $SD = 0.82$), “sights and sounds” ($M = 2.42$, $SD = 0.85$) and lastly “staff behaviour and communication” ($M = 1.73$, $SD = 0.73$). Mothers reported that the overall stressfulness of their NICU experience was *very stressful* ($M = 3.96$, $SD = 1.14$). In addition, 34% of mothers reported the overall stressfulness of the NICU experience to be *extremely stressful*. Across all items on the PSS: NICU, the mean level of stress was 2.44 ($SD = 0.65$), which is indicative of *a little stressful* or above (on the PSS: NICU Likert scale).

2.3.3.2. Sources of paternal stress in the NICU. A similar pattern of results is evident for fathers, however the most stressful subscale was “infant appearance” ($M = 2.20$, $SD = 0.77$). Paternal scores equated to *moderately stressful*, as measured by the mean level of overall stressfulness of 3.12 ($SD = 1.25$). Of the 41 fathers in this group, 17% reported that the NICU experience as a whole was *extremely stressful*. The mean level of stress across all items on the PSS: NICU was 1.99 ($SD = 0.55$), which equates to *a little stressful*.

2.3.3.3. Comparisons between maternal and paternal NICU stress. As in the Christchurch sample, mothers reported significantly higher levels of stress than fathers on the subscales of the PSS: NICU. The exception was that no sex differences were found on the “staff behaviours and communication” subscale. Maternal overall stressfulness and the mean level of stress across all items were both significantly higher than paternal stress levels on these measures. For 34% of the maternal group compared to 17% of the paternal group the overall stressfulness single item was rated to be *extremely stressful*. Although tending towards significance, this difference was not significant ($\chi^2 (1) = 2.96$, $p = .09$).

2.3.4. Maternal and paternal principal stressors in the NICU. Individual items on the PSS: NICU were examined closely to determine which specific experiences parents found most stressful. Items on the PSS: NICU were ranked in order of highest to lowest mean for each group of parents (i.e., Christchurch mothers, Christchurch fathers, Melbourne mothers and Melbourne fathers). The top 5 most stressful items were then presented in Table 2.6 (p. 46) and any common stressors across the parent groups were identified from visual inspection. As shown, although mothers and fathers from Christchurch and Melbourne differed as to which aspects of having an infant in the NICU were most stressful, there was some overlap. The item “being separated from my baby” was rated in the top 3 most stressful aspects of the NICU by parents across all four parent groups. Similarly, “when my baby seemed to be in pain”, “feeling helpless and unable to protect my baby from pain”, and “my baby’s unusual or abnormal breathing patterns” were all found amongst

three out of the four groups of parents to be in the top 5 most stressful aspects of the parental NICU experience.

Mothers and fathers in Christchurch and Melbourne differed to some degree on the most stressful components of the NICU experience. For example, the order of the most stressful items varied across all parent groups. However, results in Table 2.6 show that in general parents are finding similar experiences stressful. For instance, all the top stressors shown in Table 2.6 are from the “infant appearance” and “loss of parental role” subscales with the exception of one item from the “sights and sounds” subscale. This suggests that the highest intensity of parental stress comes from these aspects of having an infant in the NICU, and not from the “staff behaviours and communication” subscale.

Although many of the most stressful experiences are shared across maternal and paternal groups in Christchurch and Melbourne, there are noticeable differences in the amount of stress experienced for mothers and fathers. For instance, an analysis was conducted to ascertain whether there were significant differences in means for the “being separated from my baby” item. This item was chosen to identify sex differences since it was found to be in the top 3 most stressful for all four parent groups. Results showed that the Christchurch maternal group found “being separated from my baby” to be significantly more stressful than the Christchurch paternal group ($p = .03$). Similarly, the same sex difference was found for Melbourne parents ($p < .001$).

Table 2.6.
Top 5 NICU Stressors as Rated on the PSS: NICU by Parents from Christchurch and Melbourne NICU Sites

	PSS: NICU items	<i>M (SD)</i>	Subscale
Maternal: Christchurch	1.= Being separated from my baby	3.82 (1.60)	Loss of Parental Role
	1.= When my baby seemed to be in pain	3.82 (1.66)	Infant Appearance
	3. Seeing needles and tubes put in my baby	3.64 (1.50)	Infant Appearance
	4. Feeling helpless and unable to protect my baby from pain	3.18 (1.83)	Loss of Parental Role
	5. Having a machine (respirator) breathe for my baby	3.09 (1.76)	Infant Appearance
Paternal: Christchurch	1. My baby's unusual or abnormal breathing patterns	2.70 (1.25)	Infant Appearance
	2. Being separated from my baby	2.40 (1.07)	Loss of Parental Role
	3. When my baby seemed to be in pain	2.20 (1.40)	Infant Appearance
	4. The small size of my baby	2.10 (1.29)	Infant Appearance
	5. Bruises, cuts or incisions on my baby	2.00 (0.94)	Infant Appearance
Maternal: Melbourne	1. Being separated from my baby	4.06 (1.18)	Loss of Parental Role
	2. Feeling helpless and unable to protect my baby from pain	3.88 (1.31)	Loss of Parental Role
	3. Not being able to hold my baby when I want	3.74 (1.35)	Loss of Parental Role
	4. When my baby seemed to be in pain	3.57 (1.48)	Infant Appearance
	5. My baby's unusual or abnormal breathing patterns	3.47 (1.28)	Infant Appearance
Paternal: Melbourne	1.= Feeling helpless and unable to protect my baby from pain	3.00 (1.48)	Loss of Parental Role
	1.= The sudden noises of monitor alarms	3.00 (1.20)	Sights and Sounds
	3. Being separated from my baby	2.88 (1.29)	Loss of Parental Role
	4. My baby's unusual or abnormal breathing patterns	2.88 (1.21)	Infant Appearance
	5. Seeing my baby stop breathing	2.83 (1.65)	Infant Appearance

2.3.5. Associations of personal, family and infant clinical variables with maternal NICU

stress. To address aim 3 and to determine which personal, family and infant clinical variables were associated with maternal NICU stress, the Christchurch and Melbourne samples were combined (as described in the Method, p.39). This created a total maternal sample of $N = 79$. Table

2.7 (p. 48) provides a description of the relationship between the personal, family and infant clinical variables (those that were continuous variables) and mean maternal NICU stress levels. As shown, the variables that were significantly correlated with mean maternal PSS: NICU stress scores across all items were: the number of upsetting life events (as measured on the Life Events scale: this variable measured the total number of events mothers reported as upsetting), each subscale of the PSS: NICU, the overall stressfulness single item and the mean paternal NICU stress score. No other personal, family or infant clinical variables (that were continuous in nature) were found to be correlated. Significant positive correlations were found, however, between number of upsetting life events and the “sights and sounds” and “loss of parental role” subscales. This indicates that the higher the number of upsetting life events mothers experienced, the more stress they reported on these subscales. Higher levels of maternal education was also found to be correlated to higher stress ratings on the “infant appearance” subscale, indicating that the more educated mothers were the more stressful they found their infant’s physical appearance. Finally, maternal age was negatively correlated with “loss of parental role” stress, where younger mothers reported higher stress on this subscale.

As described above in the Method (p. 39), variables that were categorical (for example, ethnicity) were unable to be entered into a correlation matrix. Therefore, in order to determine whether there were any differences between the maternal group with or without these variables, Chi square tests were conducted. Accordingly, there were no significant differences in mean NICU stress relating to maternal ethnicity ($p = .11$). There were also no differences between mothers who gave birth to multiple infants compared with mothers of singletons ($p = .49$) or between single mothers and mothers with partners ($p = .63$).

Table 2.7.

Correlation Matrix of Maternal Personal, Family and Infant Clinical Variables and NICU Stress Measures

	Infant birth weight	Infant gestational age	Maternal age	Maternal education	Maternal SES	Number of other children	Number of 'upsetting' life events	Mean "sights and sounds"	Mean "infant appearance"	Mean "loss of parental role"	Mean "staff behaviour and communication"	Mean maternal overall stressfulness	Mean paternal PSS: NICU score	Mean maternal PSS: NICU score
Infant birth weight	1													
Infant gestational age	0.570**	1												
Maternal age	0.109	0.148	1											
Maternal education	0.047	0.040	0.225*	1										
Maternal SES	-0.072	-0.109	-0.164	-0.353**	1									
Number of other children ^a	0.233*	0.142	0.305**	-0.175	0.057	1								
Number of 'upsetting' life events	-0.037	0.017	-0.130	0.182	-0.011	-0.082	1							
Mean "sights and sounds"	-0.063	-0.111	-0.042	0.165	-0.103	-0.059	0.253*	1						
Mean "infant appearance"	-0.128	-0.139	-0.052	0.275*	-0.130	0.019	0.216	0.602**	1					
Mean "loss of parental role"	-0.060	-0.110	-0.259*	0.200	0.041	-0.077	0.368**	0.527**	0.582**	1				
Mean "staff behaviour and communication"	-0.037	-0.034	-0.203	-0.020	0.116	-0.140	0.220	0.399**	0.477**	0.461**	1			
Mean maternal overall stressfulness	0.148	0.010	0.000	0.132	0.050	0.040	0.153	0.304**	0.427**	0.375**	0.310**	1		
Mean paternal PSS: NICU score	-0.267	-0.217	-0.222	-0.036	-0.162	-0.306*	0.227	0.812**	0.880**	0.803**	0.724**	0.202	1	
Mean maternal PSS: NICU score	-0.091	-0.126	-0.178	0.201	-0.024	-0.079	0.338**	0.795**	0.836**	0.828**	0.716**	0.446**	0.372**	1

Note. ** Correlation is significant at the 0.01 level (2-tailed). * Correlation is significant at the 0.05 level (2-tailed).

^aThis variable includes all children currently living at home, for example, it could include biological, foster, adopted and step children.

2.3.6. Associations of personal, family and infant clinical variables with paternal NICU

stress. In addressing aim 3 for the paternal group, the Christchurch and Melbourne paternal participants were combined. This created a total paternal sample of $N = 51$. Table 2.8 (p. 50) provides a description of the relationship between the personal, family and infant clinical variables (that were continuous in nature) and mean paternal NICU stress levels. Mean paternal PSS: NICU scores were found to be negatively correlated with the number of other children at home. Mean paternal NICU stress was positively correlated with each PSS: NICU subscale, the paternal overall stressfulness single item and with maternal mean NICU stress scores. Of note is the finding that the fewer children fathers had at home, the more stressful they rated the NICU experience. Paternal stress on the “staff behaviour and communication” subscale was shown to correlate negatively with infant birth weight and the overall stressfulness single item. Number of other children was also negatively correlated with the “sights and sounds” subscale, where fathers with fewer children experienced higher stress. Unlike with the maternal group, the number of upsetting life events was not correlated with any measure of paternal NICU stress.²

Chi square tests were conducted to determine whether the categorical variables differed significantly in terms of paternal NICU stress (as described in the Method, p. 39). Similarly to the maternal group, there were no significant differences in NICU stress with respect to ethnicity ($p = .82$) and no differences emerged for fathers of multiple infants compared with fathers of singletons ($p = .15$).

² Key variables were not available, such as paternal age and number of upsetting life events as reported by fathers (as measured on the Life Events scale, this variable portrays the total number of events *mothers* reported as upsetting), and therefore, only available variables have been included in the correlation matrix.

Table 2.8.

Correlation Matrix of Paternal Personal, Family and Infant Clinical Variables and NICU Stress Measures

	Infant birth weight	Infant gestational age	Paternal education	Paternal SES	Number of other children ^a	Number of 'upsetting' life events ^b	Mean "sights and sounds"	Mean "infant appearance"	Mean "loss of parental role"	Mean "staff behaviour and communication"	Mean paternal overall stressfulness	Mean maternal PSS: NICU score	Mean paternal PSS: NICU score
Infant birth weight	1												
Infant gestational age	0.568**	1											
Paternal education	0.201	0.159	1										
Paternal SES	-0.207	-0.031	-0.635**	1									
Number of other children ^a	0.208	0.131	-0.269*	0.084	1								
Number of 'upsetting' life events ^b	-0.073	0.004	-0.045	0.102	-0.108	1							
Mean "sights and sounds"	-0.241	-0.157	0.044	-0.064	-0.281*	0.068	1						
Mean "infant appearance"	-0.124	-0.047	0.021	-0.085	-0.219	0.219	0.735**	1					
Mean "loss of parental role"	-0.210	-0.190	0.042	-0.123	-0.223	0.133	0.511**	0.541**	1				
Mean "staff behaviour and communication"	-0.326*	-0.208	-0.138	0.052	-0.258	0.336*	0.347**	0.519**	0.556**	1			
Mean paternal overall stressfulness	-0.343*	-0.198	-0.157	-0.074	-0.209	0.214	0.530**	0.478**	0.412**	0.499**	1		
Mean maternal PSS: NICU score across all items	-0.115	-0.135	-0.136	0.048	-0.095	0.328**	0.320*	0.310*	0.351**	0.238	0.364**	1	
Mean paternal PSS: NICU score across all items	-0.115	-0.217	-0.006	-0.074	-0.306*	0.227	0.812**	0.880**	0.803**	0.724**	0.591**	0.372**	1

Note. ** Correlation is significant at the 0.01 level (2-tailed). * Correlation is significant at the 0.05 level (2-tailed).

^aThis variable includes all children currently living at home, for example, it could include biological, foster, adopted and step children.

^bAs reported by the mother (these life events, however, included questions relevant to fathers).

2.3.7. Predictors of maternal NICU stress. To further address aim 3 and to identify the key predictors of maternal NICU stress, a linear regression model was fitted to the data as described in the Method (p. 39). In checking for multicollinearity, none of the assumptions of multiple regression were violated. In Tables 2.9 and 2.10 (pp. 51-52), the unstandardized and standardized regression coefficients signify the independent contribution that each variable makes to measures of maternal stress, while controlling for each of the other variables entered into the equation. However, the B (unstandardized) coefficient displays the coefficient in terms of the units of the particular variable, whereas the β weights (standardized) portray the coefficient in a unit common to all variables. Hence, one can compare the β weights of each variable to determine which is contributing the most to the outcome variable. The standard error provides an estimate of the standard deviation of each coefficient, and indicates the precision of how well each coefficient is measured.

Variables that were significantly correlated with mean NICU stress (number of upsetting life events and paternal NICU stress score) plus those that were tending towards significance (maternal age and education level, $r > .15$) were entered into a regression model. As shown in Table 2.9, the key independent predictors of maternal stress in the NICU were the number of upsetting life events that had occurred over the past 12 months ($\beta = .33$) and mean paternal NICU stress score ($\beta = .23$). The final model explained 24.4% of the variance ($F(2, 47) = 7.57, p < .01$) in mean maternal PSS: NICU scores.

Table 2.9.
Significant Predictors of Maternal Mean PSS: NICU Stress Scores

Predictors	B (SE)	β	p
Number of upsetting life events	.08 (.03)	.33	.01
Mean paternal PSS: NICU score	.39 (.17)	.23	.03

Note. B = unstandardized coefficient; SE = standard error; β = standardized Beta coefficient.

2.3.8. Predictors of paternal NICU stress. Similar to the analysis performed for mean maternal PSS: NICU scores, variables that were significantly correlated with paternal NICU stress (number of other children and maternal NICU stress) and those that were tending toward significance (infant gestational age and number of upsetting life events, $r > .15$) were entered into a regression model. The final model is shown in Table 2.10. Results showed that the key independent predictor of paternal NICU stress (using a cut-off of $p < .05$) was maternal NICU stress ($\beta = .37$). The number of other children at home tended towards predicting paternal NICU stress ($p = .06$). In total, the final model accounted for 13.9% of the variance ($F(1, 48) = 7.73, p = .01$) in paternal NICU stress scores.

Table 2.10.

Significant Predictor of Paternal Mean PSS: NICU Stress Scores

Predictor	<i>B (SE)</i>	β	<i>p</i>
Mean maternal PSS: NICU score	.28 (.10)	.37	.01

2.4. Discussion

Study 1 addressed three research objectives regarding the parental stress response to having a VPT infant admitted to the NICU. The rates and sources of maternal and paternal NICU stress in the Christchurch and Melbourne NICU sites were described and compared, and key personal, family and infant clinical predictors of parental NICU stress were identified. The major findings and conclusions from Study 1 are reviewed below.

2.4.1. Most stressful aspects of the NICU environment. In addressing the first research aim, which was to describe the most stressful aspects of the NICU environment, results showed that parents found several aspects of the NICU experience to be stressful. For instance, parental stress ratings were highest for the “loss of parental role”, “infant appearance” and “sights and sounds” subscales. This was found across both Christchurch and Melbourne sites. All groups of parents found the “staff behaviour and communication” subscale to be the least stressful subscale on the PSS: NICU with all mean scores falling below 2 (below *a little stressful* on the Likert scale) for this subscale. This finding is consistent with previous research (Franck et al., 2005; Carter et al., 2007; Montgomery-Hönger et al., 2010). In general, PSS: NICU subscale means were similar to results from previous studies (Franck et al., 2005; Carter et al., 2007; Montgomery-Hönger et al., 2010). For example, mean parental NICU stress scores fell within the same range of response categories on the Likert scale of the questionnaire for all PSS: NICU subscales as was found in Carter et al.’s (2007) study (i.e., either *a little stressful* or *not at all stressful*). In addition, all mean paternal subscale scores for the Christchurch sample were below a score of 2, suggesting that the paternal NICU experience on average was situated between the *not at all stressful* and *a little stressful* categories on the PSS: NICU rating scale. This finding replicates results from Carter et al., 2007, who found that in a sample of 172 fathers, the mean PSS: NICU subscale score was also below a score of 2.

An examination of the subscales of the PSS: NICU revealed that across all parents that were interviewed, only the Melbourne maternal group reported the “loss of parental role” subscale to be

the most stressful subscale. Although it was hypothesized and past research had consistently found “loss of parental role” to be the most stressful subscale on the PSS: NICU (Carter, et al., 2007; Akbarbegloo & Valizadeh, 2009; Montgomery-Hönger et al., 2010; Franck, et al. 2005; Miles et al., 1992), this was not the case for all parents in this study. By contrast, Christchurch and Melbourne paternal groups reported the most NICU stress relating to items on the “infant appearance” subscale. After examining the timing of when previous studies conducted the PSS: NICU there does not appear to be a clear relationship between studies that found “loss of parental role” as the most stressful subscale and timing of interview. Therefore, interview timing may not account for why the current research differed from previous findings. One explanation for this inconsistency may be that NICU staff have worked to minimise this negative experience relating to loss of parenting role for parents. However, VPT infant’s physical appearance and often fragile medical status cannot be altered despite staff training initiatives.

To gauge more specifically which aspects of the NICU environment are most stressful for parents (aim 1), all items on the PSS: NICU were ranked in order from the most stressful to the least. Results showed that “being separated from my baby” was found to be in the top three most stressful experiences across all groups of parents (means ranged from 2.40 to 4.06). This finding is consistent with research by Montgomery-Hönger et al. (2010), who found that this item was the single most stressful item on the PSS: NICU for a group of 133 mothers ($M = 4.04$). One explanation for this finding is that parents expect to be the full-time carers of their newborn, and when separation occurs following premature delivery and medical care in a NICU, this situation is an unnatural and distressing experience for parents. This finding implies that the very nature of being separated from their baby goes against parental instinct and societal expectations of the parental role to care for and protect their infant.

Parents reported that the overall stressfulness of the NICU experience was more stressful than any particular aspect of having an infant in the NICU. Specifically, mean scores on the overall

stressfulness single item on the PSS: NICU were higher than each of the subscale scores and the mean score across all PSS: NICU items for all groups of parents (Table 2.7, p. 48). For instance, the Melbourne maternal group had a mean score for the stressfulness single item that approached a 4 or *very stressful* on the scale ($M = 3.96$ compared to $M = 2.44$ for the mean level of stress of across all PSS: NICU items). This pattern was consistently found across Melbourne and Christchurch NICU sites in both maternal and paternal groups. This finding suggests that when parents are asked to reflect on the overall stressfulness of the NICU experience as a whole, their perception is that the overall experience is more stressful than they actually report each specific aspect of the NICU to be. Although not surprising, this finding highlights the need to examine whether there are factors contributing to parental stress in the NICU that are not measured by the PSS: NICU. Additional factors may account for why the overall NICU experience was much more stressful than any specific aspect of the NICU experience. This research question will be further examined in Chapter 3.

2.4.2. Comparison of sources of NICU stress between mothers and fathers of VPT

infants. In addressing aim 2, maternal groups reported significantly higher levels of NICU stress than paternal groups, which was consistent with what was hypothesized. For instance, the Christchurch maternal group reported significantly more stress than the Christchurch paternal group on all subscales except “staff behaviour and communication”. This pattern of results was replicated in the Melbourne sample. The trend that maternal report reflected higher NICU stress than paternal report has been found in past research. For example, in the UK sample in Franck et al. (2005), the maternal group reported higher mean stress scores for all PSS: NICU subscales than the paternal group. This was found across nine different NICU sites in the UK. This finding is replicated in Carter et al. (2007). Other research has found higher maternal NICU stress than paternal NICU stress for some of the PSS: NICU subscales (Shields-Poe & Pinelli, 1997: “loss of parental role” and “sights and sounds” subscales; Miles et al., 1992: “loss of parental role” subscale only). These sex differences were also found in the current study parents’ overall stressfulness ratings as well as their

mean score across all items on the PSS: NICU. Interestingly, neither Christchurch nor Melbourne parents differed in terms of amount of stress reported on the “staff behaviour and communication” subscale. This is consistent with the previous findings of Shields-Poe and Pinelli (1997) who did not find any significant sex differences on the “staff behaviour and communication” subscale.

The order of most stressful PSS: NICU subscales was the same for the maternal and paternal groups in the Christchurch sample. For example, like with the Christchurch maternal group, the “infant appearance” subscale had the highest paternal means, while the “staff behaviours and communication” subscale had the lowest paternal means. Although the paternal group tracked the maternal group in terms of the most stressful subscales, the paternal group reported significantly lower mean stress scores. This suggests that the paternal NICU stress response is similar to the maternal response, but at less elevated levels. One possible explanation for this sex difference is that females may be more open when reporting their experience of stress compared to males for whom being stressed may be considered less appropriate. Another significant sex difference emerged in relation to the degree of stress reported on the “being separated from my baby” item on the PSS: NICU. Maternal stress ratings on this item were significantly higher than paternal ratings in both the Christchurch and Melbourne sites. This is consistent with sex differences on the PSS: NICU subscales (as discussed above), with maternal stress ratings being significantly higher than paternal stress levels. This may be due to mothers having carried their baby throughout pregnancy and then after giving birth being more involved with the everyday care-giving of their infant in the NICU than fathers. Thus mothers could be experiencing higher levels of NICU stress compared to fathers.

Similarities were found between maternal and paternal responses with respect to individual items on the PSS: NICU. For instance, three items from the PSS: NICU were found to be in the top 5 most stressful aspects of the NICU environment for three out of the four groups of parents. These were: “when my baby seemed to be in pain”, “feeling helpless and unable to protect my baby from pain”, and “my baby’s unusual or abnormal breathing patterns”. This suggests that along with “being

separated from my baby” (the most consistent top stressor across all parental groups), there are commonalities irrespective of sex or NICU sites in relation to the biggest sources of stress of having an infant in the NICU. There was also considerable overlap between the maternal and paternal groups in the other items ranked in the top 5 most stressful aspects, although no clear patterns emerged. Consistent with previous research which found “loss of parental role” to be the most stressful subscale on the PSS: NICU (Carter, et al., 2007; Akbarbegloo & Valizadeh, 2009; Montgomery-Hönger et al., 2010; Franck, et al. 2005; Miles et al., 1992), the most stressful items were predominantly from the “loss of parental role” subscale, while a new finding for this study was that many of the top stressors were also from the “infant appearance” subscale. These findings indicate that there may be something inherently stressful about these specific experiences for parents which may be able to be alleviated if NICU staff were aware of these stressors. Because previous research has tended not to present data on the specific items of the PSS: NICU that parents found stressful, comparisons with the current study are therefore, difficult.

2.4.3. Pre-existing and concurrent personal and family factors associated with parental

NICU stress. Consistent with the third aim and hypothesis, a number of personal, family and infant clinical predictors of parental NICU stress were identified. Findings from the current study were consistent with previous studies in a number of areas. For instance, the finding that higher numbers of upsetting life events on the Life Events scale predicted higher mean levels of maternal NICU stress was consistent with findings from the Montgomery-Hönger et al. (2010) study. This finding is also consistent with the Preterm Parental Distress Model (Figure 1.2, p.11), where mothers’ “pre-existing and concurrent personal and family factors” are proposed to impact on their level of NICU stress. However, while this was not the case for fathers in the current study, this is likely due to the fact that the Life Events scale was completed only by the mother. Therefore, scores on this scale are unlikely to have captured fully the life events that were upsetting for fathers.

Maternal sociofamilial variables were also found to relate to NICU stress. For instance, maternal education was positively correlated to stress on the “infant appearance” subscale, indicating that the more educated mothers were, the more stressful they found their infant’s physical appearance. Although previous research has not reported this specific finding, a previous study has found a relationship between maternal education and another subscale of the PSS: NICU: the “loss of parental role” subscale (Montgomery-Hönger et al., 2010). Results showed that low maternal education was a key predictor of higher maternal stress scores on the “loss of parental role” subscale (Montgomery-Hönger et al., 2010). Although both this past research and the current study show that maternal education was linked to a PSS: NICU subscale, it is pertinent to note that in the present study, higher levels of education, rather than lower levels of education as found previously, were related to NICU stress. In Study 1, younger mothers also reported more stress on the “loss of parental role” subscale: a finding consistent with previous studies (Reid & Bramwell, 2003; Shields-Poe & Pinelli, 1997). This provides further evidence to support the argument that extra care should be given to support younger mothers of VPT infants.

A number of findings from this study relating to sociofamilial characteristics did not correspond to results from past research. For instance, contrasting with previous findings (Reid & Bramwell, 2003; Carter et al., 2007), the current study did not find SES or low income to be related to maternal or paternal NICU stress. It is interesting to note that when the PSS: NICU was administered within 48 hours of infant NICU admission (Reid & Bramwell, 2003); low SES was related to higher stress on the “sights and sounds” subscale. This suggests that after several weeks of admission (when the PSS: NICU was administered in the current study), SES may no longer be a key factor associated with NICU stress. An explanation for why income was not related to NICU stress in the current study could be because data were only available for the Christchurch cohort, therefore only Christchurch parental income was represented. In addition, although ethnicity was a key predictor of maternal stress in previous research (Montgomery-Hönger et al., 2010), this was not

found for either mothers or fathers in the current study. Unlike past research, no significant differences were found between mothers who were single parents and those who were married or with partners (Shields-Poe & Pinelli, 1997; Carter et al., 2007). This may be due to the low numbers of single parent families who participated ($n=1$ for Christchurch cohort, $n = 5$ for Melbourne cohort) or to differences in timing of the PSS: NICU interviews. Since the aforementioned previous studies interviewed parents only three weeks after NICU admission, this suggests that although being a single parent was associated with higher NICU stress, this association may not persist over time.

An examination of study results also reveals two new key findings: number of children at home was correlated with paternal NICU stress levels, and paternal stress levels predicted maternal NICU stress levels (and vice versa). The number of other children at home was found to be associated with paternal stress levels. Specifically, fewer children at home was associated with higher mean paternal stress scores on the PSS: NICU. One explanation for this could be that when fathers have several children at home to take care of, while the mother is in the NICU caring for the infant, the less involved the father is with the direct care of the VPT infant. Another explanation could be that the more children fathers have had, the more confident they are in their own and their partners' parenting ability. Because this is a new finding, replication is required in order to determine the stability of this result.

Another new finding from this study was that maternal stress levels predicted paternal stress and vice versa. This suggests an interdependence of coping with stressful events between mothers and fathers. Taken together with the finding that the number of upsetting life events predicts maternal stress, this highlights that it may not be solely the NICU-specific stressors which account for parents' overall NICU experience. Therefore, it may be inferred that stressors outside of the NICU warrant further attention, given the extent to which they influence parental NICU stress. This is discussed further in Chapter 3.

2.4.4. Infant illness, treatment and appearance factors associated with parental NICU

stress. Infant clinical variables were also found to be associated with NICU stress. For instance, low infant birth weight was correlated with higher paternal stress on the “staff behaviour and communication” subscale and the item of overall stressfulness of the NICU experience. This finding was consistent with the Preterm Parental Distress Model (Figure 1.2, p.11) that describes “infant illness, treatment and appearance factors” as a key contributing factor in parental NICU stress. This is similar to the results of a previous study, which identified birth weight as a key predictor of maternal stress relating to “loss of parental role” (Montgomery-Hönger et al., 2010), although this was a different PSS: NICU subscale. In the same study, low infant birth weight was a key predictor of higher maternal stress on the “loss of parental role” subscale. However, another study found no relationship between birth weight and NICU stress (Reid & Bramwell, 2003). It may be that Reid and Bramwell (2003) did not find this relationship 48 hours after admission, but perhaps it may have emerged if parents were interviewed later on (such as in the study by Montgomery-Hönger et al., 2010). Therefore, the relationship between infant birth weight and parental NICU stress remains unclear and would require further research to clarify under which conditions these associations are found.

In the present study, other infant clinical variables were not found to be related to parental NICU stress. This is in contrast to previous research which found that infants’ greater need for ventilator support and low gestational age were associated with maternal NICU stress (Meyer et al., 1995). Montgomery-Hönger et al. (2010) also found that the number of days infants required CPAP was also a key predictor of maternal stress relating to the “loss of parental role” subscale. Therefore, it is clear there is a discrepancy between the current study results and previous research findings, despite similar timing in PSS: NICU interviews. There was also no difference in paternal and maternal NICU stress levels relating to multiple versus singleton birth. This also differs from previous research which found that singleton birth was predictive of maternal NICU stress

(Montgomery-Hönger et al., 2010). This may be explained by the limited number of infant clinical variables (for example, only gestation, birth weight and singleton birth) being available for all infants in the Christchurch and Melbourne cohorts (Table 2.4, p.38). Other measures of infant illness common to VPT infants, which may have been related to parental stress³, were not included, such as the need for ventilator support, days on CPAP, chronic lung disease, and total number of days of NICU admission. It is recommended these infant variables are included in future research to further clarify which infant clinical variables are predictive of parental NICU stress.

2.4.5. Implications. The key implications of the results of the current study are for NICU staff, researchers in this field and future parents of VPT infants. With respect to implications for NICU staff, it appears important that there is awareness that upsetting life events that mothers experience outside the NICU, may be contributing to their NICU stress. Therefore, special consideration may need to be given to parents experiencing upsetting life events and displaying high levels of NICU stress. Interventions that address coping with challenging life events may help to decrease the degree of stress experienced in the NICU for mothers. For fathers, those with no children at home may be at an increased risk of experiencing higher NICU stress and these fathers need to be identified. Future research could examine ways in which these fathers are best supported. This is particularly important given that this study has shown that paternal levels of stress predict maternal stress in the NICU and vice versa. Therefore, if interventions aim to decrease maternal stress, for instance, they must also focus on decreasing paternal stress. Another important consideration is that although fathers consistently reported significantly lower NICU stress than mothers, this study showed it is essential to acknowledge paternal stress since this seems to affect maternal experiences in the NICU.

³ A comprehensive list of infant clinical variables were measured in the Christchurch cohort in order to account for this limitation (as seen in Table 2.2, p. 32), however, due to data having to be borrowed as a result of the Christchurch earthquake, these variables were not available for the Melbourne sample.

NICU staff could examine ways in which to prepare parents for adjusting to their “infant’s appearance”, since this was the most stressful subscale part of the NICU experience. This may involve more education and awareness of how their infant is likely to look and to what medical machinery they are likely to be attached. Further to this, results showed it is important to address the stress pertaining to “being separated from my baby” since it was consistently one of the most stressful aspects of the NICU across all parent groups. Results from this study contribute towards improving existing neonatal and early intervention services for VPT infants and their parents. It also highlights the need for new and innovative intervention strategies to address the needs of New Zealand and Australian parents with a premature infant.

Chapter 3

A Study of Staff Perceptions of Parental Stress in the NICU and External Stressors

3.1. New Perspectives on Measuring NICU Stress

As shown in Chapter 2, many parents experience stress relating to having a VPT infant in the NICU. Results showed that mothers tended to report higher stress levels than fathers and a number of factors were found to be associated with parental NICU stress. These factors can include personal, family and infant clinical variables which was consistent with the Preterm Parental Distress Model (Figure 1.2, p.11). In order to more fully understand the experience of parents of VPT infants, two new areas of research are examined in the current chapter: NICU staff perceptions of parental stress and concurrent stressors that are external to the NICU environment. The few studies on staff perceptions and external stressors were reviewed and their methodological strengths and weaknesses were identified. This review informed the design of Study 2.

3.1.1. Staff perceptions of parental stress in the NICU. Although NICU staff play an important role in the initial care of VPT infants and would undoubtedly bear witness to the parental stress response first-hand, few studies have explored staff perceptions of parental stress (see Table 3.1, p.66 for a summary of these studies combined with studies on external stressors). The extent to which NICU staff consider aspects of the NICU environment stressful for parents is relatively unexamined. Nurses' perceptions of the parental NICU experience are likely to affect their interactions with parents. Although the priority for NICU staff is to provide life-saving and stabilising treatments for infants (Jones, Woodhouse & Rowe, 2007), staff are in a unique position to support parents. Therefore, it is important to examine how closely related staff perceptions and parental NICU stress reports are and in addition, to identify any discrepancies. With a better understanding of how staff perceive the NICU experience for parents, this may help inform the way staff interact with parents which may help decrease the degree of NICU stress parents experience.

Two key studies that involved comparisons between NICU staff and parental experience showed differences between staff perceptions and parental report. Raeside (1997) constructed an 18-item stress scale and the responses of 12 nurses and 12 mothers were documented using the scale. Results showed that mothers reported lower stress than was rated in nurses' perceptions. Furthermore, nurses' perceptions of which aspects in the NICU were most stressful for mothers differed in some cases from maternal report. The highest stressors for mothers were the "heat intensity in the NICU" followed by "infant appearance" and "alarms", while for nurses it was the "monitors attached to the baby" and "alarms" that were considered to be most stressful. Senior nurses were also more accurate at predicting parental stress levels than junior nurses. In another study, the responses of 300 mothers of premature infants and 32 NICU nurses were compared (Akbarbegloo & Valizadeh, 2009). The PSS: NICU was used as the key measure of NICU stress. Mothers rated "loss of parental role" to be the most stressful subscale, whereas nurses rated "infant appearance" to be most stressful for parents. Nurses also consistently reported significantly higher stress scores (when asked how stressful they perceived the NICU was for parents) than mothers across all subscales of the PSS: NICU. In general, nurses and mothers differed in what they viewed as the most stressful aspects of the NICU experience. Therefore, it could be argued that in order to reduce NICU stress for parents, nurses may benefit from an increased awareness of the key stressors for parents (Raeside, 1997).

The present study examines the relationship between NICU nurses' views of what parents find stressful and what parents themselves report to be stressful. By contrasting NICU nurses' perceptions with parental experiences of NICU stress, discrepancies in perceptions are highlighted. Predictably, nurses' perceptions are likely to influence their interactions with parents. Therefore, alerting nursing staff to the main sources of parental stress in the NICU may increase awareness of key stressors and potentially improve existing neonatal services for parents of VPT infants in the NICU.

3.1.2. Limitations in the literature. There were a number of limitations in the literature which must be considered when interpreting study results. For example, Raeside (1997) did not use a validated measure of NICU stress (and did not report any results from reliability or validity checks). Therefore, their findings should be replicated in order to be able to generalise to other parents and staff. In another example, although the PSS: NICU was used by Akbarbegloo and Valizadeh (2009), it is not clear whether any adaptations were made to the scale for staff to complete the questionnaire. This was a measure designed for parents to complete, so this raises questions as to its validity in relation to staff perceptions. In addition, this study included parents of infants born earlier than 37 weeks' gestation; therefore the degree of stress experienced by parents may be less than in studies where infants were born VPT or EPT. The "staff communication and behaviour" subscale was also not included in the study; therefore, this area of NICU stress was not measured and discrepancies were unable to be identified. In addition, the small number of studies that have involved NICU staff indicates that further research in this area is needed in order to confirm and expand on previous findings.

Table 3.1.

Summary of Studies Examining Staff Perceptions of Parental Stress and Stressors External to the NICU: Years 1995-2009

Author/s	Study Design	Sample	Interview Timing	Main Construct	Measures	Findings	Strengths	Limitations
Akbarbegloo & Valizadeh (2009) IRAN	Cross-sectional study	300 mothers of infants born premature (< 37 weeks) -had to have been admitted for at least 1 week 32 nurses from 3 teaching hospitals -worked at least once a week in a NICU		Maternal and Staff perceptions of NICU stress (PSS: NICU)		Mothers rated “loss of parental role” most stressful whereas nurses rated “infant appearance” to be most stressful Nurses rated “sights and sounds” to be least stressful. In general, nurses and mothers differed in view of what is most stressful in the NICU. Nurses consistently reported significantly higher stress scores than mothers.	+ Good comparison between mothers and staff perceptions. + Good sample size. + Important study as little research in this area.	- Not clear whether authors adapted PSS: NICU for staff - Preterm included (<37 weeks) not VPT - Did not include the ‘staff communication and behaviour’ subscale - Large discrepancy between number of mothers interviewed (300) and number of nurses (30) – may have got different result if had more even numbers of mothers and nurses.

Table 3.1.

Summary of Studies Examining Staff Perceptions of Parental Stress and Stressors External to the NICU: Years 1995-2009

Author/s	Study Design	Sample	Interview Timing	Main Construct	Measures	Findings	Strengths	Limitations
Pinelli, Saigal, Wu, Cunningham, DiCenso, Steele, Austin & Turner (2008) CANADA	Prospective longitudinal study	152 two-parent families of infants who required intensive care at birth (regardless of gestational age, stayed in NICU for >24 hours) Non-English speaking couples, single-parent mothers and parents of infants whose death was imminent were excluded.	In the NICU (within 4 days of infant admission), 3-, 6-, and 12- months post discharge	Family function (General Functioning subscale of McMaster Family Assessment Device)	Family resources (Family Inventory of Resources for Management (FIRM)), family problem solving and coping (Family Crisis Oriented Personal Evaluation Scales (F-COPES), parental depression (CES-D), background variables	Mothers and fathers showed a significant (but small) deterioration in family function over first 3 months. Mothers showed a statistically significant decrease in resources. At time 1, 65% of mothers and 45% of fathers reported clinically significant depressive symptoms significant difference between mothers and fathers, $p < .0001$. Both mothers and fathers showed a significant decrease in mean depression scores by 3 month assessment (16% and 12%), but this reduction did not continue in a significant way (12% for mothers and 7% for fathers). Overall, 20% of parents reported clinically significant depressive symptoms between the 3 month and 12 month assessments.	+ Good retention rate (78%) over the course of a year. + Large sample size. + Comprehensive battery of tests to measure the impact on family of having a sick infant. + Included fathers' responses. + Involved multiple follow-ups, allowed for tracking of reduction in depressive symptoms.	- No comparison group from which to compare the course of reductions in depressive symptoms over time. - largely homogenous sample; Caucasian, higher SES. - large number of eligible un-enrolled couples. - independence of answers could not be assured as parents may have completed questionnaires together

Table 3.1.

Summary of Studies Examining Staff Perceptions of Parental Stress and Stressors External to the NICU: Years 1995-2009

Author/s	Study Design	Sample	Interview Timing	Main Construct	Measures	Findings	Strengths	Limitations
Raeside (1997) SCOTLAND	Cross-sectional study	12 mothers divided into mothers of infants born with low (>1500g) and very low birth weight (<1500g). 12 NICU nurses who had a minimum of 3 months NICU experience, divided into experienced and junior nurses	Not specified	Maternal and staff perceptions of NICU stress	18 item semi-structured questionnaire constructed by the researcher based on the structure of the Roy Adaptation Model	Nurses reported higher perceptions of stress levels than mothers did. Nurses reported a mean score (on a scale of 1-5) of 4.6 compared with mothers with a mean of 2.5. The total maternal stress score as perceived by senior staff (M =61) correlated with mothers of VLBW infants (M =58). Junior nursing staff rated maternal stress much higher (M =72) suggesting less nursing experience was related to less accuracy in predicting level of stress for parents. Mothers reported most stressful component of NICU was 'heat intensity', followed by 'infant appearance' and 'alarms', whereas nurses perceived 'monitors attached to the baby' followed by 'alarms'. In general, nurses perceived higher stress levels than mothers	+ Study adds to limited amount of research in this area + Highlighted key areas for further research	- Small sample size which means results may not be generalizable to other parents of infants in the NICU or to other NICUs - did not include fathers - no validated measures used
Cronin, Shapiro, Casiro & Cheang (1995) UNITED STATES	Matched control study	Parents of 96 VLBW infants Comparison with full-term controls matched for age, sex, race, domicile, singleton or multiple pregnancy, and birth order	When VLBW children were 1-5 years old	Impact on Family Scale (Stein's), positive impact on parenthood, and attitudes toward treating VLBWs		Parents of VLBW infants had higher scores for financial burden, familial/social impact, personal strain and mastery Birth and upbringing of VLBW infants associated with more long-term stress. More control families had already had another child than families of VLBW child Stress displayed in VLBW families even up to 5 years later	+ Carefully matched controls + Included fathers	- possible selection bias as most families were well-educated, employed and married - not able to generalise to VPT population since birth weight used for inclusion criteria

3.1.3. Stressors external to the NICU environment. The organising of their life around caring for an infant in hospital may have a big influence on parents' overall experience in the NICU. To date, research on parental experiences relating to having a VPT infant in the NICU has largely focused on factors specific to the NICU environment itself or on parental personality factors. However, there is some evidence to suggest that the NICU environment itself may only be part of the stressful experience for parents. Situational or external factors also may contribute to stress (see Table 3.1 which shows a summary of studies which examined external stressors). For example, Cronin et al. (1995) found that parents of VLBW infants reported more financial, familial, and personal stress than matched control parents (i.e., parents of healthy birth weight infants). Specifically, the stress related to financial factors of having a hospitalized infant included loss of money arising from inability to work, challenges and expenses in arranging childcare, and the cost of transport to and from the hospital. Parents may also experience some family instability after having an infant admitted to the NICU. For instance, in a study by Pinelli et al. (2008) mothers and fathers of infants in the NICU reported a significant decline in family functioning three months after their infant was discharged. This was measured by the General Functioning subscale of the McMaster Family Assessment Device which makes a global assessment of family functioning. Mothers in their study also reported a significant decline in family physical and emotional health, communication, esteem and mutual assistance. Families already experiencing difficulties relating to the arrival of a premature infant in the NICU may find that extra external stressors, such as organising childcare to cover hospital visits, may exacerbate parental stress levels in the NICU.

To date, few studies have examined which external stressors contribute to or exacerbate the parental stress response. Reid and Bramwell (2003) noted that future research would benefit from including a wide range of potentially stressful factors in order to better discriminate which stressors are associated with parents' NICU experience. To address this gap in the literature, the present study

examined the role stressors external to the NICU environment may play in determining the parental stress response to having a VPT infant.

3.1.4. Limitations in the literature. Three key limitations should be taken into account when interpreting previous study findings. The considerably low number of studies that have examined the role of external factors on parental NICU stress means that replication is needed in order to determine the robustness of the findings. Another limitation involves a possible selection bias that may be present. Parents who participated in the study were in general well-educated, employed, married, Caucasian and of a higher SES (Cronin et al., 1995; Pinelli et al., 2008). This implies that the stress response of several groups of parents may not have been captured. In addition, Cronin et al. (1995) interviewed parents of infants born with low birth weight; therefore these results may not be generalizable to parents of infants born prematurely who may be experiencing different stressors relating to preterm birth such as financial strain from early maternity leave following the early arrival of their infant.

3.1.5. The current study objectives. The current research aims to expand the current understanding of the parental stress experience in the NICU both in terms of how staff perceive the parental experience and the relationship between external stressors and NICU-specific stressors. The current study was designed to reduce some of the methodological problems of previous studies in the following ways: by adapting the PSS: NICU for staff to complete, by including a sample of parents of VPT infants and by conducting further research in the area of staff perceptions and external stressors to consolidate previous findings. To this end, Study 2 involved both a cross-sectional examination of NICU staff's perceptions of parental stress, and a staff and parent report of the degree of external stressors experienced as a result of the NICU environment. The aims of Study 2 were as follows:

Aim 1. To describe perceptions of sources of parental NICU stress among NICU staff and in relation to parental report.

Hypothesis. It was predicted that staff would rate parental NICU stress levels as higher than parents themselves.

Aim 2. To identify potential stressors external to the NICU environment among Christchurch parents and the perceptions of NICU staff.

Hypothesis. It was predicted that the majority of participants would experience several of the external factors listed as stressful, but that the most stressful external factors would differ amongst mothers, fathers and staff perceptions.

Aim 3. To validate the External Stressors Scale as a measure of external stressors for parents with an infant in the NICU.

Hypothesis. It was predicted that the scale would have adequate internal reliability and that several themes of external stress would be identified.

3.2. Method

3.2.1. Nursing Sample and Procedure.

Twenty-three NICU nurses participated in Study 2. The study was conducted between June 2010 and November 2010 in the level III NICU at Christchurch Women's Hospital, New Zealand. Of the 40 questionnaire booklets distributed to NICU nursing staff (who were selected randomly from staff rosters), 23 of them (58%) were completed and posted back.

Table 3.2.

Demographic Characteristics of NICU Nursing Staff from the Christchurch NICU

Staff demographics	<i>M (SD)</i> <i>N=23</i>	<i>% (n)</i>
Time spent working in NICU environment (years)	15.01 (9.31)	
Time spent working in Christchurch NICU (years)	12.72 (8.98)	
Amount of time each week working in NICU (hours)	29.74 (9.86)	
Time spent working in field of medicine (years)	25.00 (10.00)	
Ethnicity		
% (n) NZ European		73.90 (17)
% (n) Other European		21.70 (5)
% (n) Asian/Indian		4.30 (1)

The nurses in this study were experienced in working in the NICU and would have had many interactions with parents of infants in the NICU on which they could base their answers. As shown in Table 3.2, the mean amount of time the nurses had spent working in a NICU environment was 15 years, and the mean number of years spent working at Christchurch Women's NICU was 13 years. On average, the study nurses spent close to 30 hours per week in the NICU. In general, study nurses had spent 25 years working in the field of medicine. With respect to ethnicity, 74% of NICU nursing staff indicated they were NZ European, 22% were of other European ethnicity and 4% were of Asian/Indian ethnicity.

NICU nurses rated how stressful they viewed various aspects of the NICU environment would be for parents by completing an adapted version of the PSS: NICU (see Appendix I for a copy of the adapted questionnaire). Nursing staff were asked to complete the questionnaire and send it by return post to the researchers.

3.2.2. Christchurch parent Sample and Procedure. The 11 mothers and 10 fathers who completed the External Stressors Scale were those who participated in the Christchurch sample in Study 1. A full description of the sample characteristics of this group is outlined in the Method section in Chapter 2 (p. 31). Parents completed an external stressors scale at the same time as the PSS: NICU (at infant age 34 weeks' gestation). As for Study 1, data collection was cancelled following the earthquake in February 2011 and thus the small sample size resulted.

3.2.3. Measures

3.2.3.1. Staff perceptions. Although the PSS: NICU was designed for assessing parental stress, the present study was concerned with examining how parent's perceptions of NICU stress relate to *and* differ from staff perceptions. Adapted versions of the PSS: NICU and the external stressors scale were given to NICU staff to complete (a copy of the adapted PSS: NICU is provided in Appendix I).

3.2.3.2. External stressors. The development of the External Stressors Scale (ESS) was informed by the "pre-existing and concurrent personal and family factors" described in the Preterm Parental Distress Model (Figure 1.2, p.11) to contribute to parental stress as well as previous research findings. The ESS was piloted as an extension to the PSS: NICU (a copy of the ESS interview is provided in Appendix H). A list of potential external stressors was compiled by the researcher and other parental NICU stress researchers. These items were shortened to 12 items based on face validity. Because very few studies have examined external stressors, the ESS is an exploratory measure and hence the reliability and validity of the scale was calculated and is presented in the

Results (p.81). The ESS used the same 5-point Likert stress scale as the PSS: NICU (where 1 = *not at all stressful* and 5 = *extremely stressful*) and highlights potential contextual sources of stress external to the NICU's physical environment. The scale consists of 12 items, including items such as "having to organise childcare for my other children while I visit the NICU" and "having to take time off work to be in at the hospital". As for the PSS: NICU in Study 1, the ESS was coded using Metric II (see Chapter 2 Method, p. 37). Those participants who did not report an experience relating to a specific item were given a score of one (rather than a zero) to indicate that no stress was experienced. An adapted version of the ESS for staff that staff completed can be found in Appendix J.

3.2.4. Statistical analyses

3.2.4.1. Staff perceptions. Descriptive statistics were calculated for PSS: NICU scores for NICU staff perceptions of parental stress. The means of each PSS: NICU subscale were visually inspected and the most stressful through to the least stressful subscales were determined. Means were also calculated for the overall stressfulness single item on the PSS: NICU and the mean level of stress across all items. The number of staff who reported a score of 5 (equivalent to *extremely stressful* on the PSS: NICU rating scale) on the overall stressfulness single item was calculated and reported as a percentage. To determine whether statistically significant differences existed between the staff, maternal and paternal groups (using parental PSS: NICU scores from Study 1) on the overall stressfulness single item, a Chi square test for independence was conducted. One-way ANOVAs were conducted to determine statistical differences between the maternal, paternal and staff groups across all continuous NICU stress outcome measures. Post hoc comparisons using the Tukey HSD test were conducted to determine how the groups differed from each other.

NICU staff were categorised into junior and senior nurses (junior nurses having worked for less than 15 years in a NICU, while senior nurses had worked in a NICU for 15 or more years). T-tests were then run to determine whether junior and senior nurses differed in terms of the level of NICU stress they perceived parents experienced. The top 5 most stressful items on the PSS: NICU

were also calculated and placed alongside those of Christchurch mothers and fathers from Study 1 for visual comparison.

3.2.4.2. External stressors. The means and standard deviations of each item on the ESS were calculated for the maternal, paternal and staff groups. In addition, the percentage of participants who reported items on the ESS to be *a little stressful* or above was calculated. As with the PSS: NICU data, the top five most stressful items on the ESS were also calculated for the maternal, paternal and staff groups for visual comparison.

For the purposes of assessing the reliability and validity of the ESS, data from the maternal, paternal and staff groups were combined. This gave a total sample size of 42 participants who answered the ESS. To assess the scale's internal consistency, Cronbach's alpha was calculated for the total sample as well as for individual groups of participants. To assess convergent validity, a series of bivariate correlations were conducted using the ESS and mean level of NICU stress on the PSS: NICU. Discriminant validity could not be ascertained because suitable measures were not used in the parental interview. In order to determine whether the ESS consisted of multiple factors, a principal components analysis was conducted. Findings from these analyses are presented in Study 2 Results (p. 81).

3.3. Study 2 Results

3.3.1. Staff perceptions of parental stress. The first aim of Study 2 was to describe perceptions of sources of parental NICU stress among NICU staff and in relation to parental report. In order to address this aim, staff were asked to speculate how stressful they thought various aspects of the NICU environment would be for parents. Table 3.3 (p. 77) describes staff responses to perceived parental stress on each subscale of the PSS: NICU, the overall stressfulness single item and the mean level of stress across all items. Whether the groups differed significantly from each other is also presented.

As shown in Table 3.3 (p.77), staff indicated that the “loss of parental role” subscale would be most stressful for parents ($M = 4.36, SD = 0.45$). NICU staff rated that “staff behaviours and communication” would be the next most stressful ($M = 4.12, SD = 0.59$), followed by “sights and sounds” ($M = 4.04, SD = 0.41$) and “infant appearance” ($M = 3.97, SD = 0.51$). In terms of the overall stressfulness single item, staff reported a mean of 4.87. In the mean level of stress across all items, all staff rated that they thought parents would find their time in the NICU to be above *very stressful* ($M = 4.12$) on the PSS: NICU rating scale. In addition, 87% of staff reported that they perceived parents’ overall stressfulness of having an infant in the NICU would be *extremely stressful* for them, which was significantly different to 55% of mothers and 0% of fathers reporting this ($\chi^2(2) = 21.93, p < .05$).

As shown, significant differences emerged between the maternal, paternal and staff groups in terms of mean levels of NICU stress. Post hoc comparisons using the Tukey HSD test indicated that the three groups were significantly different to each other ($p < .05$) for the “sights and sounds”, “infant appearance, “loss of parental role” subscales, overall stressfulness, and mean level of NICU stress. No significant differences were found between the maternal group ($M = 1.93, SD = 0.96$) and the paternal group ($M = 1.29, SD = 0.42$) on the “staff behaviours and communication” subscale (as

reported in Study 1). Staff perceptions, however, differed significantly from both the maternal and paternal groups on this subscale.

Table 3.3.
Maternal, Paternal and Staff Perceptions of PSS: NICU Scores

PSS: NICU Subscales	Mothers <i>N</i> =11 <i>M</i> (<i>SD</i>)	Fathers <i>N</i> =10 <i>M</i> (<i>SD</i>)	Staff <i>N</i> =23 <i>M</i> (<i>SD</i>)	<i>F</i> / χ^2	<i>p</i>
Sights and Sounds	2.16 (0.77)	1.48 (0.40)	3.97 (0.51)	82.41	0.00
Infant Appearance	2.50 (0.92)	1.60 (0.31)	4.04 (0.41)	73.06	0.00
Loss of Parental Role	2.45 (1.16)	1.53 (0.35)	4.35 (0.45)	68.87	0.00
Staff Behaviours and Communication	1.93 (0.96)	1.29 (0.42)	4.12 (0.59)	78.39	0.00
Overall Stressfulness Single Item	3.82 (1.47)	2.60 (0.84)	4.87 (0.34)	24.75	0.00
% (<i>n</i>) Rated overall stressfulness single item as <i>extremely stressful</i>	54.55 (6)	0.00 (0)	86.96 (20)	21.93	0.00
Mean Level of Stress Across all Items	2.31 (0.88)	1.50 (0.28)	4.12 (0.33)	105.68	0.00

NICU staff were divided into junior and senior nurses depending on number of years experience working in a NICU and t-tests were run to examine whether perception of NICU stress differed depending on level of nursing experience (as described in the Method, p. 74). Although junior nurses tended to report higher perceptions of parental NICU stress than senior nurses, this difference was not significant.

Table 3.4 (p.78) shows the top 5 most stressful items on the PSS: NICU for Christchurch parents with an infant in the NICU (which is the same as in Study 1), with the addition of staff perception ratings entered into the table. The items common to the three groups of participants were: “being separated from my baby” and “when my baby seemed to be in pain”. In addition, staff and the maternal group shared “seeing needles and tubes put in my baby” and “feeling helpless and unable to protect my baby from pain” in their top 5 most stressful items. Although the four items shared by staff and the maternal group were in a different order of stressfulness, they shared 4 out of the 5 most stressful items. Staff and the paternal group shared only the two aforementioned items that were shared across all three groups. As shown, the mean ratings for staff perceptions of parental stress on

items on the PSS: NICU were noticeably higher than both the maternal and paternal groups. As with both parental groups, the top 5 items for staff perceptions were all related to the “infant appearance” and “loss of parental role” subscales.

Table 3.4.

Top 5 NICU Stressors as Rated on the PSS: NICU by Parents and Nursing Staff from the Christchurch NICU

	Most stressful items on PSS: NICU	<i>M (SD)</i>	Subscale
Maternal: Christchurch	1.= Being separated from my baby	3.82 (1.60)	Loss of Parental Role
	1.= When my baby seemed to be in pain	3.82 (1.66)	Infant Appearance
	3. Seeing needles and tubes put in my baby	3.64 (1.50)	Infant Appearance
	4. Feeling helpless and unable to protect my baby from pain	3.18 (1.83)	Loss of Parental Role
	5. Having a machine (respirator) breathe for my baby	3.09 (1.76)	Infant Appearance
Paternal: Christchurch	1. My baby’s unusual or abnormal breathing patterns	2.70 (1.25)	Infant Appearance
	2. Being separated from my baby	2.40 (1.07)	Loss of Parental Role
	3. When my baby seemed to be in pain	2.20 (1.40)	Infant Appearance
	4. The small size of my baby	2.10 (1.29)	Infant Appearance
	5. Bruises, cuts or incisions on my baby	2.00 (0.94)	Infant Appearance
Staff Perceptions	1. Seeing my baby stop breathing	4.91 (0.29)	Infant Appearance
	2.= Being separated from my baby	4.87 (0.34)	Loss of Parental Role
	2.= Seeing needles and tubes put in my baby	4.87 (0.34)	Infant Appearance
	4. When my baby seemed to be in pain	4.83 (0.39)	Infant Appearance
	5. Feeling helpless and unable to protect my baby from pain	4.74 (0.54)	Loss of Parental Role

3.3.2. External stressors. The second aim for Study 2 was to identify potential stressors external to the NICU environment among parents and the perceptions of staff. To address this aim, Table 3.5 (p.79) shows the means and standard deviations of each item of the ESS for staff perceptions and the maternal and paternal groups. These are presented alongside the percentage of participants who reported each item to be *a little stressful* or above (a score of a 2 or above on the 1-5

rating scale). As shown, all items on the ESS were considered to be *a little stressful* by at least 1 participant in each group of participants, except that no fathers found “paying for childcare of my other children” to be at all stressful.

Table 3.5.
Maternal, Paternal and Staff Perceptions of Parental Stress on the ESS

External Stressors Scale	Maternal group N=11		Paternal group N=10		Staff Perceptions N=23	
	M(SD)	% who reported item <i>a little stressful</i> or above	M(SD)	% who reported item <i>a little stressful</i> or above	M(SD)	% who reported item <i>a little stressful</i> or above
Travelling time to and from the NICU	2.36 (1.50)	54.5%	2.30 (1.42)	60%	3.87 (0.76)	100%
Planning day to fit in with NICU routines	2.45 (1.51)	54.5%	1.80 (1.03)	40%	3.65 (0.88)	95.7%
Fitting in everything else I need to do around the house/with other children	2.63 (1.43)	63.6%	2.70 (1.16)	80%	4.56 (0.59)	100%
Organising childcare for my other children	1.64 (1.12)	27.3%	1.90 (1.29)	40%	4.26 (0.69)	100%
Trying to keep my other children entertained when in at the NICU	1.27 (0.90)	9.1%	1.80 (1.14)	40%	4.26 (0.69)	100%
Finding a car park nearby	1.91 (1.45)	36.4%	1.80 (0.79)	60%	4.43 (0.84)	100%
Organising my own food for when in at the hospital	1.91 (1.14)	54.5%	1.30 (0.67)	20%	3.26 (0.92)	100%
Paying for several hours of car parking each time I visit	1.27 (0.47)	27.3%	1.20 (0.42)	20%	3.87 (0.76)	100%
Having to take time off work to be in at the hospital	1.36 (1.20)	9.1%	1.80 (0.79)	60%	4.04 (0.82)	100%
Paying petrol/bus/taxi fares to visit the NICU	2.00 (1.26)	54.5%	1.50 (0.85)	30%	4.00 (0.63)	100%
Paying for the childcare of my other children	1.36 (1.21)	9.1%	1.00 (0.00)	0%	4.14 (0.65)	100%
Having to spend money on cell phone calls to update friends and family	1.73 (1.01)	45.5%	1.10 (0.32)	10%	3.62 (0.92)	100%

To further identify which items of the ESS were most stressful, Table 3.6 (80) shows the top 5 most stressful items on the ESS for the maternal, paternal and staff groups. As shown, “fitting in everything else I need to do” was consistently the most stressful item across the maternal, paternal

and staff groups (and had the highest mean in all groups). Unlike previous findings where the maternal group reported higher means than the paternal group, fathers reported “fitting in everything else I need to do” as more stressful than the maternal group ($M=2.70$, $SD = 1.16$ vs. $M=2.63$, $SD = 1.43$). This was the only ESS item that was shared across the three participant groups. However, items found to be in the top 5 for two of the participant groups were: “travel time to and from the NICU”, “organising my own food for when in at the hospital”, “finding a car park nearby”, and “organising childcare for my other children”. As shown, parents and staff differed in terms of the order of the most stressful external stressors, where no particular pattern of stressfulness emerged. As was found with the most stressful PSS: NICU items (Table 3.3, p. 77), staff perceived these items to be noticeably more stressful than parents reported.

Table 3.6.

Top 5 Stressors as Rated on the ESS by Parents and Nursing Staff from the Christchurch NICU

	Most stressful items on external stressors scale	<i>M (SD)</i>
Maternal: Christchurch	1. Fitting in everything else I need to do	2.63 (1.43)
	2. Planning day to fit in with NICU routines	2.45 (1.51)
	3. Travelling time to and from the NICU	2.36 (1.50)
	4. Paying petrol/bus/taxi fares to visit the NICU	2.00 (1.26)
	5. Organising my own food for when in at the hospital	1.91 (1.14)
Paternal: Christchurch	1. Fitting in everything else I need to do	2.70 (1.16)
	2. Travelling time to and from the NICU	2.30 (1.42)
	3. Organising childcare for my other children	1.90 (1.29)
	4. Organising my own food for when in at the hospital	1.30 (0.67)
	5. Finding a car park nearby	1.80 (0.79)
Staff Perceptions	1. Fitting in everything else I need to do	4.56 (0.59)
	2. Finding a car park nearby	4.43 (0.84)
	3. Trying to keep my other children entertained when in at the NICU	4.26 (0.69)
	4. Organising childcare for my other children	4.26 (0.69)
	5. Paying for the childcare of my other children	4.14 (0.65)

3.3.3. External Stressors Scale (ESS) validation. To address aim 3 of Study 2 and to validate the ESS as a measure of external stressors for parents with an infant in the NICU, a number of statistical procedures were conducted to determine the reliability and validity of the ESS. A sample of 42 complete data sets were used for reliability analysis (included mothers, fathers and staff combined as described in Method, p. 74). The ESS displayed high internal consistency (Cronbach's alpha = .97). Cronbach's alpha scores were good for the maternal, paternal and staff samples individually (maternal group = .85, paternal group = .84, staff perceptions = .84). A visual examination of "Cronbach's alpha if item was deleted" showed no noticeable improvements in the overall reliability of the scale.

To assess convergent validity, a series of bivariate correlations were conducted using the ESS and mean level of NICU stress on the PSS: NICU. Table 3.7 (p. 82) shows a correlation matrix of each item on the ESS and mean PSS: NICU scores. The items on the ESS were expected to correlate highly with NICU stress. Accordingly, each item on the ESS was strongly correlated with mean NICU stress ($r > 0.70$, $p < .01$). Therefore, this scale can be considered to have adequate convergent validity. All ESS items were significantly correlated with each other ($r > .40$, $p < .01$).

In order to determine whether the ESS consisted of multiple factors, a principal components analysis was conducted. Only 1 factor emerged with an Eigen value above 1, which explained 73% of the variance. A visual inspection of the Scree plot indicated a clear break after the first component. Therefore, this suggests that items on the ESS were loading on 1 factor: external stressors.

Table 3.7.
Correlation Matrix of Combined Maternal, Paternal and Staff Perceptions of Items on the ESS

	Travel to/from NICU	Plan day for NICU routines	Fitting in everything else	Organising childcare	Keep other children entertained	Finding a car park nearby	Organising own food	Paying for car parking	Time off work to be at hospital	Paying petrol/bus to visit NICU	Paying for childcare of other children	Spending money on cell calls	Mean PSS: NICU score
Travel to/from NICU	1												
Plan day for NICU routines	0.749**	1											
Fitting in everything else	0.793**	0.702**	1										
Organising childcare	0.692**	0.676**	0.834**	1									
Keep other children entertained	0.677*	0.587**	0.769**	0.881**	1								
Finding a car park nearby	0.574**	0.528**	0.574**	0.707**	0.676**	1							
Organising own food	0.428**	0.564**	0.549**	0.622**	0.583**	0.703**	1						
Paying for car parking	0.576**	0.544**	0.666**	0.756**	0.801**	0.770**	0.751**	1					
Time off work to be at hospital	0.595**	0.580**	0.759**	0.852**	0.846**	0.672**	0.624**	0.806**	1				
Paying petrol/bus to visit NICU	0.659**	0.670**	0.716**	0.796**	0.799**	0.735**	0.646**	0.802**	0.871**	1			
Paying for childcare of other children	0.659**	0.617**	0.767**	0.848**	0.887**	0.715**	0.636**	0.866**	0.908**	0.885**	1		
Spending money on cell calls	0.546**	0.476**	0.649**	0.649**	0.655**	0.772**	0.732**	0.880**	0.693**	0.736**	0.740**	1	
Mean PSS: NICU score	0.707**	0.722**	0.718**	0.764**	0.779**	0.807**	0.736**	0.834**	0.739**	0.804**	0.852**	0.809**	1

Note. ** Correlation is significant at the 0.01 level (2-tailed). * Correlation is significant at the 0.05 level (2-tailed).

3.4. Discussion

Study 2 addressed three research aims regarding staff perceptions of parental NICU stress and piloted the use of the External Stressors Scale as a measure of parental stress that occurs outside the immediate NICU environment. The rates and sources of parental NICU stress as perceived by staff were described and compared with parental report. Parental and staff perception ratings of stress on the ESS were described and the scale's reliability and validity was calculated. The key findings and conclusions from Study 2 are presented below.

3.4.1. Staff perceptions of parental NICU stress. In addressing the first research aim, which was to describe sources of parental NICU stress as perceived by staff, results showed that staff perceived the NICU experience to be a highly stressful time for parents. Across all subscales of the PSS: NICU staff reported significantly higher perceived parental stress levels than parents reported themselves. This finding supports the first hypothesis of Study 2 and is consistent with research by Raeside (1997) and Akbarbegloo and Valizadeh (2009) who also found that staff perceived the NICU to be more stressful than mothers did themselves. Specifically, the current study found that 87% of nurses perceived the overall stressfulness of the NICU experience to be *extremely stressful* compared with 55% of mothers and 0% of fathers. This suggests that nurses are acutely aware that the NICU experience can be extremely stressful for parents, particularly mothers; however, they may not be clear on the degree of stress experienced (such as that no fathers reported the NICU to be *extremely stressful*).

One explanation for the discrepancy in level of stress perceived could be that staff may be thinking back to when parents are at their most stressed. Therefore, they overestimate how stressful parents find the NICU experience in comparison with parents' actual reports which took place (in the current study) when their infant was medically stable (i.e., at 34 weeks' gestation). Another explanation that may partially account for this finding is that staff

may have based their answers on their perception of *maternal* NICU stress rather than paternal stress and therefore reported perceptions of higher levels of stress more consistent with maternal rather than paternal stress levels in the NICU. This inference is supported by the finding that the maternal group and staff perceived the same four out of five most stressful PSS: NICU items, suggesting that staff are indeed more attuned to the maternal stress response. This could be because mothers are likely to be more salient for staff when asked about the parental experience of having an infant in the NICU, since mothers tend to have greater involvement in caring for their infant in the NICU. Interestingly, staff perception scores on the PSS: NICU were still noticeably higher than those in the maternal group. Another explanation for this is that there may be a social desirability bias in how staff answer questions. Staff may want to appear empathetic and that they understand how stressful the NICU is for parents. As a result, they may err on the side of overestimating the degree of stress. In essence, however, staff overestimating levels of parental stress is likely to be more beneficial than harmful in terms of how staff interact with parents.

Some differences and some similarities were found between the aspects of the NICU that were most stressful for staff and parents. For instance, staff rated “loss of parental role” to be the most stressful subscale, while for parents this was “infant appearance”. In addition, staff perceived the “staff behaviours and communication” to be just as stressful as the other subscales (in fact they ranked it the second most stressful subscale), compared to parents who consistently reported “staff behaviours and communication” to be noticeably the least stressful subscale. In general, these findings are consistent with previous research that showed to some extent staff and parents differ on the NICU factors that cause most parental stress (Raeside, 1997; Akbarbegloo & Valizadeh, 2009). However, there was considerable overlap between staff perceptions and parents, particularly mothers, in terms of the top five most stressful items on the PSS: NICU. Two items on the PSS: NICU were ranked in the top

five most stressful for staff, and both parental groups: “being separated from my baby” and “when my baby seemed to be in pain”. Furthermore, as discussed earlier, the maternal group and staff shared four out of five top five most stressful items. Findings that staff and the maternal group reported similar NICU stressors were inconsistent with previous research (Raeside, 1997; Akbarbegloo & Valizadeh, 2009). Staff and fathers, however, only shared two of the top 5 most stressful items in the current study. Given that mothers are likely to be the primary caregivers spending the most time in the NICU with their baby; this once again supports the inference that nurses may be more aware of the maternal NICU stress response. Although some differences were present between staff and parents, the top five most stressful items all came from the “loss of parental role” and “infant appearance” subscales, implying general agreement between staff and parents on the key stressors in the NICU environment.

It was interesting that senior nurses tended to be more accurate in gauging the level of parental stress than were more junior nurses, although this trend was not significant. This was consistent with Raeside’s (1997) findings, which suggests that more nursing experience results in more accuracy in predicting parental stress levels. This may be due to more senior nurses having had more interactions with parents over the years and having built a more accurate picture of how stressful parents find the different aspects of the NICU environment. Furthermore, junior nurses may be primarily focussed on treating the infant and not have the confidence in their nursing ability that senior nurses may have. As a result, senior nurses may have more capacity to consider parental responses and provide appropriate support as well as treat infants in their care. Further research with a larger sample of nurses could be undertaken in order to confirm whether this finding holds and how staff perceptions of parental NICU stress influence the way staff interact with parents.

3.4.2. External stressors. The second aim was to identify potential stressors external to the NICU environment. Consistent with the second hypothesis of Study 2, results showed

that almost all items listed on the External Stressors Scale were found to be stressful by mothers, fathers and staff. This finding is consistent with the “pre-existing and concurrent personal and family factors” described in the Preterm Parental Distress model (Figure 1.2, p.11) and with previous research which found several factors external to the NICU to be stressful for parents (Cronin et al, 1995; Pinelli et al., 2008). Consistent with Cronin et al. (1995), the current study also found there was evidence for stress related to financial factors of having a hospitalized infant including loss of money arising from inability to work, challenges and expenses in arranging childcare, and the cost of transport to and from the hospital. Although Cronin et al. (1995) found that these financial stressors were prominent for parents of VLBW infants, the current study found that items on the ESS relating to financial strain (for example, “paying for several hours of car parking”, “paying petrol/bus/taxi fares to visit the NICU”, and “paying for childcare of my other children”) were not the top stressors. The exception was that mothers found “paying petrol/bus/taxi fares to visit the NICU” was the fourth most stressful external stressor. Differences between studies could be explained by the different external stress questionnaires used in each study.

A new finding from the current study was that the most consistently stressful item on the ESS was “fitting in everything else I need to do”. This was the case for mothers, fathers and staff perceptions. This implies that managing their life around caring for an infant in hospital may be more stressful for parents than had previously been considered. Since researchers appear not to have examined this, further research is needed to confirm this finding. Families who were experiencing difficulties following the premature birth of their baby may find that any external stressors, such as organising their lives to fit in with having their infant in the hospital, may have exacerbated their overall levels of stress.

Although differences emerged between the groups of participants, which was consistent with the second hypothesis for Study, similarities were also found. Mothers,

fathers and staff differed in terms of the order of most stressful items on the ESS. This is to be expected since each group of people would likely be dealing with different aspects of organising their lives to take care of their premature infant. However, there were also a significant number of similarities across the groups of participants (for example, the most stressful item on the ESS). Of particular interest is the finding that paternal mean scores matched maternal mean scores on the ESS (and in some cases were higher), suggesting that fathers may be as or even more stressed by these external factors than mothers. The ESS may, therefore, be describing some of the practical day-to-day tasks fathers become responsible for while mothers are in at the NICU with their infant. Although the means for the ESS were not as high as the means on the PSS: NICU, this is to be expected because the primary stressors are likely to be related to the infant's premature birth and illness status. The current study piloted research in how external stressors relate to each gender, which has been previously unstudied. Therefore, external stressors warrant further research attention so that a clearer picture of these stressors can be documented for mothers and fathers. Specific support in dealing with NICU stress given by staff could be informed by study findings so that this support is tailored more closely to the needs of mothers and fathers. With this information, NICU staff may assist parents in managing their everyday lives so that spending time with their baby in the NICU is less stressful.

3.4.3. External Stressors Scale validation. Consistent with the third aim of the study, the ESS was found to have good internal reliability and adequate convergent validity, suggesting that it will be a useful scale for future research. This also confirmed the first part of the third hypothesis for Study 2. All items on the ESS were found to be significantly correlated to mean NICU stress, which implies that the level of external stress experienced is related to the level of NICU-specific stress experienced. Because this study was cross-sectional, the direction of causality of this relationship was unable to be identified, that is,

whether it is the external stressors which cause NICU-specific stress or vice versa. However, given that stressors occur concurrently, it is important to document all stressors and ensure results inform interventions that support parents of VPT infants. These findings also highlight that those parents who are experiencing high external stress are also likely to be experiencing high NICU-specific stress. Therefore, this group of parents require extra care and support.

Although it was hypothesized that the ESS would be made up of several different themes, results showed that the ESS comprised only one factor: external stress. It is possible that if a larger number of items were included on the ESS combined with a larger number of participants, different themes could have emerged. Again, further research is needed to determine whether multiple external stress themes exist. However, as it stands, the ESS has been shown to be a useful instrument in researching stressors occurring concurrently to having an infant in the NICU and therefore can be used in future research.

3.4.4. Implications. Research findings could inform interventions that support parents during their infants' stay in the NICU. For example, NICU staff could examine why more senior nurses tended to be more accurate at gauging the level of parental stress in the NICU than less experienced staff. Staff training could be given on the following: the key areas of stress for parents, where the discrepancies are between staff perception and parental experience, and the role that external stressors play in influencing parents' overall experience in the NICU. This training could also potentially help reduce the number of years' experience needed for staff in order for them to be accurate in assessing the degree of parental stress.

As shown, external stressors, although often unacknowledged, are a key component of the parental NICU experience. This research highlights the extent to which, on average, parents find many day-to-day tasks stressful. Therefore, greater focus on how to support parents to manage their life circumstances and challenges outside caring for their infant in the NICU may in turn lower parents' level of stress in the NICU. Because this area of research is

relatively unexamined, this study should be considered exploratory. Future research could expand on the relationship between external stressors and NICU-specific stressors.

Researchers could also examine and develop effective strategies to support parents in reducing their level of stress.

Chapter 4

General Discussion

4.1. General Discussion

This thesis addressed several key aims: to describe and compare sources of NICU stress for mothers and fathers of VPT infants, to identify key predictors of parental stress, to describe staff perceptions of parental NICU stress, and to identify parental stressors external to the NICU environment. As shown in Chapters 2 and 3, parents of VPT infants experience several stressors specific and external to the NICU environment. There were also some differences and some similarities found between maternal and paternal reports and staff perceptions. The results of this research extend knowledge on the parental NICU experience and show support for the Preterm Parental Distress Model (Figure 1.2, p.11).

4.1.1. Overall strengths of the current studies. Strengths of Studies 1 and 2 include that a representative cohort of parents of preterm infants was interviewed, a good overall sample size was reached and interviews were conducted across multiple NICU sites. Other strengths were that findings build upon limited amounts of previous research. This research has examined the following: the paternal NICU stress response; staff perceptions of parental NICU stress; and the extent to which factors external to the NICU environment are stressful for parents; and it has provided contemporary information on the parental stress response to having a VPT infant in the NICU in an Australasian sample. For instance, unlike in some previous studies, the current research included paternal perceptions. Given the differences found between maternal and paternal perceptions in terms of the key NICU stressors and the degree of NICU stress experienced, the current research expands our understanding of the paternal stress response. Documenting staff perceptions also allowed for a unique comparison of the aspects of the NICU that staff perceive are stressful for parents with parental report.

Another key strength of the study was that data were collected on other life events that parents had experienced prior to and concurrent with their infant being admitted to the NICU (as measured on the Life Events Scale and the External Stressors Scale). This meant that parental NICU stress could be viewed within the broader context of participants' lives rather than just in terms of their NICU experience alone.

The current research findings also contribute towards a better understanding of the experience of parents relating specifically to VPT birth (rather than parents of VLBW infants or parents of infants admitted to a NICU for other reasons). Findings also provide contemporary information on how staff working in NICU sites today perceive parental stress as well as providing up-to-date information on relevant external stressors for parents. Data were also presented from two different NICU sites and across two different time points, namely in the Christchurch NICU where participants were interviewed in 2010-2011 and in the Melbourne NICU, where parents were interviewed between 2001-2004. This allowed for the current research to present findings from a more contemporary sample of parents than many of the previous studies.

4.1.2. Summary of key findings. Results from Studies 1 and 2 have shown that having a VPT infant in the NICU is stressful; both the NICU environment itself and in organising parents' lives around having a baby hospitalised. Mothers were shown to report higher levels of NICU stress than fathers. The most stressful subscales of the PSS: NICU for parents was "infant appearance" and "loss of parental role". For staff, they perceived the most stressful subscales to be "loss of parental role" and "staff behaviours and communication". In terms of the single most stressful aspect of the NICU experience, for Christchurch and Melbourne mothers and fathers (and NICU staff perceptions) this was most commonly "being separated from my baby".

Predictors of maternal NICU stress were number of upsetting life events and paternal level of NICU stress. The key predictor of paternal NICU stress was the level of maternal NICU stress. Staff consistently overestimated the degree of parental NICU stress compared to parental report. In general, all external stressors on the ESS were stressful for parents. In particular, “fitting in everything else I need to do” was the most stressful item for fathers, mothers and staff perceptions. The ESS was shown to be internally reliable and have good convergent validity.

4.1.3. Support for the Preterm Parental Distress Model. Study findings can be linked to the different aspects of the Preterm Parental Distress Model (Figure 1.2, p.11) indicating good support for this model. In general, results from the current studies showed that having a VPT infant in the NICU is stressful for parents. This section that follows shows how results from the current research specifically supports each component of the model.

4.1.3.1. Infant illness, appearance and treatment. In support of the “infant illness, appearance and treatment” factors hypothesized by the model to cause stress for parents of VPT infants, the “infant appearance” subscale on the PSS: NICU was found to have the highest ratings of stress for Christchurch parents and the Melbourne paternal group. It was also rated as the second highest subscale for the Melbourne maternal group and the third highest subscale for staff perceptions of parental stress (who reported higher means on this subscale than each parental group). In addition, when Christchurch and Melbourne paternal stress responses were combined, low infant birth weight was also found to correlate with the overall paternal stressfulness single item. These results show that infant clinical factors, such as a VPT infant’s illness, appearance and treatment factors are related to some extent to parental NICU stress.

4.1.3.2. Loss of the parental role. In support of the loss of parental role aspect of the model, the “loss of parental role” subscale of the PSS: NICU was shown to have the highest

ratings of stress for the Melbourne maternal group and was rated the second most stressful subscale for Christchurch parents and the paternal Melbourne group. “Being separated from my baby”, an item from the “loss of parental role” subscale, was also found to be a shared item ranked in the top 3 most stressful single items on the PSS: NICU across all participant groups (i.e., the Melbourne maternal and paternal groups as well as the Christchurch maternal, paternal and staff perceptions groups). This suggests that parents experience stress relating to a sense of loss of their parental role when their infant is cared for by nursing staff in the NICU; results which support this facet of the Preterm Parental Distress Model.

4.1.3.3. Pre-existing and concurrent personal and family factors. The extent to which “pre-existing and concurrent personal and family factors” might relate to parents stress experiences was documented through results from the Life Events scale, the External Stressors Scale (ESS) and data on background demographic variables. In Study 1, the number of upsetting life events that had occurred over the previous 12 months was found to be a key predictor of maternal NICU stress. This is an important finding as few other studies included measures of parental stress outside the NICU, and as a result the extent to which personal and family factors may impact on the parental NICU experience was largely unknown. Furthermore, in Study 1, partners’ mean NICU stress levels significantly predicted the other partner’s mean level of NICU stress experienced; a finding which had not been previously reported in a sample of parents of premature infants. Therefore, the interdependence between maternal and paternal partners in terms of the degree of stress experienced was highlighted.

Further to these findings, in Study 2, parents and staff perceived almost all items on the ESS to be stressful and ESS scores were shown to also positively correlate with parental NICU stress. Specifically, “fitting in everything else I need to do” (from the ESS) was the most stressful factor external to the NICU environment for the maternal, paternal and staff groups and was strongly correlated to mean PSS: NICU stress scores. Another finding from

Study 1 was that having fewer children at home tended towards significance in predicting higher mean paternal stress scores on the PSS: NICU. Findings such as these show that contextual factors contribute to the parental experience of having a VPT infant in the NICU. As shown, the current research found strong support for “pre-existing and concurrent personal and family factors” being a key component of the Preterm Parental Distress Model.

4.1.3.4. Prenatal and perinatal experience. Parents’ prenatal and perinatal experiences were not directly measured in the current research. Therefore the extent to which factors such as previous perinatal or infant death or problematic labour/delivery contributed to parental stress in the NICU is unable to be verified in these studies.

4.1.3.5. Health care providers. The Preterm Parental Distress Model also proposes that health care providers contribute to parental stress. Ratings of stress on the “staff behaviours and communication” subscale on the PSS: NICU measured the degree to which “health care providers” influenced parental NICU stress levels. Although this subscale consistently had the lowest mean parental stress scores, staff perceived that their behaviour and communication with parents would be very stressful for parents (and even more stressful than the “infant appearance” and “sights and sounds” subscales). Through the examination of staff perceptions, Study 2 has highlighted similarities and discrepancies between staff perceptions and parental report. Results also revealed that staff showed a general over-estimation bias of parental NICU stress. Therefore, there is only partial support for this aspect of the Preterm Parental Distress Model.

4.1.3.6. Concern about infant outcome. Although the final component of the Preterm Parental Distress Model “concern about infant outcome” was not measured directly, it is plausible that some of the stress that was recorded across the other components of the model could also be related to parental uncertainty and concern for infant outcome. For

example, parental stress pertaining to “infant illness, appearance and treatment” could also include worry for their infant’s later development.

Overall, it is clear that the current research supports the Preterm Parental Distress Model (Figure 1.2, p.11) as a useful framework for conceptualising parental NICU stress. This is not surprising given the model was developed based on 20 years of parental stress literature (Holditch-Davis & Miles, 2000), as well as more contemporary research findings (presented in this thesis) have also been found to support the model. Importantly, there are also three key extensions that the results of the present research make to this model: 1) the degree of parental NICU stress experienced is predicted by levels of partner NICU stress; 2) staff perceive the NICU environment to be significantly more stressful for parents than parents; and 3) external stressors are also relevant and essential to consider in the evaluation of parental stress.

4.1.4. Limitations. The current research is characterized by some methodological limitations which should be considered when interpreting the results. The first limitation concerns the small sample size of the Christchurch cohort. Owing to the Canterbury earthquake, participant recruitment for Study 1 and Study 2 had to be cancelled, thus leaving the sample significantly smaller than anticipated. This raises questions as to the generalisability of the findings relating to the Christchurch sample. In order to address this limitation, data from Melbourne were included for Study 1. However, there are a number of limitations related to using data across two different NICU sites. For example, there was approximately an 8 year time difference between when the Melbourne and the Christchurch data were collected (since the Melbourne data had been previously collected in 2001-2004). This may partially explain why, in general, Melbourne parents reported higher stress levels than Christchurch parents. Specifically, possible improvements in the care of VPT infants and in staff communication with parents over the past decade may be accountable for the lower

levels of stress evident in the more recently interviewed parents (i.e., the Christchurch parent sample). However, given Study 1 was not concerned with comparisons between NICU sites and instead focussed on maternal and paternal comparisons, this limitation is not considered to substantially affect the validity of the results. With respect to Study 2, despite the small sample, results are valuable in highlighting the importance of future research to consider and address staff perceptions of parental stress as well as stressors external to the NICU environment.

Another limitation of Study 1 relates to differences across the cohorts in infant clinical characteristics. For example, the infants in the Christchurch sample were born earlier than 32 weeks' gestation, whereas in the Melbourne sample, infants were born earlier than 30 weeks' gestation. The younger gestational age found in the Melbourne sample may also partially account for why Melbourne parents reported higher mean NICU stress scores than Christchurch parents. Moreover, in the Melbourne sample, the birth weights of infants born as twins or triplets were not recorded/or available. A possible implication of this limitation is that these infants may have had lower birth weights than the singleton infants. Therefore, if this data was available for the current study, birth weight may have been a stronger predictor of stress than it was presently. There were also a larger number of mothers who had multiple births in the Melbourne sample ($n = 27$) compared to in the Christchurch sample ($n = 1$), however, this difference was not significant. Therefore, it is possible that differences in infant clinical factors between the two cohorts may partially explain site differences in findings relating to parental stress.

A further limitation that spans both Study 1 and Study 2 concerns variation in the timing of when the PSS: NICU interview was administered. For Study 1, Christchurch parents were interviewed within a week of when their infant was 34 weeks' gestation, while Melbourne parents were interviewed when their infant was at term equivalent age (40 weeks).

However, for both groups, interviews were conducted when infants were no longer in the most critical stages of medical care but had been in the NICU for several weeks. Therefore, for both cohorts the PSS: NICU is likely to have captured the on-going NICU stress experience for parents rather than the acute stress response. A further limitation relating to Study 2 was that staff were not interviewed at a particular gestational age of any given infant in their care, and staff were not asked to think of a particular time in the NICU stay when answering the PSS: NICU. Therefore, staff may have been thinking back to a time of most stress for parents. Although parents were also not asked to answer items on the PSS: NICU based on a particular time-point, Christchurch parents did complete the questionnaire when their infants were medically stable (34 weeks' gestation). Therefore, this may have partially accounted for the significantly higher perceptions of parental NICU stress that staff reported who may have been answering retrospectively. In future research, it is recommended that staff are asked to base their answers on parents' NICU experience at the same time as parents or when the infant is medically stable.

Another limitation found in Study 2 is that there was a notable ceiling effect for staff responses on the PSS: NICU. For example, 64% of items had mean scores higher than a 4 on the 5-point scale. Therefore, staff responses were skewed towards the higher end of the scale and thus their scores were clustered and less varied. It is possible that by implementing the aforementioned recommendation of asking staff to base their answers on a particular time period during the infant's NICU stay that staff results would show a more normal distribution. Another limitation relating to staff perceptions is that although the PSS: NICU is widely considered a valid instrument for measuring parental NICU stress, it has not been used to measure staff perceptions. Therefore, the adapted version has not been previously validated.

Another factor to consider when interpreting the results is the possibility that all participants may have been influenced by a social desirability bias when answering questions on the PSS: NICU. For instance, fathers in Study 1 may have felt it was inappropriate to report answers that would show them as weak or fragile and as a result may have reported muted stress scores. Although this bias may also occur to some extent for mothers, because society implies men are psychologically strong, it is possible that a social desirability bias would have a greater impact on paternal responses. A social desirability bias may also have been prevalent in the staff group of participants in Study 2. However, in this case, staff may have wanted to appear more empathetic and as a result amplified their parental stress perception ratings. This limitation is often difficult to account for and is inherent in the very nature of conducting research on sensitive issues.

A final limitation concerns a possible selection bias when recruiting parents for Study 1. It was not possible to randomly select participants because of the already small number of eligible participants to recruit from; therefore, it is possible that study results only present findings from parents who were coping sufficiently to participate. Because no data were available on the parents who did not consent, no analyses are possible to determine whether there were significant differences between participating and non-participating parents in terms of the sources and rates of NICU stress experienced. Therefore, it must be considered that the parents who were most stressed in the NICU may potentially not be represented in the current research.

4.1.5. The need for follow-up post-discharge: The Transactional Model of

Development. Studies 1 and 2 have established that having a VPT infant in the NICU is a stressful time for parents. However, once the emergency is over and parents have their VPT infant at home, previous research has found that the stress can continue (Singer et al., 1999; Cronin et al., 1995). Combined with VPT infants' developmental vulnerability and

likely need for increased sensitivity in care-giving, this may result in a more chronic case of parenting stress (higher than that of parents of full-term infants). Using the framework of the Transactional Model of Development (as outlined in Chapter 1, p. 6) it can be argued that children born VPT are not only disadvantaged due to being born early but also because of possible poorer parenting as a result of parental stress (Muller-Nix et al., 2004). As Pesonen et al. (2008) showed, the effect of parental stress on poorer infant outcomes was greater than the effect of infant behaviours on parental stress. Therefore, findings from the present research support the inference that infants of stressed parents may show poorer developmental outcomes, specifically, that VPT infants with stressed parents could be at high risk of poorer developmental outcomes. Since it is not possible to alter the circumstances that led to a premature delivery, interventions that are targeted at reducing parental stress are essential. Parental stress cannot be lowered if research has not clearly identified the key sources of stress. Therefore, because the current research has identified sources of stress for mothers and fathers, this paves the way for interventions to effectively target the key sources of stress for parents, such as being separated from their baby. Further attention is also warranted on the longer-term impacts of on-going parental stress; specifically, how this impacts on the parent-child relationship and how infant and child outcomes might be affected.

4.1.6. Implications for practice. Results of the current studies have relevance for professionals working with parents of premature infants hospitalized in a NICU.

Interventions with parents in the NICU should include both mothers and fathers, although interventions may focus on different aspects of the NICU experience for each. For instance, the finding that mothers reported higher levels of NICU-specific stress than fathers suggests that mothers may be at increased risk of higher stress and poorer parenting than fathers. For example, the maternal group reported significantly higher levels of NICU stress than the

paternal group on three out of the four PSS: NICU subscales. In contrast, in Study 2, these sex differences were not as strong when examining ratings of sources of external stress on the ESS. This suggests that mothers are mostly stressed as a result of the infant characteristics associated with prematurity and the NICU environment, and are less stressed by external factors. Paternal NICU-specific stress levels and external stress levels were, however, found to be similar. Because it was found that paternal NICU stress levels predict maternal NICU stress levels (and vice versa), both the maternal and paternal response to having a VPT infant warrants further attention. Different interventions, however, may be needed for mothers and fathers.

Informing staff of the importance of contextual factors, such as more general life events and other stressors outside of the NICU environment, may improve the support that staff can give parents. For instance, it may be beneficial to provide staff training on how concurrent external stressors and previously upsetting life events contribute to parental levels of NICU stress. With this in mind, nursing staff or social workers may be able to tailor their support to parents. Interventions which target enhancing maternal skills in coping with challenging life events may reduce the level of NICU stress experienced. Also, since it was also found that fathers of VPT infants who had no other children at home may be at an increased risk of experiencing high NICU stress, paternal interventions may involve building parenting confidence as one way to reduce their degree of stress. As mentioned above, interventions may need to be tailored specifically to maternal and paternal needs.

Another implication for practice is to address any discrepancies between staff views and parental report of the most stressful aspects of the NICU. Staff were unaware that items on the “infant appearance” subscale were rated as most stressful by parents. If staff were made aware of this in the future, they could focus on supporting parents in adjusting to their infants’ appearance. In addition, since senior nurses were found to be somewhat more

accurate at gauging parental stress levels, an initiative could be set up that involved a mentoring programme for junior nurses. This may minimise the amount of nursing experience needed in order to accurately determine the degree of stress parents are experiencing and thus increase early referral of highly stressed parents for further assistance. It is possible that, if staff are over-estimating the degree of stress parents are experiencing, they may be less effective at accurately discriminating between parents who are highly stressed and parents who are mildly stressed. It is important to note that these staff perception results obtained in the current study are preliminary findings and future research is needed to confirm their reliability.

Finally, one other possible way to reduce parental NICU stress could be to implement new initiatives in the NICU to support parents. For example, with “being separated from my baby” being the highest rating single item on the PSS: NICU, one possible way to minimise stress associated with this would be if parents could stay overnight on-site in the hospital with their infant. If funded in-hospital stays were made available for all parents with VPT infants in the NICU, this may enable parents to be more involved in the day-to-day care of their infant and not feel as though they are separated as much. The ability for parents to choose in-hospital stays may also minimise the extent parents would experience external stressors, such as finding a car park, travelling time to and from the NICU and planning their day to fit in with NICU routines. In addition, assistance with organising and funding childcare of parents’ other children, whether in-home care or capacity to stay overnight in-hospital with one or both parents, may help reduce overall parental stress levels. Eliminating some of these external stressors and by increasing the proximity of parents to their VPT infants may in turn lower the amount of stress experienced in the NICU.

4.1.7. Avenues for future research. While the current research provides a useful foundation for future research, findings may be considered preliminary and largely

exploratory. For instance, the results concerning NICU staff perceptions of parental stress are in need of replication. Researchers could also expand on how staff over-estimating the degree of parental NICU stress influences the ways staff interact with parents. Specifically, researchers could examine whether staff having higher accuracy in assessing levels of parental stress improves staff-parent communications and in turn lowers parental stress.

Another avenue for future research could be to clarify the mixed findings (as evidenced by the discrepancy between Miles et al., 1992 and the current research findings) on whether the degree of parental NICU stress decreases over the course of an infant's stay in the NICU. In Miles et al. (1992), they showed that in the case of the "loss of parental role" subscale, parents reported lower NICU stress levels two weeks after infant admission to the NICU than when first interviewed one week after admission. This suggests that some of the NICU-specific stressors may diminish as parents adjust to having an infant in the NICU. However, in the current research, this finding was not supported. Despite the six weeks difference between when Christchurch and Melbourne parents completed the PSS: NICU, scores on the PSS: NICU were similar. This implies that parents still experience NICU stress even after their infant has been in the NICU for many weeks. Longitudinal research could examine which sources of NICU stress decrease over time and which remain constant.

Future research may also benefit from including a wide range of infant clinical variables as well as personal and family variables in order to further examine how they are related to parental NICU stress. This may include additional research into the specific differences between mothers and fathers and which background and infant clinical variables predict higher levels of NICU stress. In addition, researchers could examine whether infant clinical variables are related to the degree of external stress experienced on the ESS, since they are related to NICU-specific stress. Given that the ESS was shown to be internally

reliable and have adequate convergent validity, further use of the ESS in research is certainly warranted.

Finally, since Study 1 showed that maternal and paternal levels of NICU-specific stress are interdependent to some extent, future research may benefit from examining the potentially different ways in which couples cope following a stressful event. Coping with a stressful event such as having a VPT infant is something that couples often face together. Partners not only have to manage their own distress, but they also have to support their partner. Research could examine and develop interventions which enhance couples' ability to support each other and as a result lower both partners' NICU stress levels.

4.1.8. Conclusions. The current research contributes to the existing literature on parental stress following the birth of a premature infant in a number of ways. The key strengths of the present studies include the documentation of paternal stress responses, staff perceptions of parental stress and the extent to which contextual and external factors contributed to the parental NICU experience. The current research findings also showed strong support for the Preterm Parental Distress Model. Interpreting these findings within the framework of the Transactional Model of Development highlights the double vulnerability of the VPT infant. Early developmental delay and parental stress may lead to on-going parenting stress and poorer parenting over time culminating in more adverse developmental outcomes. It is becoming increasingly evident that VPT infants and their parents are a uniquely high-risk group. For that reason, continued research in this field is essential due to the high levels of parental stress experienced and the potential consequences for the parent-child relationship and later infant and child outcomes.

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APPENDIX A Infant Medical Treatments and Procedures

Any case of the following were included in Figure 1.1 (p. 4):

IPPV – Intermittent Positive-Pressure Ventilation

HFV – High Frequency Ventilation

CPAP – Continuous Positive Airways Pressure

Oxygen

ETT – new or change

UAC – Umbilical Artery Catheterisation

PAL – Peripheral Arterial Line

PAL – new site

UVC – Umbilical Vein Catheterisation

CVL - Long line

CVL – new site

Any case of Peripheral IV

Peripheral IV – new site

TPN – T Parenteral Nutrition

IV lipid

Tube feeds

Phototherapy

Blood transfusion

Plasma or albumin

Amoxicillin

Gentamicin

Cefotaxime

Vancomycin

Other antibiotics/antimicrobials

Morphine

Dopamine

Indomethacin

Surfactant

Dexamethasone

The following were not included (not considered a medical intervention/procedure):

Oral feeds via breast, bottle or cup

APPENDIX B Ethics Approval Letter



Upper South A Regional Ethics Committee

Ministry of Health
4th Floor, 250 Oxford Tce
PO Box 3877
Christchurch
Phone (03) 372 3037
Fax (03) 372 1015
Email: uppersouth_ethicscommittee@moh.govt.nz

2 August 2010

Dr Verena Pritchard
Postdoctoral Fellow
Canterbury Child Development Research Group
Department of Psychology
University of Canterbury
Private Bag 4800
CHRISTCHURCH

Dear Dr Pritchard,

Ethics ref: URA/10/05/039 (please quote this reference in all correspondence)
Study title: Parental experiences in the Neonatal Intensive Care Unit and Early Mother-Infant Bonding
Investigators: Dr V Pritchard, A/Prof L Woodward, Ms A Montgomery-Honger, Ms E Ballenden
Localities: Christchurch Women's Hospital

This study was given ethical approval by the Upper South A Regional Ethics Committee on 2 August 2010. A list of members of the Committee is attached.

Approved Documents

- Paternal invitation letter (very pre-term) dated July 2010
- Maternal invitation letter (full-term) dated July 2010
- Maternal invitation letter (very pre-term) dated July 2010
- Paternal information sheet and Consent form (very pre-term) dated July 2010
- Maternal Information sheet and Consent form (very pre-term) dated July 2010
- Maternal Information sheet and Consent form (full-term) dated July 2010
- Interview questions dated July 2010
- Post Partum Bonding questionnaire dated July 2010
- Parental Stressors Scale: NICU
- CLIP Interview and Coding Scale
- Maternal responsiveness instrument
- Victoria Infant Brain Study – Parental Interview

This approval is valid until 30 April 2011, provided that Annual Progress Reports are submitted (see below).

Amendments and Protocol Deviations

All significant amendments to this proposal must receive prior approval from the Committee. Significant amendments include (but are not limited to) changes to:

- the researcher responsible for the conduct of the study at a study site
- the addition of an extra study site
- the design or duration of the study
- the method of recruitment
- information sheets and informed consent procedures.

Significant deviations from the approved protocol must be reported to the Committee as soon as possible.

Annual Progress Reports and Final Reports

The first Annual Progress Report for this study is due to the Committee by . The Annual Report Form that should be used is available at www.ethicscommittees.health.govt.nz. Please note that if you do not provide a progress report by this date, ethical approval may be withdrawn.

A Final Report is also required at the conclusion of the study. The Final Report Form is also available at www.ethicscommittees.health.govt.nz.

Requirements for the Reporting of Serious Adverse Events (SAEs)

For the purposes of the individual reporting of SAEs occurring in this study, the Committee is satisfied that the study's monitoring arrangements are appropriate.

SAEs occurring in this study must be individually reported to the Committee within 7-15 days only where they:

- are *unexpected* because they are not outlined in the investigator's brochure, and
- are not defined study end-points (e.g. death or hospitalisation), and
- occur in patients located in New Zealand, and
- if the study involves blinding, result in a decision to break the study code.

There is no requirement for the individual reporting to ethics committees of SAEs that do not meet all of these criteria. However, if your study is overseen by a data monitoring committee, copies of its letters of recommendation to the Principal Investigator should be forwarded to the Committee as soon as possible.

Please see www.ethicscommittees.health.govt.nz for more information on the reporting of SAEs, and to download the SAE Report Form.

We wish you all the best with your study.

Yours sincerely



Alieke Dierckx
Administrator
Upper South A Regional Ethics Committee
Email: alieke_dierckx@moh.govt.nz



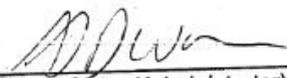
Upper South A Regional Ethics Committee

Ministry of Health
4th Floor, 250 Oxford Tce
PO Box 3877
Christchurch
Phone (03) 372 3037
Fax (03) 372 1015
Email: UpperSouth_ethicscommittee@moh.govt.nz

List of members of the Upper Region A Ethics Committee, May 2010

Liz Richards (Chair)	Consumer Representative Lay member	Female
Carolynn Bull	Legal representative, Maori representative Lay member	Female
Murray Cameron	Health Researcher Health Professional Member	Male
Allison Franklin	Consumer representative Lay member	Female
John Horwood	Biostatistician Lay member	Male
Ellen McCrae	Pharmacist Health Professional member	Female
Edie Moke	Maori representative Lay member	Female
Barbara Nicholas	Ethicist Lay member	Female
Russell Scott	Health Practitioner Health Professional member	Male
Jane Ward	Researcher Health Professional Member	Female

Edie Moke was not present at the meeting of 17 May 2010.


Alieke Dierckx (Administrator)

2/08/10
Date

APPENDIX C Maternal Invitation Letter⁴

Canterbury Child Development
Research Group
Department of Psychology
College of Science

July 2010

Invitation for mothers of very preterm infants

Dear

Your name was selected from the neonatal admission book as someone who gave birth to a baby earlier than 32 weeks' gestation in 2010.

We would like to invite you to participate in this study as a new parent of an infant born prematurely.

We are asking you and your infant to participate because we wish to compare parental perceptions and experiences of giving birth between mothers and fathers of infants who were born prematurely with mothers of infants who were born at about their due date.

This study would involve an interview completed when your infant is 34 weeks', and a home visit 4 weeks after your discharge from hospital.

We would appreciate the opportunity to talk with you about the study shortly and what it might involve for you and your new baby should you be interested in helping.

Thank you for your help. Your involvement in this study will help us to better understand the experiences and needs of the families of premature infants born in New Zealand and admitted to neonatal intensive care.

Yours sincerely,

Elizabeth Ballenden
Researcher
366 7001 Ext. 3406

Argène Montgomery-Hönger
Researcher
366 7001 Ext. 3406

Professor Lianne Woodward
Researcher
372 0406

Dr Verena Pritchard
Researcher
3642987

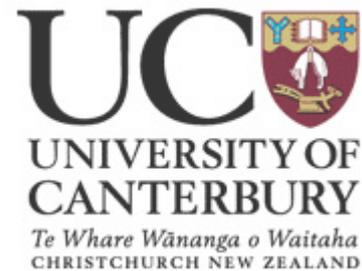
Dr Nicola Austin,
Neonatal Paediatrician,
364 4699

Carole Spencer
Research Nurse Specialist, Neonatal Services
3644742

We are committed to treating all our study participants in a fair and ethical manner.

**This study has received ethical approval from the Upper South A Regional
Ethics Committee: Ref URA/10/05/039**

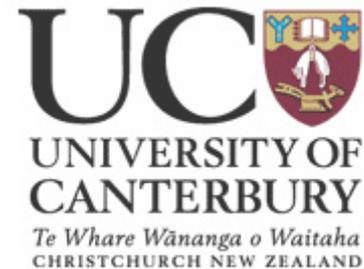
⁴ Although only the maternal invitation letter is presented, paternal participants also received a letter tailored to them.



APPENDIX D Maternal Information Letter⁵

Canterbury Child Development
Department of Psychology
College of Science

July 2010



PARENTAL EXPERIENCES IN THE NEONATAL INTENSIVE CARE UNIT (NICU)

MATERNAL INFORMATION SHEET (Very Preterm)

You and your infant are invited to take part in a study of a group of mothers and fathers of infants born very preterm and mothers of a group of infants born full term. This study is being carried out by Elizabeth Ballenden and Argène Montgomery-Hönger as part of their MSc thesis projects under the supervision of Dr Verena Pritchard and Professor Lianne Woodward (Canterbury Child Development Research Group, Psychology, University of Canterbury). Ms Carole Spencer, Research Nurse Specialist (Christchurch Women's Hospital) and Dr Nicola Austin, a Paediatrician (Christchurch Women's Hospital) will also be involved in this study.

WHAT IS THE STUDY?

The purpose of the study is to learn more about parents' experiences of premature birth. Approximately 20 mothers and fathers of very premature infants and 20 mothers of full term infants born between June and December 2010 at Christchurch Women's Hospital will be taking part in the study. The father of your infant will also be invited to participate in this study and he will also receive an information sheet about the study.

WHAT DOES THE STUDY INVOLVE?

With your consent you will be interviewed regarding your experience in the hospital since the birth of your infant. The total time involved in taking part in the study will be 1.5 hours on two separate occasions. With your consent, we will ask you to complete two interviews. The first will take place when your infant is around 34 weeks' gestation and the second, four weeks after your arrival at home. Questionnaires used will include:

1. You and your partner/husband (where applicable) will be asked to fill out a general questionnaire including background information about your family and your pregnancy.

⁵ Although only the maternal information letter is presented, paternal participants also received a letter tailored to them.

2. You will be asked about your experiences in the NICU since giving birth and the transition to home after discharge from the hospital.
3. You will be asked to fill in a further questionnaire focusing on your relationship with your infant.
4. With your consent, members of the research team will access medical data about your baby and your pregnancy for the purposes of gaining hospital infant and mother clinical information.
5. Half of the mothers in the study will be asked to complete an additional interview focussing on their pregnancy and birth experience and half will not.
6. With your consent you will be visited once at home 4 weeks after your baby has been discharged from the hospital. Here you will have an interview where we will discuss how you feel you have bonded with your baby, levels of parenting stress and if there were any on-going problems after the transition to home.
7. With your consent, one of the researchers will make 2 short video-recordings, one when you are involved with a care giving routine such as changing a nappy and one whilst you are engaged in face to face interaction with your baby. You will be offered a copy of these video-recordings.

PARTICIPATION

Your participation in this study is **entirely voluntary** (your choice). You do not have to take part in this study, and if you choose not to take part we will respect your choice. If you agree to take part in the study **you are free to withdraw at any time** without having to give a reason. If you decide not to participate or to withdraw, this will not affect the health care of you or your child. In addition, participating in Part 1 does not mean that you have to participate in Part 2.

You are welcome to have family/whanau or kaumatua to support you during any of the interviews.

If you have any queries or concerns about your rights as a participant in this research study you can contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act.

Telephone: (NZ wide) 0800 555050

Free Fax (NZ wide): 0800 2787 7678 (0800 2 SUPPORT)

Email (NZ wide): advocacy@hdc.org.nz

CONVENIENCES OR HAZARDS WHICH MIGHT BE EXPECTED

There are no known risks of these evaluations. All information that is collected will be done with great care for you and your infant so as not to cause any upset.

CONFIDENTIALITY

All information you give us will be treated in the strictest confidence. Your identity will not be revealed in any reports based on the study. No information will ever be released about you or your child to a third party without your written consent. The study has a comprehensive security system, with all information you provide being stored anonymously on computer files. Access to these files will be confined to study investigators. Data will be destroyed after 20 years or longer.

With your permission, data from this study may be used in future-related studies, which have been given ethical approval from a Health and Disability Ethics Committee.

Finally, we would like to thank you for considering assisting us with this research.

IF YOU WANT TO KNOW MORE ABOUT THE STUDY

Please feel free to contact at any stage:

Dr Verena Pritchard, Department of Psychology, University of Canterbury, Private Bag 4800, Christchurch. Tel: (03) 364 2987 Ext. 4201

Principal Investigators

Dr Verena Pritchard, Department of Psychology, University of Canterbury, Private Bag 4800, Christchurch. Tel: (03) 364 2987 Ext. 4201

Professor Lianne Woodward, Department of Psychology, University of Canterbury, Private Bag 4800, Christchurch. Tel: (03) 364 2255

Dr Nicola Austin, Neonatal Paediatrician, Christchurch Women's Hospital, Private Bag 4771, Christchurch. Tel: (03) 364 4699

Carole Spencer, Research Nurse Specialist, Neonatal Services, Christchurch Women's Hospital, 2 Riccarton Avenue, Christchurch. Tel: (03) 364 4742

Elizabeth Ballenden; BA Hons (Psyc), Department of Psychology, University of Canterbury, Private Bag 4800, Christchurch. Tel: (03) 366 7001 Ext. 3406

Argène Montgomery-Hönger; BA Hons (Psyc), Department of Psychology, University of Canterbury, Private Bag 4800, Christchurch. Tel: (03) 366 7001 Ext. 3406

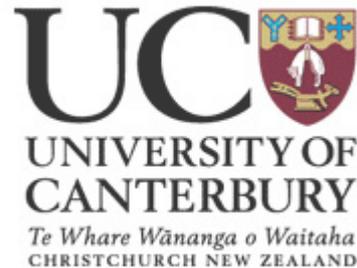
We are committed to treating all our study participants in a fair and ethical manner.

<p>This study has received ethical approval from the Upper South A Regional Ethics Committee: Ref URA/10/05/039</p>
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APPENDIX E Maternal Consent Form⁶

Canterbury Child Development Research Group
 Department of Psychology
 College of Science

July 2010



STUDY ID NUMBER

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(Reference number: _____)

MATERNAL CONSENT FORM (VERY PRETERM) FOR THE STUDY ON PARENTAL EXPERIENCES IN THE NEONATAL INTENSIVE CARE UNIT

- I have been invited to participate with my infant in a study that will involve parents of infants born very preterm and infants born full term. I have read and understood the Information Sheet of the study dated July 2010. I heard and understood an explanation of the study, and have been given an opportunity to discuss this study and to ask questions. I am satisfied with the answers I have been given.
- I have had enough time to consider whether we will participate in the Study, and to discuss my decision with the researcher or a person of my choice.
- I know who to contact if I have any questions about the study.
- I understand that our participation in this research is **confidential** and that no material which could identify me or my infant will be used in any study reports, or made available to anyone else without my approval in writing.
- I understand that I will be videotaped whilst involved with my baby and that this information will only be used for further observation by the named study investigators and that the material will be secured and kept strictly confidential. A copy will be made available.

⁶ Although only the maternal consent form is presented, paternal participants also received a consent form tailored to them.

- I consent to the use of my data for future related studies, which have been given ethical approval from a Health and Disabilities Ethics Committee.
- I also understand that my infant and I can withdraw from the study at any time.
- I understand that I may have family/whanau or kaumatua present during the interviews.
- I understand the compensation provisions for the study.

I agree to members of the research team having access to medical information about my baby and my pregnancy-related information for the purposes of gaining background information.

YES/NO

I consent to my infant and me taking part in the Study.

Infant's Name: _____

Parent's Name: _____

Signature of Parent: _____ **Date:** _____

In my opinion, consent was given freely and the participant understands what is involved in this study.

Researcher's Name: _____

Signature of Researcher: _____ **Date:** _____

APPENDIX F Parental Stressors Scale: NICU⁷

YOUR EXPERIENCE OF NEONATAL INTENSIVE CARE

Nurses and others who work in neonatal intensive care units are interested in how this environment and experience affects parents. The neonatal intensive care unit is the room where your baby is receiving care. Sometimes we call this room the NICU for short. We would like to know about your experience as a parent whose child is presently in the NICU.

Following is a list of experiences that other parents have reported as stressful when their baby was in the NICU. We would like to know how stressful each of these experiences has been for you. If you have not had an experience, you can just let me know. **By stressful, we mean that the experience has caused you to feel anxious, upset, or tense.**

Below is a list of the various **SIGHTS AND SOUNDS** commonly experienced in an NICU. We are interested in knowing about your view of how stressful these **SIGHTS AND SOUNDS** are for you. (Circle the number that best represents the parent's level of stress).

	Not applicable	Not at all stressful	A little stressful	Moderately stressful	Very stressful	Extremely stressful
The presence of monitors and equipment	8	1	2	3	4	5
The constant noises of monitors and equipment	8	1	2	3	4	5
The sudden noises of monitor alarms	8	1	2	3	4	5
The other sick babies in the room	8	1	2	3	4	5
The large number of people working in the unit	8	1	2	3	4	5

⁷ As administered to mothers and fathers in the Christchurch and Melbourne cohorts.

Below is a list of items that might describe the way your **BABY LOOKS AND BEHAVES** while you are visiting 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 just let me know if you have not experienced or seen this in your baby.

	Not applicable	Not at all stressful	A little stressful	Moderately stressful	Very stressful	Extremely stressful
Tubes and equipment on or near my baby	8	1	2	3	4	5
Bruises, cuts or incisions on my baby	8	1	2	3	4	5
The unusual colour of my baby (eg looking pale or yellow jaundiced)	8	1	2	3	4	5
My baby's unusual or abnormal breathing patterns	8	1	2	3	4	5
Seeing my baby suddenly change colour (eg becoming pale or blue)	8	1	2	3	4	5
Seeing my baby stop breathing	8	1	2	3	4	5
The small size of my baby	8	1	2	3	4	5
The wrinkled appearance of my baby	8	1	2	3	4	5
Having a machine (respirator) breathe for my baby	8	1	2	3	4	5
Seeing needles and tubes put in my baby	8	1	2	3	4	5
My baby being fed by an intravenous line or tube	8	1	2	3	4	5
When my baby seemed to be in pain	8	1	2	3	4	5
My baby crying for long periods	8	1	2	3	4	5
When my baby looked afraid	8	1	2	3	4	5
When my baby looked sad	8	1	2	3	4	5
The limp and weak appearance of my baby	8	1	2	3	4	5
Jerky or restless movements of my baby	8	1	2	3	4	5
My baby not being able to cry like other babies	8	1	2	3	4	5

	Not applicable	Not at all stressful	A little stressful	Moderately stressful	Very stressful	Extremely stressful
Clapping on baby's chest for chest drainage	8	1	2	3	4	5

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, can you tell me how stressful it was.

	Not applicable	Not at all stressful	A little stressful	Moderately stressful	Very stressful	Extremely stressful
Being separated from my baby	8	1	2	3	4	5
Not feeding my baby myself	8	1	2	3	4	5
Not being able to care for my baby myself (eg changing a nappy, bathing)	8	1	2	3	4	5
Not being able to hold my baby when I want	8	1	2	3	4	5
Sometimes forgetting what my baby looks like	8	1	2	3	4	5
Not being able to share my baby with other family members	8	1	2	3	4	5
Feeling helpless and unable to protect my baby from pain and painful procedures	8	1	2	3	4	5
Being afraid of touching or holding my baby	8	1	2	3	4	5
Feeling staff are closer to my baby than I am	8	1	2	3	4	5
Feeling helpless about how to help my baby during this time	8	1	2	3	4	5

We are also interested in whether you experienced any stress related **STAFF BEHAVIOURS** and **COMMUNICATION**. Your answers are confidential and will not be shared or discussed with any staff member.

	Not applicable	Not at all stressful	A little stressful	Moderately stressful	Very stressful	Extremely stressful
Staff explaining things too fast	8	1	2	3	4	5
Staff using words I don't understand	8	1	2	3	4	5
Telling me different (conflicting) things about my baby's condition	8	1	2	3	4	5
Not telling me enough about tests and treatments being done to my baby	8	1	2	3	4	5
Not talking to me enough	8	1	2	3	4	5
Too many different people (doctors, nurses, others) talking to me	8	1	2	3	4	5
Difficulty in getting information or help when I visit or telephone the unit	8	1	2	3	4	5
Not feeling sure that I will be called about changes in my baby's condition	8	1	2	3	4	5
Staff looking worried about my baby	8	1	2	3	4	5
Staff acting as if they did not want parents around	8	1	2	3	4	5
Staff acting as if they did not understand my baby's behaviour or special needs	8	1	2	3	4	5

Using the same rating scale, indicate how stressful in general, the experience of having your baby hospitalised in the NICU has been for you.	8	1	2	3	4	5
---	---	---	---	---	---	---

Thank you for your help. Now, was there anything else that was stressful for you during the time that your baby has been in the neonatal intensive care unit? Please describe below:

APPENDIX G Life Events Scale⁸

In the last year, have any of the following events occurred to you?

INTERVIEWER: IF "YES" ASK "HOW UPSET OR DISTRESSED WERE YOU BY THIS?"

	Very Upset	Upset	Mildly Upset	Not Upset	No Event
Moved house	5	4	3	2	9
Took out a mortgage	5	4	3	2	9
Built a home or had one built	5	4	3	2	9
Remodelled a home	5	4	3	2	9
Increased financial problems from taking on a mortgage or purchasing a business	5	4	3	2	9
Partner became unemployed	5	4	3	2	9
Partner changed his job	5	4	3	2	9
Partner took a cut in wage or salary without a demotion	5	4	3	2	9
Respondent started a new job	5	4	3	2	9
Respondent took a cut in wage or salary without a demotion	5	4	3	2	9
Someone stayed on in the household after he/she was expected to leave	5	4	3	2	9
Serious family argument other than with spouse	5	4	3	2	9
Family member other than partner or child died	5	4	3	2	9
Close friend died	5	4	3	2	9
Had serious or prolonged disagreements with parents/in-laws	5	4	3	2	9

⁸ As completed by Christchurch mothers and fathers and Melbourne mothers.

Serious financial problems	5	4	3	2	9
Suffered a financial loss or loss of property not related to work	5	4	3	2	9
Foreclosure of mortgage or loan	5	4	3	2	9
Became engaged	5	4	3	2	9
Married	5	4	3	2	9
Relations with partner changed for the worse without separation or divorce	5	4	3	2	9
Serious or prolonged arguments with partner/ex-partner if separated within year	5	4	3	2	9
Divorce	5	4	3	2	9
Separation from partner	5	4	3	2	9
Reconciliation with partner (after divorce or legal separation)	5	4	3	2	9
Robbed	5	4	3	2	9
Legal problems	5	4	3	2	9
Partner involved in court case	5	4	3	2	9
Injury (respondent)	5	4	3	2	9
Unable to get treatment for an illness or injury (respondent)	5	4	3	2	9
Serious illness or accident of partner	5	4	3	2	9
Serious illness or accident (study child)	5	4	3	2	9
Serious illness or accident of child (other than survey child)	5	4	3	2	9
Serious illness (other family members)	5	4	3	2	9
Miscarriage or still-birth	5	4	3	2	9
Pet died	5	4	3	2	9

APPENDIX H External Stressors Scale⁹

Below is a list of items that might describe what it is like organising your life to be with your baby while they are hospitalised in the NICU. How stressful have you found these to be?

	Not applicable	Not at all stressful	A little stressful	Moderately stressful	Very stressful	Extremely stressful
Time						
Travelling to and from the NICU to be with my baby	8	1	2	3	4	5
Planning my day to fit in with NICU visiting hours/routines	8	1	2	3	4	5
Fitting in everything else I need to do around the house/with my other children as well as spending time in the NICU	8	1	2	3	4	5
Childcare						
Organising childcare for my other children e.g. A babysitter, nanny, husband/partner, friend, family member	8	1	2	3	4	5
Trying to keep my other children entertained when I bring them to the NICU	8	1	2	3	4	5
Accessibility						
Finding a car park nearby	8	1	2	3	4	5
Organising my own food for when I am at the hospital	8	1	2	3	4	5
Money						
Paying for several hours of car parking each time I visit	8	1	2	3	4	5
My husband/partner having to take time off work to be in at the hospital	8	1	2	3	4	5
Paying petrol/bus/taxi fares to visit the NICU	8	1	2	3	4	5
Paying for the childcare of my other children	8	1	2	3	4	5
Having to spend money on cellphone calls to update friends and family while I'm in the NICU	8	1	2	3	4	5

Was there anything else not covered in the above that was stressful for you during the time your baby has been in the NICU? If yes, please describe below:

⁹ As administered to Christchurch mothers and fathers.

APPENDIX I Parental Stressors Scale: NICU – Staff Perceptions¹⁰

Nurses and others who work in neonatal intensive care units are interested in how this environment and experience affects parents. As you know, parents of very preterm or very low birth weight infants find themselves in a foreign environment and often worry about their infant's outcomes.

Following is a list of experiences that parents have reported as stressful when their baby was in the NICU. We would like to know your view of how stressful each of these experiences are for parents. **By stressful, we mean that the experience caused parents to feel anxious, upset, or tense.**

Below is a list of various **SIGHTS AND SOUNDS** commonly experienced in an NICU. In your opinion and from past experience working with parents, how stressful are these **SIGHTS AND SOUNDS** for parents in the NICU?

	Not applicable	Not at all stressful	A little stressful	Moderately stressful	Very stressful	Extremely stressful
The presence of monitors and equipment	8	1	2	3	4	5
The constant noises of monitors and equipment	8	1	2	3	4	5
The sudden noises of monitor alarms	8	1	2	3	4	5
The other sick babies in the room	8	1	2	3	4	5
The large number of people working in the unit	8	1	2	3	4	5

¹⁰ As adapted for NICU staff to complete.

Below is a list of items that might describe the way a **BABY LOOKS AND BEHAVES** while in the NICU as well as some of the **TREATMENTS** that parents have seen done to the baby.

In your opinion, how stressful is the infant's appearance for parents in the NICU?

	Not applicable	Not at all stressful	A little stressful	Moderately stressful	Very stressful	Extremely stressful
Tubes and equipment on or near baby	8	1	2	3	4	5
Bruises, cuts or incisions on baby	8	1	2	3	4	5
The unusual colour of baby (e.g. Looking pale or yellow jaundiced)	8	1	2	3	4	5
Baby's unusual or abnormal breathing patterns	8	1	2	3	4	5
Seeing baby suddenly change colour (e.g. Becoming pale or blue)	8	1	2	3	4	5
Seeing baby stop breathing	8	1	2	3	4	5
The small size of baby	8	1	2	3	4	5
The wrinkled appearance of baby	8	1	2	3	4	5
Having a machine (respirator) breathe for baby	8	1	2	3	4	5
Seeing needles and tubes put in baby	8	1	2	3	4	5
Baby being fed by an intravenous line or tube	8	1	2	3	4	5
When baby seemed to be in pain	8	1	2	3	4	5
Baby crying for long periods	8	1	2	3	4	5
When baby looked afraid	8	1	2	3	4	5
When baby looked sad	8	1	2	3	4	5
The limp and weak appearance of baby	8	1	2	3	4	5
Jerky or restless movements of baby	8	1	2	3	4	5

Baby not being able to cry like other babies	8	1	2	3	4	5
Clapping on baby's chest for chest drainage	8	1	2	3	4	5

Another area of interest is about a parent's **RELATIONSHIP** with their baby and their **PARENTAL ROLE**. In your opinion, can you tell me how stressful you think the following situations or feelings might be for a parent?

	Not applicable	Not at all stressful	A little stressful	Moderately stressful	Very stressful	Extremely stressful
Being separated from baby	8	1	2	3	4	5
Not feeding baby themselves	8	1	2	3	4	5
Not being able to care for baby (e.g. Changing a nappy, bathing)	8	1	2	3	4	5
Not being able to hold baby when want to	8	1	2	3	4	5
Sometimes forgetting what baby looks like	8	1	2	3	4	5
Not being able to share baby with other family members	8	1	2	3	4	5
Feeling helpless and unable to protect baby from pain and painful procedures	8	1	2	3	4	5
Being afraid of touching or holding baby	8	1	2	3	4	5
Feeling staff are closer to baby than they are	8	1	2	3	4	5
Feeling helpless about how to help baby during this time	8	1	2	3	4	5

In your view, please indicate how stressful parents may find any of the following aspects of **STAFF BEHAVIOURS** and **COMMUNICATION**.

	Not applicable	Not at all stressful	A little stressful	Moderately stressful	Very stressful	Extremely stressful
Staff explaining things too fast	8	1	2	3	4	5
Staff using words I don't understand	8	1	2	3	4	5
Telling me different (conflicting) things about my baby's condition	8	1	2	3	4	5
Not telling me enough about tests and treatments being done to my baby	8	1	2	3	4	5
Not talking to me enough	8	1	2	3	4	5
Too many different people (doctors, nurses, others) talking to me	8	1	2	3	4	5
Difficulty in getting information or help when I visit or telephone the unit	8	1	2	3	4	5
Not feeling sure that I will be called about changes in my baby's condition	8	1	2	3	4	5
Staff looking worried about my baby	8	1	2	3	4	5
Staff acting as if they did not want parents around	8	1	2	3	4	5
Staff acting as if they did not understand my baby's behaviour or special needs	8	1	2	3	4	5
Using the same rating scale, indicate how stressful in general, the experience of having a baby hospitalized in the NICU is for parents.	8	1	2	3	4	5

APPENDIX J External Stressors Scale – Staff Perceptions¹¹

Below is a list of items that might describe what it is like for a parent organising their life to be with their baby while they are hospitalised in the NICU. In your view, how stressful would parents find these to be?

	Not applicable	Not at all stressful	A little stressful	Moderately stressful	Very stressful	Extremely stressful
Time						
Travelling to and from the NICU to be with baby	8	1	2	3	4	5
Planning my day to fit in with NICU visiting hours/routines	8	1	2	3	4	5
Fitting in everything else I need to do around the house/with my other children as well as spending time in the NICU	8	1	2	3	4	5
Childcare						
Organising childcare for my other children e.g. A babysitter, nanny, husband/partner, friend, family member	8	1	2	3	4	5
Trying to keep my other children entertained when I bring them to the NICU	8	1	2	3	4	5
Accessibility						
Finding a car park nearby	8	1	2	3	4	5
Organising my own food for when I am at the hospital	8	1	2	3	4	5
Money						
Paying for several hours of car parking each time I visit	8	1	2	3	4	5
My husband/partner having to take time off work to be in at the hospital	8	1	2	3	4	5
Paying petrol/bus/taxi fares to visit the NICU	8	1	2	3	4	5
Paying for the childcare of my other children	8	1	2	3	4	5
Having to spend money on cellphone calls to update friends and family while I'm in the NICU						

¹¹ As adapted for nursing staff to complete.