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**MĀORI WHĀNAU EXPERIENCES OF A NEONATAL  
INTENSIVE CARE UNIT: WAIKATO HOSPITAL**

**A thesis submitted in partial fulfilment of the requirements for the  
Degree of Master of Social Sciences in Psychology at the  
University of Waikato**

**Keri Thompson**

**University of Waikato  
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## ABSTRACT

This thesis topic emerged from my personal experience of having a premature baby in the Neonatal Intensive Care Unit (NICU) at Waikato hospital. My whānau and I felt like aliens; culturally inept, and totally alone during our time in the NICU. It was not until I spoke to other Māori mothers that I realised our stories were similar.

I sought to understand how other Māori whānau members made sense of their own experiences, how they coped/adjusted to the experience of having a premature baby in an NICU and at home, and the sources of support they utilised. This study did not seek to delineate parents' experiences but attempted to allow whānau members to share their stories and explore their experiences of having a premature or special-care baby in an NICU.

The event of childbirth and the placing of a natural event into a pathological illness model through necessity has repercussions for the ways in which women experience and make sense of the event. Knowing this, six whānau stories were collected comprising of four individual interviews with the mothers and two whānau hui (focus groups). My use of a narrative methodology and kaupapa Māori approach enabled all the participants the opportunity to share their stories on how they make sense of their own experiences without the frame of pathological illness.

The findings present each whānau story autonomously, to highlight the key events that occur once the birth of a premature/special-care infant is admitted into an NICU. The participants' narratives followed their transitions through an NICU and return home. The narrative analysis and discussion confirmed that this research had been successful in creating a space for the mothers and their whānau members to share their stories. The discussion combined their narratives to reveal that the effective coping strategies did not remove the sources of stress but rather lessened the impact of the stresses. In situations where sources of stress were unable to be removed or reduced, participants perceptions of ineffective coping translated into narratives of negative perceptions of the NICU, and birthing experience.

The importance of positive relationships within an NICU, and in particular, the role of the nurse as a key facilitator, highlighted that efficacious communication resulted in positive experiences for Māori whānau. Whānau support was identified as one of the most important coping strategies for mothers in the NICU. Those participants who were encouraged to maintain connections with whānau members reported more positive experiences overall.

Three levels of implications were identified in this research. Firstly, that the participants' narratives provided a range of coping strategies for future Māori parents and their whānau who enter an NICU. Secondly, there are implications for NICU policy, and best practice particularly when supporting Māori in an NICU environment. Lastly, the narratives provided meaningful insights that contribute to gaps in local, national, and international literature. Overall, I realised that just like me, these mothers, and other whānau members, constructed narratives that are meaningful accounts to be shared with others.

## ACKNOWLEDGMENTS

I am dedicating this thesis to my children Anaru and Ariana Adams and my granddaughter Hinemaia. Since the beginning of this research journey, my children have continued to inspire me to be the best mother and nana that I could be. This research has been a family affair and I am grateful for having a hugely supportive whānau that continue to love and support me in whatever ventures I choose to undertake.

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## **CHAPTER ONE: INTRODUCTION**

Imagine the joy of expecting a child; then envision yourself in a heated room surrounded by machines beeping, lights flashing, and medical staff dedicated to keeping your baby alive. Thirteen years ago my baby was born (24wks gestation) three months premature. His low birth weight (1 pound 6 ounces), chronic lung disease and traumatic arrival thrust our whānau into a whole new world. Our whānau went through a tumultuous and emotionally confusing experience while we were in the Neonatal Intensive Care Unit (NICU) at Waikato Hospital. We felt like aliens, culturally inept, and totally alone. It was not until I spoke to other Māori parents that I started to hear similar stories and experiences and I realised our whānau experiences were even more comparable.

There were many questions that arose for me, based on my personal and whānau experiences, that became the driving force behind this research. The factors that I chose to explore included: how other Māori whānau members make sense of their own experiences; how they cope/adjust to the experience of having a premature baby in an NICU and at home; and the sources of support they utilised. This study does not seek to delineate parents' experiences but attempts to allow whānau members to share their stories and explore their experiences of having a premature or special care baby in an NICU. Specific attention is given to the stories of Māori families of NICU graduates and how processes surrounding the construction and telling of these stories enable whānau to make sense of their experiences and move forward after being in the NICU.

### **Justification**

This thesis journey began in 2004 and has taken five years to complete. There were two major reasons that delayed the completion of this thesis. Firstly, during the completion of research, Family Care/Awhina Whānau closed their doors and the NICU at Waikato Hospital were no longer able to provide parent-to-parent support within the hospital. Secondly, my personal health and whānau required my attention. Therefore, my thesis includes a literature review and interviews that were completed in 2005.

This thesis is still warranted because past research has shown that the birth of an infant needing the specialised care of an NICU is a worldwide phenomenon. International research has shown that significant technological advances in the Neonatal Intensive Care field have reduced infant mortality and increased survival rates within developed countries (Davanzo, 2004; Doucette & Pinelli, 2004; Henry, 2004). However, locally, we now know more about the ways in which such services are tailored to meet the needs of indigenous groups, such as Māori, who are over-represented in the premature birth statistics (2004, p. 44). For example, Māori women continue to hold the highest pre-term birth rates in Aotearoa/New Zealand (Craig, Mantell, Ekeroma, Stewart, & Mitchell, 2004). Wepa (2004) suggests that we still need to strengthen how policies translate into practice.

This research brought to light the gaps that exist in available literature relating to Māori families of premature infants, which necessitated a wider-ranging search of international literature that included indigenous perspectives of NICU experiences. International indigenous literature highlights that irrespective of the marked improvements in the average indicators of health within western nations, indigenous and aboriginal women continue to be disadvantaged (Cass, 2004). They suffer poorer birth outcomes, and share a pattern of premature morbidity and mortality, including higher rates of low-birth weight infants (Cass, 2004; Laws & Sullivan, 2004; March of Dimes, 2005b; Wenman, Joffres, Tataryn, & the Edmonton Perinatal Infections Group, 2004). The New Zealand context was reviewed to provide a framework for understanding the current NICU environment that Māori experience.

### **Thesis contribution**

My research seeks to explore the ways in which theories of narrative might be significant in the study of childbearing. The event of childbirth and the process of women becoming mothers are significant events for individual women, their families and communities. Medicalisation of childbearing and the placing of a natural event into a pathological illness model have repercussions for the ways in which women experience and make sense of the event. The complex interweaving of public and lay narratives that surround this period of transition

can lead to bafflement and the eventual construction of personal counter narratives. The context in which narratives are managed is explored.

## **Thesis structure**

This thesis consists of five chapters. The current chapter reviews the relevant national and international literature in order to develop an understanding of the Waikato Hospital NICU, and the importance of whānau stories. Chapter two establishes the rationale for using a narrative methodology and describes the method employed for participant selection and data collection. Chapter three presents the participants' narratives as self-contained findings. The findings are presented in the present tense to allow for their state of being at the time of the interviews and/or whānau focus groups. Chapter four is an analysis and discussion of the findings. Emergent themes and similar experiences that are identified within the findings are discussed. Chapter five presents the conclusion and researcher reflections concludes the thesis with a discussion on how the findings relate to the wider literature.

## **Literature review**

### ***Introduction***

This study draws upon material from a nursing orientation and will discuss the NICU context and how the barriers and stresses in a highly medical oriented environment impact on parents' experiences. Formal support roles that are available and accessible for parents of an infant through the transition from hospital to home are investigated and include such sources as the Medical staff in the NICU. Informal support sources identified as family, friends, and peer support people were identified in the literature as a source of support that could identify with those who had experienced the same stressors because of their own experiences (Ireys, Chernoff, Stein, DeVet, & Silver, 2001; Purk, 2004; Talmi & Harmon, 2004).

Much of the literature focuses on the families experiences while dealing with the range of stresses in the NICU which is foreign and very stressful environment that is usually initially overwhelming for families (Franck, Cox, Allen, & Winter,

2005; Heermann, Wilson, & Wilhelm, 2005; Holditch-Davis & Miles, 2000). The stresses and barriers involved in the transitions that parents encounter as an infant progresses from admission to home are explored. Barriers to natural bonding due to the separation between infant and parent that can intensify anxieties and cause post traumatic stress (Golish & Powell, 2003; Heermann et al., 2005; Holditch-Davis, Bartlett, Blickman, & Miles, 2003; Tilokskulchai, Phatthanasiriwethin, Vichitsukon, & Serisathien, 2002) are explored (Davis, Edwards, & Mohay, 2003) and family (Jackson, Ternstedt, & Schollin, 2003). Thus, enabling the literature to identify the stresses and barriers associated with being a parent of an infant admission. Although there is a growing body of research that aims to address the stresses associated with the NICU, more research is needed in order to understand Māori experiences from a Māori perspective.

An area of focus within the literature is also on the practice of 'Kangaroo Care' (KC). Acknowledged as a common practice used within the NICU environment, KC is recognised for aiding the strengthening of the maternal bond and parental identity (Ludington- Hoe & Golant, 1993; Roller, 2005).

The sources of literature within this study stem from a predominantly nursing orientation since it was necessary to access and understand relevant sources of research pertaining to families in the NICU. While conducting this literature search the gaps that exist in available literature relating to Māori families of premature infants was brought to light, which necessitated a more wide-ranging search into international literature encompassing indigenous perspectives of an NICU experience.

### ***Ethnicity and infant premature birth rates***

Ethnicity and health are intrinsically linked and there has been worldwide recognition that ethnicity is a contributing factor to health inequalities (World Health Organisation, 2005b). In particular, the disparities in infant mortality bring to light the alarming realities of ethnicity being identified as a significant contributing factor to the rise in neonatal rates. Factors that contribute to, or influence, poorer birth outcomes include: inadequate nutrition, lack of access to

antenatal care, smoking, drinking alcohol, stress, obesity, maternity resources, and a mothers pre-existing health condition.

Indigenous women, globally suffer poorer birth outcomes signified by the higher rates of low-birth weight (lbw) in infants (Cass, 2004). Research by Shiono, Rauh, Park, Lederman and Zuskar (1997), and Alexander and Kogan (1998) reported that other contributing factors to poor birth outcomes were socio economic position, environmental and health circumstances impact severely on indigenous peoples. Common across both studies was the need to understand all factors impacting on indigenous women experiencing poorer health outcomes. Gathering such knowledge was seen as an essential step towards providing equitable and quality health care able to meet the heterogeneous needs within ethnic groups.

Unsurprisingly, underdeveloped countries such as Africa continue to be statistically significant in infant mortality low birth weight; with low birth weight recorded as a major determinant of neonatal mortality (World Health Organisation, 2005b). Indigenous women of ethnic minorities in developed countries also experience similar outcomes, for example, in Australia, babies born to indigenous women were more than twice as likely to be of low birth weight than those born to non-indigenous women (12.9% compared with 6%) (Laws & Sullivan, 2004). During 2001-2003, pre-term birth rates were highest for African-American infants (17.7%), followed by Native Americans (13.2%) and then Hispanics (11.6%). Furthermore, the latest March of Dimes special report (2005a) announced that the Hispanic population as a heterogeneous group, are the fastest growing in the United States of America and even with infant health improvements, rates for pre-term birth were projected to increase for Hispanic women.

Canadian Aboriginal women (First Nations and Métis women) had infants that are more likely to need neonatal specialised service because their babies were either

low birth weight or more than 4000g (macrosomia), or were born at less than 37 weeks<sup>1</sup> gestation (Wenman et al., 2004).

In the United States of America, one in eight babies arrived too early in 2003 (March of Dimes, 2005c). Prematurity low birth weight is recognised as the leading cause of infant death among black infants and the second leading cause of all infant deaths in the USA (March of Dimes, 2005c).

In New Zealand, the Ministry of Health (2002b) recognised ethnicity as a significant part of health inequalities, and that disappointingly marked differences continued in health status between Māori and non-Māori (Durie, 2001; Ministry of Health, 2002b). By 2004, the New Zealand Report on Maternity (Ministry of Health, 2004a) stated that overall, the numbers of low birth-weight babies had increased. The ramifications of the increased numbers are extremely significant for Māori (Midland Health, 1995; Ministry of Health, 2004a). During 1980-1994, Māori women held the highest preterm birth rates in Aotearoa, despite a 30% increase in preterm birth rates that occurred for European/non-Māori (Craig et al., 2004).

In 2001, Hamilton had a population of 121,000, with an ethnic distribution of the population including 78% NZ European, 19% Māori and 7% Asian (Hamilton City Council, 2003). In 2001, Hamilton City became involved in the Quality of Life report that provides a snapshot of life in urban New Zealand. Eight of the largest cities in New Zealand were involved in this project, these being Auckland, Christchurch, Dunedin, Hamilton, North Shore, Manukau, Waitakere, and Wellington. Within the period of 1997 to 1999, there were 4,915 low birth weight babies born in New Zealand; with Hamilton and Dunedin reporting higher rates than any other cities of low birth weight babies (Auckland City Council et al., 2003). With Māori having higher recorded fertility rates than non-Māori, increases in the rate of low birth weight babies are disproportionately related to Māori mothers. During 1988-1992, 9% of all Māori born in the Midland region alone were low birth weight compared to 6% of non-Māori infants born in the

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<sup>1</sup> A commonly accepted definition of a premature baby is one born at less than 37 weeks gestation.

Midland, and 8% of all Māori infants born in New Zealand (Midland Health, 1995).

Māori comprise of nearly 15 percent of the population, the 2001 Census of Population and Dwellings, reported that 526,281 New Zealanders were recorded their ethnicity as Māori (Statistics New Zealand, 2002). The Māori population is increasing; Māori children make up 25% of all children and is expected to increase to 37% by 2051 (Te Puni Kokiri, 2000). Given this, the number of Māori requiring specialised maternity services will increase (Mantell, Craig, Stewart, Ekeroma, & Mitchell, 2004; Ministry of Health, 2004a). Another disturbing factor that has been connected with neonatal statistics is child poverty. Child health statistics in New Zealand identifies that one in three children live in poverty (Wepa, 2004).

Here in the the Waikato, the Waikato District Health Board is one of the largest providers of health care in New Zealand, and is most populous district health board in the Midland health region<sup>2</sup>. The Waikato DHB region encompasses our base hospital (Waikato Hospital) in Hamilton, and our district hospitals at Thames, Tokoroa, Te Kuiti, Taumarunui, Te Awamutu and Morrinsville. The Waikato hospital is situated in the Health Waikato catchment area. With the Māori population in Hamilton predicted to grow at a rate of 24.8%, nearly three times the rate of the total Health Waikato population as well as rates greater than the national average (Health Waikato, 2001).

Research into ethnicity and maternity issues has focused primarily on establishing statistical trends, and in particular, differences across ethnic groups such as comparative studies that use non-indigenous groups as the norm from which to illustrate health dilemmas for indigenous peoples (Badr, Abdallah, & Mahmoud, 2005; March of Dimes, 2005a, 2005b, 2005c). Despite such, revelations of health disparities in Aotearoa have been useful tools to bring about strategies that aim to address the health inequities Māori endure (Ministry of Health, 2002b).

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<sup>2</sup> The Midland region is made up of five mid-North Island District Health Boards including Waikato, Lakes, Bay of Plenty, Tairāwhiti, and Taranaki.

### *Neonatal Intensive Care Units (NICU)*

The premature birth of a baby is an interruption in the natural progression of a full term pregnancy. A premature infant is defined as a baby born prior to the 37th week of gestation, commonly with a low birth weight. An infant born at least 2200g (5.5 pounds) is considered to be at a low birth weight; an infant of less than 1500g (3.5 pounds) is considered to be at very low birth weight, and is usually at least 8 weeks premature (O'Brien, Soliday, & Mcluskey- Fawcett, 1995).

There is substantial literature on the medical needs of such premature infants, the developmental issues they face, and the risks of mortality (Little & Goodman, 2003; Ministry of Health, 2004a; National Advisory Committee on Core Health and Disability Support Services, 2003; O'Brien et al., 1995; Tracey & Maroney, 1999). For instance, the premature infant of low birth weight is: at risk of dying during infancy; more susceptible to child illness; more likely to need intensive care for a longer period; and more likely to develop complications such as chronic lung disease; and more likely to need continual medical care after leaving the NICU (Ministry of Health, 2004a; National Advisory Committee on Core Health and Disability Support Services, 2003). Premature infants have many issues; the primary complications involve immature development of major organs, such as heart and lungs, which can impact on the infant's ability to adapt to an out of uterine environment (O'Brien et al., 1995). The acute needs of these babies have been responded to primarily through the development of hospital based NICUs.

There are many reasons associated with an infant's admittance into an NICU. In some cases these births are obvious, such as being premature, having a low birth weight, or in instances of multiple births (Bradford, 2000; MacArthur & Dezoete, 1992). The Neonatal Intensive Care Unit functions as a specialised medical care unit for premature or special care newborns, and in some settings is also known as a Special Care Babies Unit (SCBU) (Harrison & Kositsky, 1983; O'Brien et al., 1995).

There have been vast improvements in the medical field, with technological advances within the neonatal intensive care field reducing infant mortality and increasing survival rates (March of Dimes, 2005b; World Health Organisation,

2005b). The New Zealand maternity system maintains a regionalised system of perinatal and neonatal care. A tertiary hospital is located in each major city within their geographic region. The coordination of the care for high-risk pregnancies and critically ill infants is fully state funded (Cust, Darlow, & Donoghue, 2003). The Waikato hospital is one of the six regional facilities that maintain a Level 3 Neonatal unit:

*A Level 3 unit provides neonatal intensive care and high dependency care. This means that they have the facilities to care for extremely premature infants (from 24 weeks gestation) and sick babies requiring ventilation, intravenous feeding and other types of intensive care monitoring and treatment (Ministry of Health, 2004b, p. 1).*

The Waikato Hospital NICU team consists of staff working within a formal support model of care that provides essential specialised services.

### ***Formal support***

There is a plethora of literature advocating that neonatal nurses are a vital source of support for families in the NICU (Bartle, 2004; Davis, Edwards, & Mohay, 2003; Davis, Edwards, Mohay, & Wollin, 2003; Griffin, Wishba, & Kavanaugh, 1998; Holditch-Davis & Miles, 2000; Roller, 2005; Wepa, 2004). Alongside the formal NICU and affiliated hospital support services, families also utilise informal supports. Health care research on nurses have reported on the mothers' experiences so that the NICU could provide more appropriate services to meet the needs of the mothers (Ministry of Health, 2004b).

Worldwide, research has identified that the nurse plays a critical part for all involved in the NICU environment, being key facilitators of care and information. Understanding the mothers' experiences are seen as crucial to the further development of nursing practice in the NICU environment (Cho, Holditch-Davis, & Belyea, 2004; Davis, Edwards, & Mohay, 2003; Davis, Edwards, Mohay et al., 2003; Griffin et al., 1998; Holditch-Davis & Miles, 2000; Hurst, 2001; Tilokskulchai et al., 2002; Wepa, 2004; Wielenga, Smit, & Lex, 2006).

### ***Culturally safe practice***

NICU medical care and practice in Aotearoa is guided by policies based on the Ministry of Health national health strategy (Ministry of Health, 2004b). The

Ministry of Health's approach to addressing Māori Health, He Korowai Oranga (2002a) establishes the provisions of providing a culturally appropriate environment within the hospital, and guides cultural models that are developed to meet the needs of Māori within the NICU. A critical component of enhancing personal empowerment and promoting more effective practice and meaningful experiences for Māori is incorporating culturally appropriate delivery of support services.

Formal support in the NICU at Waikato Hospital comprises of neontologists, doctors, nurses, and a range of various specialists that are available for the physical needs of the infant. Allied support available for families in the NICU includes administrators, social workers, and spiritual support (chaplain). The affiliated services of community health nurses, Child Development Unit (CDU), and the Mothercraft unit are available for families after their transition home. An example of the type of support that the Mothercraft unit provides is a live-in residential supportive environment to help parents within the first year of an infant's life.

In 1990, the Kawa Whakaruruhau report (Ramsden, 1993) was published, which established the development of cultural safety practices within the nursing field, and has also guided cultural safe practice within the health field. Culturally safe practices encapsulate the principles of the Treaty of Waitangi (Durie, 1998), and have become a significant component of the Māori health strategy, and Nursing Council New Zealand guidelines.

Within Aotearoa cultural safety has strongly influenced the implementation of nursing education, practice, and service delivery to the point where the ideal working partnership being a family centred approach and baby friendly hospitals initiative (BFHI) that supports cultural safety and builds relationships with whānau.

### ***Informal support***

Parents within the NICU tend to seek emotional support from sources that they can identify with, such as their family members and friends. Alongside these

built-in support systems, there's a potentially valuable source of informal support from other NICU parents who can identify with the stressors of the environment because of their own experiences (Griffin et al., 1998).

### ***Support groups***

Support groups during times of illness and trauma have become quite widespread, and the establishment of these systems are generally related to the specific needs of the group (Purk, 2004). The basic concept of Parent-to-parent stems from the theory that parents gain experiential knowledge when dealing with issues arising from raising a child with a special need, and in turn, can provide personalized experiential expertise that has value to others in similar situations (Ireys et al., 2001; Purk, 2004; Talmi & Harmon, 2004).

Ireys and colleagues (2001) classified parents' support needs into three categories. Firstly, informational support in which a parent identifies and refers other parents to new services, or persons, and provides advice and practical tips on how to negotiate a service system. Secondly, is emotional support; which is when there is a sense that someone is available to listen to concerns, and wants to help people understand their experiences and feelings, and has an interest in their viewpoints. Thirdly, affirmation support refers to the verbal or nonverbal messages that enhance a parents' confidence so he or she can respond effectively to the demands of parenting a child with special needs.

Within the NICU environment parent support networks have evolved out of informal parent-to-parent support networks, involving "graduate" parents being available for parents who currently have preterm babies in the NICU (Talmi & Harmon, 2004).

Research has emerged that identifies the benefits of parent-to-parent support groups. These include a forum where parents are encouraged to discuss what they are thinking and feeling; creating informational sessions with graduate parents and/or invited speakers; a sense of camaraderie; and lowering anxiety for parents. Furthermore, Purk (2004) reported that being able to attend a group where you have a chance to meet others with similar issues and obtain information relating to

their situation was recommended by healthcare professionals, and those that attended viewed their participation as empowering.

Mothers who participated in a parents' buddy programme for mothers of very preterm infants in Canada found that mothers reported less stress, anxiety and depression than other mothers. A standout factor was with peer support, which was very effective for mothers who had a relatively low income and diverse ethnic background (Preyde & Ardal, 2003).

### *Not-for-profit organisations*

Within New Zealand there are a number of non-profit organisations that provide support for families once they leave the NICU, such as: La Leche League, Crippled Childrens Society (CCS), Parent to Parent, and the Multiple Births Association. One type of group created by parents of NICU graduate infants focuses on providing onsite informal support and taking a proactive role in providing appropriate and relevant support for their NICU community. Examples of such groups are, Parent Care (Maatua Tiaki) at National Women's Hospital in Auckland (Parent Care/ Matua Tiaki, 2005), and Family Care/Awhina Whānau that was in Hamilton at the Waikato Hospital.

Family Care/Awhina Whānau operated as a bicultural service that aims to provide emotional practical and educational support. A bicultural approach was adopted because the founding parents recognised two distinctive cultures (Māori and non-Māori) were represented in the NICU. This 'grass roots' organisation was established in 1996 by a group of parents, who identified a need in the Waikato to have resources available, and decided to provide support NICU parents in the Waikato. Family Care/Awhina Whānau provided knitted hats and booties free of charge, access to literature relevant for families in the NICU, and premature sized clothing at affordable prices. The organisation was driven by volunteers who were parents of NICU graduates. In 2006, Family Care/Awhina Whānau closed its doors. The rationale recieved from the Waikato hospital was that there was no longer space available for non clinical services.

As parents of NICU graduates they faced many challenges involved with taking home an NICU graduate, which is directly relevant and impacts on their ability to provide support for “new” parents. Since its inception, volunteer turnover rates have constantly been an issue for Waikato Hospital and have impacted on the level of services offered. This study was initiated within the context of Awhina Whānau, and Māori whānau within the NICU, hence all whānau members were graduates of the NICU at the Waikato hospital.

### **Admission and transitions in the NICU**

An infants’ admission into the NICU is unique to each family, with progression through the levels associated with the infants’ medical well-being. Delivering early can be a traumatic experience, particularly since most families are unprepared emotionally for such a delivery. Mothers have reported that the realisation their newborn infant is going to be whisked away to an NICU is frightening for them (the mother) and the family. Unsurprisingly, mothers also reported feeling unsupported during this transition (Franck et al., 2005; Griffin et al., 1998; Jackson et al., 2003). The flashing lights of the life saving technical equipment, heat from the incubators, and specialised language of the NICU staff creates a foreign and very stressful environment that can be initially overwhelming for families (Franck et al., 2005; Heermann et al., 2005; Holditch-Davis et al., 2003). At the same time the NICU can be an overwhelming experience for even the most prepared parent (Harrison & Kositsky, 1983; Madden, 2000).

There are some recognised approaches that lessen the initial trauma for parents. Pre-admission visits (where possible) enable the family to familiarise themselves with the NICU environment and transitions that will occur (Harrison & Kositsky, 1983; Madden, 2000). Providing mothers who are unable to visit the NICU with a picture and information about their infants’ courses of treatment has also been known to ease a mother’s anxieties associated with being separated from their infant (Griffin et al., 1998).

The level of stresses that complicate the mother’s ability to bond with her baby continues to heighten researchers’ interest in understanding the complex

interactions of the mother-infant dyad (Cho et al., 2004; Davis, Edwards, & Mohay, 2003; Hurst, 2001; Tilokskulchai et al., 2002). Consensus within studies advocate that neonatal nurses have a pivotal role in facilitating the early mother-infant relationship while the infant is hospitalised (Davis, Edwards, & Mohay, 2003).

Separation can make it difficult for a mother and baby, delaying bonding (Ludington- Hoe & Golant, 1993), which can be exacerbated when the parent has to commute because they live a distance from the hospital (Griffin et al., 1998). The model of care for parents and their babies as discussed by MOH (2004b) is progressively evolving into providing increased contact between parents and their babies to facilitate attachment between parents and babies. Separation can increase the psychological/emotional trauma experienced by both baby and mother (Franck et al., 2005) and adversely affects the breastfeeding process (Bartle, 2004).

Having a baby that you cannot touch, hold, feed or take care of, and not being able to assume the role as a parent because you have to relinquish control to the health professionals and medical equipment, is one of the greatest stresses involved with being in the NICU (Franck et al., 2005; Griffin et al., 1998). Further contributing to the bonding difficulties during this time was the perceived lack of parental control experienced by mothers, who revealed in Tilokskulchai et al. (2002), fear of hurting the child, so being unwilling to engage, thus waiting for the nurse's or other professional's permission to touch or interact with their babies. Tilokskulchai et al. (2002) noted that a large proportion of mothers would wait until they were told by the researchers that they could touch their child and could do so without waiting for permission. The families within the NICU's recognise the power and control that medical personnel have over their environment. For instance, parents within a study by Hurst (2001) displayed an acute awareness of the power differentials that existed in their interactions with neonatal personnel and the mothers' narratives reflected their experiences as they watched vigilantly over their infant.

*Most mothers indicated that being perceived positively by the nursery personnel, particularly nursing staff, was an insurance policy for your baby (Hurst, 2001, p. 44).*

These mothers preferred to be in a collaborative partnership with their health care providers. Parents are not visitors to the NICU, and the feeling of powerlessness and wanting good working relationships with staff are issues mentioned within the literature. Research by Heermann et al. (2005) used a continuum to illustrate how mothers' experiences progress from them feeling like outsiders within the NICU environment, to being engaged parents as they became more comfortable in their environment. As their babies' condition improved, mothers were more likely to "claim" the babies as their own, illustrating that engaging in a partnering relationship required the active participation of nurses. It has been widely documented that although parents start off being passive receivers of information, they become active seekers. Interventions to maximise parents' willingness to learn is an important part of creating a positive and affective NICU environment (Hummel, 2003).

Currently mothers with infants in the NICU at Waikato hospital are required to stay in rooms on the postnatal wards or in accommodation nearby. The model of care for parents and their babies as discussed by MOH (2004b) is progressively evolving into providing increased contact between parents and their babies to facilitate attachment between parents and babies. Presently, strategies to increase mother infant contact include; kangaroo care; promoting breastfeeding, and rooming in with their infant prior to going home. Such parenting strategies are discussed below.

### ***Kangaroo care***

Kangaroo Care (KC) began in 1983 and is now an accepted practice within NICU units worldwide. An approach that has revolutionized the care of premature babies, KC focuses on facilitating mother and infant attachment. Kangaroo Care was named as such because it resembles the way in which marsupials care for their young, and is when the premature infant is placed on the parent's (mother or father) chest in an upright position to allow for skin-to-skin contact (Ludington-

Hoe & Golant, 1993; Roller, 2005). The criterion for using such care is dependent on many factors, such as weight or medical stability. Some of the benefits include stable infant heart, more rapid weight gain and increased bonding for parent and baby. The benefits of the synergistic interaction of skin to skin contact with an infant extend beyond the essential physical gains, providing an important means of developing and strengthening maternal identity and their infants patterns and preferences.

*Mothers providing KC become familiar with their babies' breathing patterns, they learn which sleep position their babies prefer, and they begin to get to know themselves as mothers. KC facilitates maternal-infant acquaintance and initiates the development of maternal identity (Roller, 2005, p. 216).*

KC is an accepted practice utilised in the Waikato hospital, and is considered to be a unique shared experience between the parent and infant.

### **Breastfeeding a neonate**

Directly after a low birth weight delivery mothers need to establish milk supply through artificial means, such as breast pumps as the babies, due to immaturity or sickness, are weak and have an ineffective suck reflex (Callen & Pinelli, 2004). Another significant barrier is the inability to maintain milk supply due to NICU related stress factors (Callen & Pinelli, 2004). However, even when mothers are faced with adversities and barriers, there are many ways that formal and informal support personnel can promote and support breastfeeding (Davanzo, 2004).

Beyond the already noted nutritional and medicinal value benefits to breastfeeding an infant in the NICU (Callen & Pinelli, 2004; Davanzo, 2004) are the social contributions this has to maternal bonding.

The World Health Organisation (WHO) and UNICEF promote a 'baby friendly hospital initiative' (BFHI) that encourages and supports the promotion of breastfeeding (UNICEF, 2005; World Health Organisation, 2005a). Although some studies have found that mothers have generally decided during their pregnancy whether or not they will breastfeed (Jaeger, Lawson, & Filteau, 1997), the stressful nature of the NICU, and the anxiety related to the infant's condition, mother and infant separation, delaying of milk expression or breast-feeding, can

make it difficult for mothers to initiate the process, and although these stressors cannot be removed, their feelings adversely affect their ability to breastfeed (Bartle, 2004; Jaeger et al., 1997; Spangler, 1995). A significant finding by Latto (2004) stated that steps needed to be taken to provide a truly holistic environment including listening and addressing mothers concerns so that expressing breast milk for their babies is supported and encouraged. Here in Aotearoa/New Zealand, the way that the BFHI is applied within the NICU can create for positive experiences of expressing milk and breastfeeding (Bartle, 2004).

### ***Rooming in***

Reducing the stresses of the NICU environment by changing the environment can improve short and long term outcomes for the infant and the families (McGrath, 2005). Increased provisions for keeping mothers and premature babies together include transforming neonatal units to include more areas that are family friendly (UNICEF, 2005; World Health Organisation, 2005a). In England, the High Wycombe Hospitals put into place a 'rooming in' policy and created an environment with a family-centred care approach, so that mothers and babies can stay together if they choose (UNICEF, 2005). A similar situation occurs at the Tallinn Children's hospital in Estonia in Northern Europe, where the basis of care is derived from three guiding principles of; 24 hour care of the neonate by the mother involves minimal use of technology, and minimal contact between the baby and medical staff (UNICEF, 2005). Their attempt to have staff use minimal use of technology and contact with the baby is so that the mother-infant attachment is allowed to form naturally without an overt amount of technological and medical interference. Here in Aotearoa, a shift is starting to occur that will see the Waikato hospital NICU redesigned according to the Ministry of Health's recommendations to improve neonatal care (Ministry of Health, 2004b).

### ***Transition to home***

The transition from the NICU to home can be plagued with difficulties that are very different to that of a "normal" delivery and homecoming. Mothers often do not feel prepared to take on the responsibility for their infants after discharge from an NICU (Holditch-Davis et al., 2003; Hummel, 2003; O'Brien et al., 1995). Some of the difficulties experienced by women included: lack of confidence;

needing and receiving support; developing confidence; feeling guilty; and experiencing smallness measuring (Sankey & Brennan, 2001). Hummel (2003) reported the majority of mothers in their study of neonatal staff, in particular, nurses, as key facilitators of providing the information necessary for a smooth transition from hospital to home, assist parents to become confident in the transitional period and directly impacted on whether a parent felt well supported (Hummel, 2003).

However, the mothers who needed more information and did not receive it were more anxious and less confident in caring for their infant. May and Hu (2000) compared mothers of normal birth weight babies with mothers of low birth weight (LBW), and found that in both groups, mothers desired help from a variety of mostly non-professional sources, for everyday concerns regarding their infant. Where mothers of LBW infants spend an extended time with nurses prior to going home, such contact with NICU nurses affords them with a prime opportunity to strengthen the mother's confidence in caring for their infant. Through providing information, nurses were promoted as the facilitators of quality parenting skills that could assist parents in their transition to home. Hummel (2003) also believed that positive parenting and home environment were crucial factors in maximising favourable outcomes for LBW infants.

Henry (2004) was the first NZ study that looked specifically at Māori families who were caring for a technology dependent infant after being in an NICU in Auckland. This study differed because it highlighted cultural support as an invaluable component to enhancing the facilitation of care for Māori families. Four significant issues were raised within this study and these included being heard; negotiating partnerships; transition points; and family/whānau health. These four points within the study emphasised the need for culturally responsive services that are inclusive and empowering for the families needs.

### ***Stress and the NICU***

In reviewing the literature, researchers have tended to focus on stressors such as grief, fear, anxiety, guilt, depression, feelings of inadequacy, and postpartum depression brought on by the stresses in the NICU (Davis, Edwards, & Mohay,

2003; Heermann et al., 2005). Nurses are the main source of information for parents because of the ongoing interactions that they have with the parents of neonates. It has been acknowledged that when nurses are responsive in their efforts to help mothers cope more effectively during their infant's hospitalisation by providing information, and creating a more effective environment (Griffin et al., 1998; Tilokskulchai et al., 2002), the relationship promotes positive outcomes in the home (Davis, Edwards, & Mohay, 2003).

Where the loss of a full-term pregnancy and loss of a normal birthing experience for a mother can present a 'joy-grief contradiction', Golish & Powell (2003) advocate the term 'ambiguous loss' for parents in the NICU. According to Golish and Powell (2003), a significant loss of something that is not tangible - that is, an expected experience (normal delivery and full term pregnancy), is a loss that is maintained while being in the NICU. Further to this, the NICU experience can feel like an emotional roller coaster ride.

The diverse emotions associated with mothers during times of crisis has produced a large body of mental health research that explores the mental health of mothers during crisis (Caplan, Mason, & Kaplan, 2000), and understanding post-traumatic stress which results from having an infant in the NICU (Holditch-Davis et al., 2003). A clinical study in Germany by Jotzo and Poet (2005) explored whether an intervention could reduce the severity of symptomatic response to the traumatic impact of a premature birth. Jotzo and Poet (2005) found that mothers in a structured psychological programme that included counseling, relaxation and additional support, experienced significantly less trauma impact and showed lower levels of symptomatic response to the traumatic stressor of "premature birth" at hospital discharge. Such research highlights that when families are able to have their questions answered, they feel supported, informed, and valued and are more likely to cope better with trauma.

A recent Christchurch study compared the psychiatric history, pregnancy related factors, couple relationship, and social supports of the mothers and fathers of infants admitted to an NICU, with those not admitted to an NICU. The study found that generally, parents do adapt to the NICU and it was decided that any

added interventions would be unnecessary because of the ‘parent friendly’ atmosphere in the NICU. Having said that, there was however a small but significant group of mothers and fathers who experienced significant distress, and would benefit from an intervention (Carter, Mulder, Bartram, & Darlow, 2005).

### ***Efficacious communication***

The stressful nature of the NICU, with multiple health care professionals involved in their infant’s care, does not generate a conducive environment for parents to be able to fully understand all the information being communicated. Additionally, cultural differences due to communication barriers through language, can intensify the feelings of isolation for the families, which can lead to the parents perceiving their infant’s caregiver to be displaying professional indifference (Talmi & Harmon, 2004). Trust as stated by Henry (2004) is based on the assumption by parents that health professionals will interact with families in a positive manner.

Efficacious communication is a phrase that epitomises the ideal outcomes that are achieved when verbal and non-verbal communication achieves positive results, and in this instance, for the parent. Nurses take on the momentous responsibility of being the key communicators of information and primary facilitators of care for the infant during their hospitalisation (Bartle, 2004; Davis, Edwards, Mohay et al., 2003; Griffin et al., 1998; Holditch-Davis & Miles, 2000; Roller, 2005; Wepa, 2004). Furthermore, nurses are generally the ones conveying critical information. Research has advocated that parents want open and honest communication (Griffin et al., 1998), communicated in a dignified way that respects the vulnerability of the whānau (McGrath, 2005).

### ***Family experience***

Nursing research by Holditch-Davis and Miles (2000) captures mothers’ experiences through the voices of nurse interventions that has helped identify and understand the difficulties mothers cope with in an NICU. Holditch-Davis and Miles (2000) found that one of the most rewarding aspects for nurses was helping mothers cope with the stresses in the NICU. For their study, Holditch-Davis and Miles (2000) interviewed 31 mothers (Caucasian, African American, and one

Asian) of preterm infants that were involved in a nursing support intervention. The primary aim was to let the mothers tell their stories and to determine if their experiences fit the Preterm Parental Distress Model (PPDM). The PPDM suggests that there are six sources of stress: pre-existing and concurrent personal and family factors; prenatal and perinatal experiences; infant illness treatments and appearance; concerns about outcomes; loss of parental role; and health care providers. Within this study, the use of quotes were extensive and allowed for participant stories to be told. The findings verified that the Preterm Parental Distress Model satisfactorily captured the sources of stress and support experienced by mothers. Furthermore, the study concluded that the neonatal nurses have a major role in reducing distress, maintaining ongoing communication, and providing competent care.

Research by Wielenga, Smit, and Lex (2006) sought to measure parental satisfaction within a changing environment and culture of an Amsterdam NICU. The NICU there had introduced a family centred approach, where the central role of the parent in the care of the infant was paramount to fostering the parent as a competent caregiver. Wielenga (2006) found that there were many obstacles within the NICU that mothers and their families needed to deal with before taking their baby home; particularly when going home was revealed to be as potentially daunting as the day the family were first admitted into the NICU.

Family experiences have been typically based on the mothers' responses and family representatives, and thus based on the mothers' interpretation of the family status. Fathers' experiences and views are generally under-represented within the literature and other family members are not included at all (Doucette & Pinelli, 2004). Research specifically looking to understand how families adjust over time by examining their coping strategies and resources was conducted by Doucette and Pinelli (2004), who found that 18 to 24 months after the NICU experience, mothers' and fathers' perceptions of family adjustment differed significantly.

Studies have also looked at the differing levels of support that mothers and fathers receive, suggesting that attention to increasing support for the absent parent, such as those experienced by mothers within the infants initial hospitalisation and some

fathers once the mother establishes regular visitation (Griffin et al., 1998). Jackson, Ternstedt and Schollin (2003) took an interesting stance when they compared the experiences of fathers and mothers' aiming to find out how mothers and fathers of preterm infants described their experiences of parenthood during the infant's first 18 months of life. Their research involved a longitudinal study that postulated mothers were to have more responsibility and control over their infants care, whereas fathers were to leave the care to staff while focusing on balancing work and family life.

There are also complex contextual factors that can create difficulties that impact on a families experience in the NICU, such as: financial burden; being able to travel to the hospital; responsibilities to other siblings; status of marital relationship; and family history (Talmi & Harmon, 2004).

While there continues to be a steady increase in support literature available for families in need of guidance, these tend to come from a medical perspective. Easy to read books that explain the medical equipment (Bradford, 2000), enlighten parents on the realities of the NICU, and provide practical guidance on matters, such as breastfeeding (Gotsch, 1999; Spangler, 1995), and how to care for your baby (Klein & Ganon, 1998), are just some examples of the resources published. Another avenue of support literature is the World Wide Web (internet). With access to blogs and other chat groups, I believe that the connection and understanding a parent feels when they hear or read another parent's story, continues to be the most powerful source of confirmation that they are not alone, and that someone else understands their situation.

An emergence in the narrative literature available is the first account experiences of parents as a means of sharing their stories of being families of NICU graduates. Many examples exist via cyberspace and these are accessible via websites. Some parents have used their discussions to advance political stances. Davis and Stein (2001) considered their NICU experience to be an emotional journey.

The NICU environment is a stressful environment, and through narratives, parents have been given a voice. When a parent shares their story, they are provided with

a means to make sense of their own experience and to move forward after being in the NICU. For instance, Montavalo and Vilo (1999) summarised frustrations and feelings of parents:

*No parent should have to come into a high-risk delivery as uninformed as we were. No parents should have to stand by helplessly as their baby is treated against their wishes. Parents must have the right to be truly informed consent even if there are no choices to be made, simply because it is the only ethical thing to do. (p. 527)*

Not only does the previous statement allow them to share their dissatisfaction, it also empowers their experiences of the NICU, enabling them to inform others while providing a personalised and constructive way of letting others know what would have been better. Their narrative also provided recommendations to neonatal staff on what they could do to support families in the unit so that others did not experience the same traumas. All the stories available to other families were unique, but also had commonalities that could be quite healing for others. However, a cultural perspective has yet to emerge and in particular this study seeks to explore, through narratives, the Māori experience of an NICU.

### ***Māori health and whānau***

Prior to colonisation, use of traditional Māori healing practices was commonplace with some practices still available within whānau, hapū and iwi today. Māori had therapeutic strategies and sociocultural mechanisms for dealing with physical, emotional, and spiritual stresses (Ritchie, 1976). With the onset of colonisation, the shift into a westernised model of care and the long-term impacts of colonisation Māori perceptions of hospitals are negative (Ramsden, 1993). Hospitals are seen as places where people die and where medical interventions are founded on negative experiences (Ramsden, 1993). Furthermore, research on Māori has involved approaches that have highlighted negative statistics within the health sector without effecting positive change (Jahnke & Taiapa, 2003).

He Korowai Oranga Whānau Ora is the overarching aim for Māori health, described as Māori families supported to achieve their maximum health and wellbeing. With whānau acknowledged as the foundation of Māori society, He Korowai Oranga recognises the interdependence of people; that health and

wellbeing are influenced and affected by the collective as well as the individual, and the importance of working with people within their social contexts. He Korowai Oranga supports Māori models of wellness and approaches to health and disability that support Māori aspirations for greater participation and control over health outcomes. This document goes further than acknowledging the interdependence and intergenerational nature of whānau and communities, but also outlines directions to assist the public sector to apply this understanding in practice.

Currently, Māori participation in health and the realisation that one size does not fit all has brought about more meaningful understandings of Māori health in Aotearoa and the development of Māori health approaches (Cunningham & Durie, 2005; Durie, 1994). Understanding the cultural factors that influence Māori health has seen the development of cultural safety, cultural congruent care, and accessibility to culturally appropriate practitioners and services (Cunningham & Durie, 2005; Ramsden, 1993).

Several Māori models provide better understanding for Māori health from holistic Māori worldviews. One model frequently used within medical institutions to understand dimensions of optimal health and wellbeing is the Whare Tapa Wha published by Mason Durie (1998). Te Whare Tapa Wha involves maintaining a balance within the four dimensions of (1) Wairua (spirituality), (2) Hinengaro (mental), (3) Tinana (physical), and (4) whānau (family) dimensions (Durie, 1998). One of the most recent strategies for Māori health that has been implemented to address the area of improving Māori health and reducing health inequalities is He Korowai Oranga (Ministry of Health, 2002a).

Addressing and challenging the negative outcomes for Māori, demands developing and delivering prenatal and postnatal services that ensure a strong healthy start for new whānau members. Colin Mantell and colleagues (2004) recommended that reducing the disparities for Māori needed to focus on social and policy interventions that address the wider health and social needs of Māori whānau.

Whānau is integral to any Māori health initiative. The term whānau has accumulated a range of meanings over the years that are differentiated by context (Durie, 2001; Hirini, 1997; Metge, 1995). Commonly used as the English translation of a ‘nuclear family’, within a Māori context, whānau is primarily associated with whakapapa (genealogical ties), involving connections of close relatives as well as those connected more distantly through common ancestral links (Metge, 1995). The term whānau endorsed the notion of an extended family, and is still recognised as a basic social structure within Māori society (Ministry of Social Development, 2004).

Due to the diversity of Māori connections, the modern whānau has evolved beyond whakapapa links. The whānau concept has grown to recognise the diverse and complex interactions and relationships that occur within and between kinship groups (Durie, 2001; Hirini, 1997; Metge, 1995). Metge (1995) demystifies the many meanings of whānau, and provides a comprehensive breakdown of how the term whānau has evolved to include social kinship groups that are not necessarily connected by whakapapa. Durie (2001) discusses other forms of whānau, such as: kaupapa whānau (whānau comrades); whānau as a model for interaction; whānau as neighbours; whānau as households; and the virtual whānau. Irrespective of the composition of a whānau, literature acknowledges that whānau are the preferred support system for Māori (Durie, 2001).

Within my thesis I will be using the term whānau in its broadest sense; that is, my research participants include graduate parent/s of an NICU experience and their whānau members, irrespective of their types of connections. The birth of a Māori baby is a whānau experience and there has been a very little research surrounding Māori women childbirth experiences and practices (Ellis, 1998; Rimene, Hassan, & Broughton, 1998).

## **Chapter summary**

From what we know within the literature, future medical advancements in the neonatal field will continue to increase the survival rates of sick infants. However, the disparities in infant mortality experienced by indigenous women worldwide reinforce the need to understand an indigenous experience in the NICU. Within this context, Māori continue to be over represented in the neonatal

field. Informal support from friends, whānau, and other parent groups allows the families in the NICU to obtain the emotional reinforcement that they need to cope with their infants' confinement. Formal support from medical and allied NICU staff is an essential component of the services provided by the NICU. The complex environment stresses in the NICU has the potential to either create or ameliorate issues for families, such as anxiety and post traumatic stress, as well as infant and family bonding through the power and control dynamics between the family and health professionals. Withstanding these stresses through the utilisation of support systems, people, and services is crucial for the transition of the whānau from hospital to home. This research seeks to understand Māori whānau experience of the NICU.

The following chapter describes the methodological approach and procedure, including the recruitment process, ethical issues, the interview schedule, and analysis process.

## **CHAPTER TWO: METHODOLOGY**

This study explored Māori whānau experiences of having a premature or special care baby in the Neonatal Intensive Care Unit, at Waikato Hospital in Hamilton. The methodology used assisted the participants in sharing their experiences and provided a means of accessing their stories. Narratives were retrieved through individual interviews and whānau hui designed to allow participants to share their birthing stories; their coping strategies, support systems within the hospital environment, and the transition from hospital to home. This chapter describes the methodological approach, insider researcher perspective, research procedure (including the recruitment process), ethical issues, the interview schedule, and analysis process.

### **Qualitative approach**

A qualitative approach can provide research that is rich in its descriptive depth (Ashworth, 2003), allowing a researcher to uncover a diverse range of experiences. Moving away from a positivist research paradigm and using a design located within interpretivist social science (Neuman, 2000) enables the researcher to move beyond the view of a researcher as a passive and indifferent observer, and instead allowing the researcher to be reflexive in their views, experiences, and expectations within the research topic (Crotty, 1998; Etherington, 2004; Hodgetts et al., 2004).

When conducting research from an interpretivist perspective, the aim is to learn what is meaningful or relevant to the people being studied, or how individuals experience daily life and specific events. A researcher does this by getting to know a particular social setting and seeing it from the point of view of those within it (Neuman, 2000). The aim of this research was to learn about the lived experiences of a specific group of people who have experience of the NICU. I was concerned with developing an empathic understanding of feelings and experiences of participants, rather than testing laws of human behaviour (Neuman, 2000). The interpretive approach adopts a practical orientation to social research, the goal of which is to develop understandings of social life and how people construct meanings in natural settings (Neuman, 2000).

The setting of this research was one that I was familiar with, and so required me to be a reflexive researcher. As previously mentioned, researcher reflexivity relates to the researcher being aware that their own life experiences impact on the way they work and can have an effect on their research participants (Hodgetts et al., 2004). Since the nature of this research was potentially sensitive, due to the fact that I was collecting the personal thoughts and experiences of the participants, a narrative approach was more suited to exploring those experiences of having a premature infant at the NICU at Waikato. The narrative approach to data collection and analysis allowed the participants the scope needed to articulate their stories as social artefacts founded in their own meanings (Neuman, 2000).

### *Narratives*

Narratives are a common means of making sense of life events and linking these events into meaningful accounts that can be shared with others (Frank, 1995; Murray, 2000). They can be used to repair ruptures in the fabric of daily life or to respond to situations such as illness, or being presented with a premature baby. Storytelling enables people to share experiences and render events important, thus warranting social support and expressions of concern and caring from others (Bury, 2001; Jovchelovitch & Bauer, 2000). Myths, fairytales, novels, life experiences, and personal events are just a few examples of stories that have provided people or groups of people, with a means to communicate their own meaning of significant challenges in their life (Swatton & O'Callaghan, 1999; Te Awekotuku, 2003).

The construction of a story commonly includes sequencing events or experiences into a beginning, middle and end (Rappaport, 2000). Understanding those components of a narrative that occur out of such a sequence are just as significant to understanding the events/experiences (Jovchelovitch & Bauer, 2000). The construction of a personal narrative involves processes in which ascribing meanings are based on a person's experiences and/or events (Flick, 2001).

Interpersonal engagements also happen during the sharing of stories with researchers, and it provided with a way of understanding peoples' interpretations

of their own worlds and important life events (Flick, 2001; Murray, 2000; Murray, 2003). When two or more people are participating in a conversation, the interactions involved in their conversation are just as important because of the reactions that occur between the storyteller and the listener, with the narrative becoming a joint venture (Murray, 2000). As a result, narratives have become increasingly popular within social science research as a means of emancipating the participant/s constructions of their stories, experiences and knowledge of their lives (Bury, 2001; Hodgetts, Pullman, & Goto, 2003; Lapsley, Nikora, & Black, 2002; Murray, 2000).

The context of this research necessitated understanding illness narratives as participants' stories involved an invasive medical intervention, termed by Bury (1982) as a "major disruptive experience" that linked the body, self and society (Bury, 2001). Trauma or biomedical intervention, the array of literature based on illness accounts provides evidence that people need to tell their story (Murray, 2000). For example, the published accounts from Arthur Frank in *At the Will of the Body* (1991) storied his experience during illness (cancer and heart attack); and *The Wounded Storyteller* (1995) that presented a collection of personal accounts from those schooled in a 'pedagogy of suffering'. Frank (1995) argued that people with illness are more than victims of disease, they are wounded storytellers, and they tell stories to make sense of their suffering, so that they can find healing.

The illness narrative is based on the individuals' traumatic experience or adverse condition and the story that they construct is their way to re-examine, and modify their life so as to maintain a sense of identity (Bury, 2001; Lawton, 2003). Illness narratives are personal stories that place the storyteller in a position of authority about their body changes. Literature has also acknowledged that the illness narrative can also provide other benefits such as:

- A forum for understanding their world as they see it,
- A therapeutic way that empowers them; and,
- A means of informing and including others, who also have the same illness so that they are not alone (Frank, 1995; Lawton, 2003; Murray, 2000; Williams, 1984, 2000).

Patient stories are increasingly becoming of primary importance and not seen as secondary to that of the medical professional (Frank, 1995). When a patient reflects on their experiences with a person who is newly diagnosed with an illness, their narrative provides a reflexive view from a seasoned person who understands the long term effects of an illness (Williams, 1984, 2000). Williams (2000) found that to repair the rupture that had occurred between their body, self and society allows the person in the aftermath of a disruptive event to create a sense of coherence.

It is in this context that I set out to explore whānau experiences and stories of premature birth. For the purposes of this research, an experience was defined as being the personal account/reflection from a participant. The narratives that the participants shared were recollections of their experiences of having an infant that needed the specialised services of the NICU. During the narrative interviews participants were encouraged to tell their stories and share their experiences of significant events from their perspective (Jovchelovitch & Bauer, 2000).

## **Methods engaged**

The following sections review the procedures and techniques used for eliciting and analysing participant's stories.

### ***Insider-researcher experience***

Past experiences of the NICU context founded my approach to this research. My first-born child was a normal delivery and we had enjoyed the customary rights of passage that accompany this kind of experience. There were well-wisher cards, lots of visitors, and an easy transition to home life with a newborn baby. My second pregnancy was not comparable with the first birth experience, with my son being born prematurely, and us being admitted into the NICU. The disruption that occurred to my whānau as we were inducted into the NICU community was strongly influenced by our past experiences within another NICU when my aunt's premature baby died. The experiential knowledge that we had formed made us unwilling participants in the NICU, with our preconceptions of the hospital being

that the environment was hostile and a place of death. With the complications associated with being born premature, we had to spend a considerable amount of time in the NICU, paediatric wards, and the Waikato hospital. I firmly believe to this day, that my son's survival and later transition to home occurred because of the excellent medical care and continual support that we received from the hospital staff and community health support.

Alongside the formal support offered by the NICU, I also met other parents who shared the commonalities of being a member of this community. This exchange allowed me to develop an empathetic understanding with others, a shared bond that no parent who hadn't experienced the NICU could understand. In 1999, a group of parents of an NICU graduate formed the Family Care/Awhina Whānau organisation.

Family Care/Awhina Whānau is a small organisation that adopted a bicultural approach because as parents, we appreciated the importance of Māori working with Māori. The organisation had continued to provide essential access to resources and has miraculously survived despite limited volunteer support. While working as a support person, I realised that the literature available for parents was always constructed from a western perspective and this has precipitated the need to explore Māori experiences.

### ***Consultation***

The first stage of the recruitment process involved consultation with key stakeholders. Māori whānau, hapū, and iwi were the core focus of this research; hence a kaupapa Māori research approach was adopted. Consultation is vitally important to any research involving the community and even more so with a Māori community. Respecting the validity and legitimacy of the Māori language and culture while researching Māori should include Māori input and recognition of their own developmental aspirations (Smith, 1997; Tuhiwai-Smith, 1999). The purpose of consultation is to inform and consult with relevant communities, gain feedback on the proposed research, and to elicit support in undertaking this research in an ethically and culturally safe way (Health Research Council, 1998).

The key stakeholders that I consulted with were staff at all levels of the NICU; affiliated Waikato hospital staff such as the Mothercraft unit, the Child Development Centre, the Community Health department, and community agencies working in the area of supporting Māori families who have been in the NICU; such as Family Care/Awhina Whānau, McKenzie Centre, CCS (Crippled Children's Society), Parents Centre, and Parent to Parent. Key Māori organisations in the consultation process included my own whānau, iwi and hapū networks within the Tainui rohe, such as Te Hauora o Ngati Haua, Māori Women's Welfare League (MWWL), Te Runanga o Kirikiriroa Trust Inc, and a group of Māori midwives. These relationships have occurred through years of involvement in supporting families of premature babies in the Waikato area.

Ethical consent was sought and received from the Psychology Department at the University of Waikato, and research information sheets and consent forms<sup>3</sup> were provided to any people interested in becoming potential participants.

### ***Participants***

To participate in the research, the criteria included being of Māori descent and being experienced the specialised services of the NICU at the Waikato Hospital. Potential participants were recruited through the snowballing technique (Fife-Schaw, 2000). This technique was suitable because I was able to use my own networks. Publicising my topic and searching for participants through these networks provided access to a wide range of potential participants, and once a person from my networks had identified a whānau member, they were initially asked to consider participating; given an information sheet (see Appendix 1) and then referred to me. I made initial contact with potential participants by way of phone, in person, or email so that we could discuss the research and answer any questions that they might have.

Whānau members were invited to participate in the whānau hui by the parent. The participants were diverse in age, background, and whānau circumstances.

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<sup>3</sup> Copies of the relevant documents are attached in Appendix 1, 2 and 3

There were a total of eight participants, four individual interviews with mothers and two whānau hui with a total of four whānau members involved. The ages of the mothers ranged from 17 years to 37 years of age, and participants involved in whānau hui were: two nanas, a dad, and a younger sister. For some participants', it was their first child and some had other children with previous birthing experiences, and all had very different types of birthing experiences that contributed to a robust collection of stories. Participants had various tribal affiliations, including Tainui, Raukawa, Ngati Kirihika, Ngati Haua, Ngati Te Oro Ngati Maniapoto, Tuwharetoa, Tuhoe, Nga Puhi, and Ngati Hako. Their whānau circumstances included single parent families and defacto relationships.

### *Individual interviews*

There were two phases to the collection of data; individual interviews with the mums and whānau hui with the other whānau members. The semi structured interview method was used for data collection. This is a common method used in narrative research, as it allows for the interview to be relatively relaxed, and included open-ended questions that elicited parental self report. I facilitated the interview using open-ended questions that were aimed at not being restrictive. This allowed questions to evolve as a result of the direction that the discussion took during the interview. This method of data collection provided a means of accessing the participants' narratives as they reconstructed their experiences.

### *Interview settings*

Participants were asked to choose a time and place convenient for them. Every attempt was made to allow for the interview environment to be comfortable, free from distractions, and private. For this reason, a variety of settings were used for the interviews. For example, a parent with an infant in the hospital felt more comfortable having the interview onsite, so a quiet space within the NICU at the Waikato hospital was used for the interview. Accessing an interview space at the Waikato hospital was part of the consultation process for this research. Two different interviews with mums that had babies who had left the NICU preferred to have the interviews in their homes, and two mums working for a Māori iwi health organisation felt comfortable having their interviews at their workplace.

It was essential for me to build a rapport based on trust and safety for the participants, as the research had the potential to be sensitive in nature. Within this research a kaupapa Māori research approach was adopted (Smith, 1997; Tuhiwai-Smith, 1999). Utilising a Kaupapa Māori approach supported the facilitation of culturally appropriate processes when engaging with Māori (Tuhiwai-Smith, 1999). The greatest strength of utilising this approach is that Māori have been able to define the processes used in this project, and the project has been conducted in a culturally appropriate manner, with eventual outcomes specifically targeting Māori whānau/hapū/iwi communities in Hamilton and the Waikato. In particular, Māori cultural practices were upheld when necessary. These included the use of *kanohi ki te kanohi* (face to face) engagement during all phases of the research. The use of *karakia* (prayer), *mihi* (speech) and *whakawhanaungatanga* (introductions of oneself) were practices utilised when necessary. A Kaupapa Māori approach acknowledges the *taha tinana* (physical), *taha wairua* (spiritual), *taha hinengaro* (mental), and *taha whānau* (extended family) (Durie, 2001). The importance of tikanga practices as a means of ensuring that Māori participants are not misunderstood or taken for granted (Smith, 1997; Tuhiwai-Smith, 1999) and to help with their introduction into the literature so they can contribute to the body of knowledge about family experiences that already exists within the research field.

The process of whanaungatanga between the researcher and participant was done in an informal way. A mix of Māori and English language was utilised and accepted as a suitable medium within this process. The participant's rights were outlined (See Appendix 1). Four question areas were developed in order to ensure that their stories were sequenced in a way that allowed for the discussion to flow easily, and provided a way in which the conversation would allow the interview participant to feel relaxed. As the researcher, I facilitated the open ended questions in a way that acknowledged the diversity of the participant experience, and was considerate of the personal nature of their stories without straying from the uniformity of the process of interviewing (See Appendix 3).

The initial question of "Tell me about when you got pregnant" allowed each participant to reflect, providing them with an opportunity to journey to that

moment in time and start their story from their personal and familiar starting point. The interview then moved into the research specific questions such as: How did you adjust to the NICU after your baby was born; who were your support people while you were in the NICU; what support services (if any) did you access while you were in the NICU; and how did you adjust to being at home, including the transition, and the support people or organisations that may have helped.

Each interview with the parent caregiver was audio-taped and took approximately one hour. Food and drink was made available, and petrol vouchers were given to participants who had to travel to be at the interview. A koha as a token of appreciation was given to each participant.

### ***Whānau hui***

Whānau, as previously discussed, are those members' chosen by the parent/s of an NICU experience. Whānau hui are similar to focus groups as a method of data collection, as the data collection process can be used to explore the shared and negotiated narratives that can occur within a whānau dialogue. The whānau hui provided a means of creating an environment in which the participants accounts stimulated others to tell their own stories, and develop a communal story of shared experiences (Wilkinson, 2003). Interactive data can enhance disclosure within a whānau hui, empower the participants' control, and improve access to participants language and meanings (Wilkinson, 1998) and is more appropriate for exploring sensitive topics as the group situation can enhance personal disclosure (Wilkinson, 2003).

Participants from the individual interviews approached whānau members that they wanted to include in a whānau hui. Information sheets (see Appendix 1 and 2) were provided for those whānau members interested in sharing their story within a group setting. While participants were given the option to choose a desirable interview setting, in all cases whānau opted to have the hui in their homes. Each whānau hui was facilitated by the researcher. Participants were told their rights and given the option to use their real names, or for anonymity, by using pseudonyms (false name). The whananaungatanga process provided a way for the

researcher and family members to connect and answer any questions that were necessary prior to the commencement of the hui. For the most part, the questions that were used in the individual interviews were also used in the whānau hui to facilitate discussion. One of the planned whānau hui did not occur due to the participants' personal circumstances. However, all whānau members felt that they wanted to participate in the study so individual interviews and whānau hui were organised to gather their dialogue.

### ***Narrative analysis***

All the interviews and whānau hui were tape-recorded and transcribed in full. After each transcript was read, notes were taken to identify the initial issues for each participant. Each transcript contained a personal story and analysis took place through the reading of each story, going back and analysing each transcript and extracting the information relevant to the questions.

The stories were presented in a format that enabled each whānau narrative the ability to inform the other narratives. The first narrative represented a current experience and led into the past experiences that spanned over a period of five years to be shared. Their experiences captured their significant moments in time and this allowed each story to be analysed separately while acknowledging that each story informed the other.

The analysis of the data collected from whānau hui (shared dialogue) identifying the initial issues also involved recognising the interactive elements that occurred between the participants. The responses to the questions were collated so as to combine their stories and produce a composite story that reflects their general processes, experiences and concerns for all the whānau hui participants.

Murray (2000) proposed that there are four levels of analysis, and these are personal, interpersonal, positional, and societal, with the challenge being to integrate these levels so that emancipatory narratives emerge. These levels of analysis were utilised as a template for analysing participant's stories. The analysis provided a means of accessing and understanding peoples' knowledge and experiences in the constructed stories. It documented the emergence of

themes within shared dialogue and the necessity of a researcher being reflexive (Etherington, 2004).

The personal analysis of each participant's story cultural context, background and birthing experience adds value to the complexity and depth of a lived experience. The personal analysis (Murray, 2000) treats the autobiographical story as the social reality of the individual (Bruner, 1991; Frank, 1995; Riessman, 1993). This research sought to identify how participants adjusted to the NICU, who supported them, and how they adjusted once they went home. For this reason, specific and significant events or experiences, situated in the personal narratives, were broken down into those themes.

The interpersonal level of analysis (Murray, 2000) recognises the shared dialogue and relationship of reciprocity that happens between the people involved in an evolving conversation of an interview (in this case both the individual interviews and the whānau hui). While the positional level of analysis extends on the interpersonal level to include any differences in social position of the characters and researcher, on an ideological level, analysis acknowledges the broader sociocultural assumptions that exist and permeate our society. The impact of social representations within societies' everyday thoughts and beliefs reinforces that people do not exist and experience life in a void.

Case studies are particularly useful for understanding and exploring complex issues and can extend experience or add strength and depth to what is already known through previous research (Soy, 1997), as well as providing detailed contextual analysis to investigate and explore 'real-life situations' (Chamberlain & Radley, 2001).

## CHAPTER THREE: FINDINGS

This chapter presents the findings of six Māori mothers and two whānau hui in which whānau share their experiences of being in the Neonatal Intensive Care Unit (NICU) at the Waikato Hospital. The reconstructions of their experiences cultivated unique insights into their personal and whānau narratives as parents and whānau members during their time in the NICU and how they adjusted to going home.

The structure of this chapter presents each whānau story autonomously, whilst outlining their pathway through a birthing experience, their infants' entry into the NICU, through to their transition to home. The narratives identified some fundamental issues such as adjusting to the NICU, the NICU environment, the transitions that occurred, and their support systems that were utilised.

The first collection of stories involves the four mums who participated in individual interviews. Jade is the mother of Te Hinairo, and shared her story through participating in an interview during her stay in hospital accommodation while her baby was in the NICU. Subsequent mothers' stories are post-NICU departure and involve the mothers' reconstructions at varying times after exiting the hospital. These interviews occurred four months, two years, and five years after their NICU experience. Carianne had left the hospital four months earlier with her baby Jayton and was living at home. Hine's son Matai, was two years of age at the time of the interview. Her children had been removed from her care and she was rebuilding her life with a goal of having her son returned. Shanette's child was five years of age at the time of the interview and as such, her reflections were based on experiences that occurred five years after her time in the NICU.

The second collection of stories involved mothers who chose to participate in a whānau korero, involving a whānau hui. The first whānau dialogue enabled Hirini (Mother), Mavis (grandmother), and Shyanne (Hirini's sister) to participate in a discussion of their experiences, demonstrating a whānau shared narrative. They had recently exited from the NICU.

The second whānau hui came from a whānau that had been in the NICU five years ago and their shared dialogue exemplifies the development of a complete whānau story. Their dialogue allowed Waihekerangi (Mother), Jason (father), and Te Ao Marama (Grandmother) to communicate their experiences. Because of personal circumstances that restricted their ability to gather at one time, this whānau asked for a series of individual interviews. Their narratives provide a composite story that reflects their shared experiences. The development of their shared story was central to their adjustment and coping with the rupture to their family so that they could move forward with their family life.

To facilitate the reconstruction of their personal narratives, the participants' were asked to talk about the birthing experience in the first instance, which then led to their infants' NICU admission. The experiences of the each whānau member are told as they constructed their story about being in the NICU at the Waikato hospital. The orders in which the stories are presented allow for each story or korero being a unique case study.

This framework was designed to lead the reader along each participant's journey while preserving the uniqueness of their experiences, and as such, each story is a distinct representation of their personal journey, and unique to that whānau. All discussions were initiated with the question "*Tell me about when you got pregnant?*" and the questions that followed were categorised into identifiably separate areas. The categories were as follows:

- a) Experiences of the NICU and how the whānau adjusted;
- b) Support people who are/were the whānau members that supported you and your baby while in the NICU, and;
- c) Support services if any support services you accessed while in the NICU.

## **Te Whaea o Te Hinairo: *Jade's korero***

### ***Background***

Jade is of Tuhoe/Maniapoto descent. She is 19 years of age, and has a partner, who is working as a shearer. They both live in Taumarunui. She comes from a large whānau. Her parents live in Australia and her six sisters and two brothers live elsewhere. Te Hinairo is her first baby and was born at 27 weeks gestation.

I met Jade through the Family Care/Awhina Whānau resource centre, where I have been volunteering for the past eight years. Jade had come into the resource centre seeking support. The interview with Jade occurred in a support room on the NICU level at Waikato hospital. It was important for Jade to be near her son as she was expecting visitors' and did not want to be away from the NICU. Jade's son Te Hinairo was five weeks old when we talked and prior to the interview she had cuddles with her son and was feeling very relaxed.

### ***Birthing experience***

Jade's birthing experience is unusual because prior to giving birth, she didn't know she was pregnant, even when she was sick, feeling tired, and had stopped menstruating. Her friends and colleagues kept asking her if she was pregnant, but she never took a pregnancy test, and continued to work in the shearing sheds without receiving any antenatal care. Jade initially thought she had back pain, however, this turned out to be contractions and she was told that there was a baby inside her when a scan was done in the hospital at Taumarunui. She was then rushed to Waikato Hospital and Jade's partner, his mum, and one of her best friends escorted her.

She knew that she was about to deliver the baby, however, she did not realise that premature babies stayed in the hospital. Jade did not suffer from medical complications throughout the delivery, but her son Te Hinairo was born three months premature. Due to Te Hinairo being premature and of low birth weight, he had primary complications of immature development of his major organs and needed to be admitted into the NICU.

### ***Entering the NICU***

The hospital staff took Jade's baby up to the NICU after he was born and she was informed what would happen next. *"Yeah, I thought that I'd go straight home, and not even, and then they told me that I had to stay here for almost three months, and I almost cried"* (Jade). Whilst Jade was in the hospital with Te Hinairo, she learnt about the technical and medical equipment that keeps her baby alive and spoke excitedly about her medical education. The nursing staff provided her with rudimentary lessons in understanding why the machines beep and her increased knowledge of her son's condition, and she was also shown how to conduct his cares. The nurses encouraging words and praise also elevated her confidence and this helped her to feel more comfortable with her baby's environment. Jade's initiation into motherhood had included a steep learning curve, and her increased knowledge and belief that she was informed enough by medical staff was apparent in her choice of words, when she described herself as *"I think I'm a doctor sometimes."* Jade felt fully informed and understood her son's medical and surgical needs.

A negative consequence of being separated from her son and the delay of breastfeeding due to his prematurity and inability to breastfeed, was that her milk supply decreased. Whenever she was in the hospital she had to work hard at building up her milk supply (by using the electric breast pump machines), which was physically tiring. She would then feel homesick and want to leave again, thus perpetuating the cycle of decreased milk supply.

Jade could not remember when she had her first hold or her first kangaroo care cuddle. Jade looked forward to her cuddles with her son and recognised that those moments of time spent with him close to her through skin to skin contact (down her shirt) helped her to make sense of why she was within an environment that she didn't want to be in.

### ***Support networks***

While in the NICU, Jade presented herself as a very friendly and approachable young woman that enjoys talking to people. Hence, a strategy that she employed

so that she could cope with being away from home was to actively seek out the company of others.

*I always need someone to talk to, I love talking to people, and yeah so I just meet other mothers. Yeah, that will be very good for me, heaps of visitors, and anyone really just to talk to, and then I'll be all right.*

Jade was not from Hamilton and had no whānau living here. After a couple of days in the ward, NICU staff arranged accommodation for her at Hilda Ross<sup>4</sup>, so that she could be near her baby. Jade did not like being in Hilda Ross and only used the space for sleeping. She became quite stressed with being in Hilda Ross, at the hospital, and away from her whānau.

*I'm not used to being locked up in the one place, for too long. I wanted to go home, so I went home for the weekend, that was a good weekend but I still want to go home.*

By the time of our interview, Jade had become familiar and comfortable with her environment as well as her baby's medical caregivers. While she felt lots of support from her whānau and friends, she was saddened that even though her whānau and friends who all lived out of town tried to visit her when their work commitments allowed, they were unable to visit as often as she would have liked. Her whānau were an important part of her coping strategy and she considered Te Hinairo's dad to be the most important support person for her as she felt their relationship had gotten stronger since their son was born. It was Jade's whānau who she felt most comfortable speaking to about personal issues that were impacting her. For this reason, Jade began to travel back to Taumarunui as often as possible so that she could seek support.

Jade spoke about how she was starting to think about the transition to home with her baby and she felt comfortable utilising any service that may be necessary for her homecoming with her baby. Jade has decided that when they leave the NICU they will be going to live with her partner and his mum in Taumarunui. She also

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<sup>4</sup> Hilda Ross is the name of the building in which patients and visitors can pay to stay in on-site accommodation.

plans to move to Australia in the near future when her baby is older so that she can be near her parents.

## **Te Whaea o Jayton: *Carianne's korero***

### ***Background***

Carianne is of Ngati Maniapoto/Tainui descent, she is 20 years of age, and lives in Hamilton with her baby and dog. Jayton is her first baby and he was born at 29 weeks gestation. Carianne was introduced to this research through a support worker within the hospital and after being given an information sheet outlining the project. After reading the forms she informed the support worker of her wish to participate. I then contacted her and we arranged an interview time and place. She felt more comfortable having the interview in her home, as she had only been home with her son Jayton for a couple of months. Jayton was present at the time of the interview.

### ***Birth experience***

Carianne had experienced a miscarriage prior to getting pregnant with Jayton. When she became pregnant she enlisted the services of a midwife and planned to have the birth of her baby at River Ridge (a birthing centre in Hamilton). She felt that she received really good antenatal care. At 29 weeks gestation she went into premature labour because, unbeknown to her, she had an infection. Carianne's waters broke and she carried on as normal at home. Fortunately, a whānau member (her aunt) was at home with her and informed her that it wasn't normal and that she should go to the hospital.

### ***Entering the NICU***

Carianne was admitted into hospital so she could be monitored, however, within two days she started having contractions again and these progressed until the hospital staff decided that they would deliver her baby through caesarean section because he was breech. That day, she recalled being in a big room with her partner and a lot of strangers. After the procedure, she woke up and her partner showed her a picture of their baby who had been taken up to the NICU.

*I remember waking up, in the midwifery room, and my partner's got this photo of baby, and I'm going, oh give me a look, I can't even see the photo cause I'm still wasted, yeah even the next morning I couldn't go and see him cause I was*

*too bugged, and I was sore and didn't want to get off the bed, but um a couple of days after that I went down to go see him, but yeah those rooms got too hot for me, I started to get a bit dizzy, so I had to leave.*

Carianne reconstructed her perception of the events and vaguely remembered that she had being given a tour of the NICU a day or so prior to the caesarean section procedure so that she would know where her son would go. Carianne's initial experience within the NICU also involved adjusting to the heat of the NICU, which emanates from the medical equipment used to keep the babies warm and alive. Once the nurses had shown Carianne how to care for her baby, she gained confidence and attempted to be there every time so that she could take care of her baby's needs. Cares included taking his temperature and partaking in normal parenting tasks such as changing his nappy. She enjoyed those moments when she was could be actively involved in Jayton's care.

Carianne was another mother who spoke fondly of having her first cuddle and she recalled that this happened on her second visit. When Carianne spoke of her cuddle with her son she also reconnected with how she felt during those moments.

*Skin to skin cuddle, yeah, and that felt really, I like, I could've just stayed like that for ages, yeah I liked that, that was cool. He was only little, I had let the nurses change him for a while cause he was just too little, too fragile, thought I was going to bend his fingers.*

Carianne lived in Hamilton so she could travel home every night, leaving her son at the hospital because she had confidence in the NICU staff. However, in her experience, some nurses would inform her of where things were and some wouldn't.

When reflecting on how she felt as a Māori woman in the NICU, Carianne started by focussing on her overall perceptions of how the staff treated her and her whānau. Carianne further explained how she perceived NICU service delivery and the quality of care that her son received. Her experiences and observations were that all the infants received the same excellent quality of care, and she formed positive relationships with the NICU staff.

*Oh I just felt like everybody else, cause, you know pākehā nurses, they treated, dark babies like all the rest of the babies, that's a good thing to see, not just taking the coloured babies, that's what I liked up there so I was all happy about that, so I knew he'd get looked after.*

### ***Support networks***

Carianne was discharged from hospital a couple of days after Jayton's birth. She commuted daily from her home in Hamilton to be with Jayton for the seven weeks that he was in the NICU. As Carianne did not have any transport, she caught the public bus a couple of times. During one her visits to the NICU she came across a brochure that provided information about the St Johns free van shuttle service to the hospital. From that point on she utilised the service so she could see her son on a daily basis.

*Yeah that was cool, it was choice, so I could just go up there in the morning and just stay up there till they did the last drop offs, and that was just time for my whānau to come home, to cook tea and whatever and go back after tea.*

Accessing transport through the free St Johns service allowed her the convenience of being able to live at home so that she could access her whānau support which eased her anxieties about how she would get to the hospital.

### ***Transition to home***

Carianne was initially not prepared for the transition to home. She talked about how she had not bought any baby items during her pregnancy, and when her son was born prematurely, it hastened her need to prepare for home. While Jayton was in the NICU Carianne took time to prepare for Jayton's homecoming.

## **Te Whaea o Matai: *Hine's korero***

### ***Background***

Hine is of Ngati Hako descent. She is 33 years of age, works part time and is rebuilding her life after separating from the father of her children. All the children were removed from her care until she could provide a good home for them. Hine is currently living in Hamilton. Matai, her youngest child and was delivered at 26 weeks. He is currently in CYPS care and his sisters Te Mania, Mereana and Horiana are living with their grandparents.

A community health nurse at the Waikato hospital asked Hine if she would like to be involved in this research and then referred her on to me. We spoke on the telephone and she arranged to have me interview her at her house. The interview occurred in her home that she is preparing to live in with her son Matai.

### ***Birth experience***

In terms of pathways to the NICU, Hine was living and working in Thames when she went into labour with her son. She was 26 weeks pregnant and had just got home from work when her waters broke. She rang her midwife and was told that her waters couldn't have broken because she was only 26 weeks. Following that conversation, Hine went to the hospital in Thames and was told that she was 'in labour' and that they would have to take her to Waikato hospital. Hine's previous birthing experiences with her children had been normal birthing processes.

Unlike the first time mothers in the previous stories, Hine had expectations and experience of a normal term delivery.

A helicopter was arranged to transport Hine to Waikato hospital, but because she was scared of heights, they took her by ambulance to Hamilton. Once, at Waikato hospital she was given steroid injections that are given, because at 26 weeks (if her baby arrived) his lungs would be too immature. Steroids can help strengthen the infant's lungs. Another twelve hours went by before she started having more contractions. It was at this time that she was told that she was going to have an emergency caesarean. She was informed about the processes that would happen to her and her baby and that she would be able to see her baby for a moment

before he would be rushed up to the NICU. Matai born at 26 weeks and weighed 1 pound 15 ounces.

*When baby was down in the NICU, he was all settled and everything and then they brought me a photo and said he was Ok Umm so that put me at ease. I just wanted to get myself better.*

### ***Entering the NICU***

Similar to Carianne's experience, Hine recalled being informed of her son's condition. It is common practice for the NICU staff to provide a photo of the newborn infant to a mother who is unable to be moved due to their medical trauma. Hine's whānau were not able to be at Matai's birth because the transfer from Thames to Hamilton happened so fast. Once her partner and children had arrived in Hamilton, she went with them to see him in the NICU. Hine remembered her first experience of being in the NICU as an emotionally overwhelming experience that made her feel physically sick.

*When I went down there, I cried for quite some time and I was very sick I puked everywhere in the NICU.*

Similar to the previous stories, Hine had never been in an NICU and although she had been told about what it was going to entail, she didn't want to go until her whānau arrived. Hine felt that having them by her side would help her cope and make it real for herself and her whānau.

*I wanted to wait for them to be there too... umm yeah and it was an experience for all the children because they didn't know why I couldn't take their brother home.*

Her expression of concern for her children's feelings and wanting to make sure that they had an understanding of what happened to their brother was reflective of her mother care. Waiting for her whānau to arrive served two purposes. Firstly, Hine was sensitive to her children's expectations concerning their brother's wellbeing. Secondly, she was in shock and wanted to have her whānau with her. This was Hine's fourth pregnancy, with her other children being full-term pregnancies and normal birthing experiences.

Matai breathed autonomously for 12 hours before he had to go on to a ventilator, Hine was told that this was a phenomenal feat for a premature baby. He was so fragile and medically unstable that five days passed before she was able to have a cuddle. Hine was knowledgeable about the seriousness of her son's condition and understood that there were certain factors that needed to be taken into account before he would be able to participate in kangaroo care. Similar to Carianne's experiences, Hine was very nervous about holding her baby because he was so tiny. At first she was apprehensive, but this dissipated as time went by and as she spent more and more time with her baby. Hine fondly recalls those experiences of holding her baby close so that they could bond.

In the NICU Hine watched and documented in a book her son's feeding regime as he progressed from being tube fed 1ml of milk, through to being able to be bottle fed 100mls. The nurses provided the writing book so that she could keep a record of all his behaviours.

Hine's reconstruction of events in the NICU differed from the previous mothers' as she included the medical details that were significant time markers which also set her son's birthing experience apart from those of her other children.

After a week of being in at the Waikato hospital, Hine's milk supply ran out. Matai was put on a bottle which hastened Hine's plans to go home to Thames so that she could spend time with her whānau who were in Thames.

*He went on to be bottle fed. I had to stay in the Waikato hospital for the week and then I went home for two days back in Thames. I rang them up every day, every hour of the day to see how my baby was.*

Hine's family (partner and children) did not live in Hamilton, providing additional stressors such as not being able to travel to the hospital without it negatively impacting on their personal and financial circumstances. Similar to Jade's viewpoint, Hine coped by taking time out, highlighting that she rang the NICU constantly to make sure her son was "*Still in this world with us*". She was not living in Hamilton, communicating with the NICU was an essential link for her to her baby. Although she was confident in the medical care that he was receiving,

staying in contact provided her with a sense of assurance that he was alright. After two days she received a call from the NICU staff to say that Matai had to have a blood transfusion, so she rushed back to Hamilton to be with her son. While her son was in the NICU, she was provided with accommodation at Hilda Ross so that she could be near her son. However, this was disheartening for her as she could not afford the charge for her other children to stay, meaning that (once again) they were separated as a whānau. Hine's partner was allowed to stay with her when he came to Hamilton, however, they always had to pay for the children to be able to stay in Hilda Ross.

Hine's impressions of the NICU staff were in general, very positive. She talked about how they demystified the medical jargon associated with her son's condition and explained the purpose of the technical equipment. She was also assisted in understanding how to care for her baby while he was in the NICU.

*I knew about all his cares. I knew about his medication how to monitor it, how to know that he was going to have a blue moment, and when that was happening for him.*

Matai progressed slowly through the NICU levels. Due to his erratic needs for oxygen, it was two months before he progressed to Ward 54 (the Nursery). Hine recalled a situation that made her aware that she was not in control of her environment. She wanted to sit with her son but the nurses on night duty would always send her to bed.

*I didn't want to sit up in my room all by myself, I wanted to sit by my baby all night. Yeah, and so they would always say can you go to bed Miss Clarkin, because your son needs to sleep, and so do you. Yeah but I'll sleep. I did ah I was there at every feed... If I didn't, If I wasn't at the feed then I'd get upset with myself cause I wasn't there to feed him and stuff like that cause I felt like that was my baby, that it's my baby and I need to do it they won't be there when I go home so I need to know everything about my baby.*

Hine's statement contained a powerful message about her experience and what she encountered as she attempted to care for her baby.

### *Transition to home*

Hine spent a week in 54 Nursery and then went to the Mothercraft Unit so that she could adjust to going home with a baby with special needs. In 54 Nursery, Hine was provided with an Apnoea mattress and consequently was taught how to monitor and utilise this piece of equipment, she was also shown how to perform CPR on an infant. Hine took advantage of all the areas of support available to her before she left the hospital environment.

When Hine left the hospital environment she went to Rotorua so she could be near her mother-in-law and her older children. After 24 hours of being home Matai stopped breathing and she started the resuscitation process and kept that going for 20 minutes while waiting for an ambulance to arrive. Once Matai was admitted to Rotorua hospital, the Waikato hospital was contacted and they asked for Matai to be returned to them because they were able to provide the ICU services that he required. Unfortunately, by the time they arrived in Hamilton, Matai's lung had collapsed and although Hine thought that Matai would be able to return to the NICU, she was informed that once you are out of the NICU you don't go back. Another medical complication that Matai needed was hernia surgery, and once she was fully informed about the procedure, she chose not to have it done, as she felt that the risks of having the operation were too high and was unwilling to put her son at risk.

### *NICU reflections*

Reconstructing her story raised some very sensitive issues, and Hine chose to be open and honest about what she believed to be relevant information for understanding her experiences. She had not spoken to her parents in three or four years, and at the time of this interview, her parents were raising her three daughters. During her time in the NICU, she felt that her mother-in-law was her main support person. While in the hospital she utilised about five different whānau who lived in the area to support her during her stay in Hamilton. Her whānau and friends made themselves available to her when she needed a hand or something to eat; at times, this even involved bringing food up to the hospital. Hine commented that the support provided for a parent of NICU babies did not include the simple act of being fed.

*Yeah it's like where is the food side to enable the mother to be fit and healthy for the baby they need to supply food, but no, that didn't happen.*

Hine's comment reflects a real source of concern that mothers experience at Waikato hospital. Food is an essential basic requirement needed for human beings to function, and mothers attempting to breastfeed their infant in hospital are in an incredibly vulnerable position. In Hine's case, she was not from Hamilton, hence the availability of popping home to have a meal was not possible.

### ***Support networks***

Hine received support from a number of differing organisations, such as CYFS and WINZ involved in her life during her time at the hospital and after she left. The NICU social worker was a formal part of the support networks that Hine utilised. Her relationship with the social worker provided the catalyst that would change her life. At the time, Hine assumed that all information provided to the social worker would be confidential, however, she found out that this was not so, and information that she had spoken to the social worker about was relayed on to the Department of Child, Youth & Family Services (CYFS). While she was in Mothercraft, they did an investigation and this continued once she was in the children's ward. CYFS were granted a child and safety warrant and when she went home with her son the second time, CYFS came and uplifted her children.

Family Start first came in when Hine had her baby, and they provided regular visits and on-going support. Family Start then referred her on to Anglican Action so that she could get help with rehabilitation and deal with the domestic violence that had occurred within her life.

*I just thank Christ that they were there. I don't know where I would be these days... but yeah I'm just so happy to be here and be able to tell my story. Two years ago I don't think I would have been able to sit here and tell you same thing. I just worked on what I needed to work on in terms of myself.*

Hine's statement really illustrates how she had been working through her experiences so as to make sense of what has happened for herself. Another

relevant part of this statement was her acknowledgement that the way she viewed her experiences had changed and the story that she had reconstructed for this interview was different to how she had viewed it earlier.

While she had been in the NICU she had experienced support, and when she was presented with the opportunity to provide support to a friend, her experiences guided her dialogue. During the interview I asked if she had any advice for someone going through the NICU and she reflected on the support advice that she had shared with her friend.

*I actually just had a friend that just came out of there about a month ago and the advice while she was in there was to look at every single need or every single medical thing that they do with your baby.*

As a graduate parent of the NICU, Hine was a very empathetic source of information and support for her friend.

*Ensure yourself that your baby is being safely looked after by the nurses and ensure that they are helping you in every single way to make sure you and your baby are fine and that when you move out of here that you're Ok.*

Hine also tutored her friend to be a proactive mother and seek out help from staff so that the transition to home would be a smoother process. She had realised from her NICU admission that as a parent, there were support services that were available and she accessed them while she was in the hospital. Family Care/Awhina Whānau is an organisation that she utilised while she was in the NICU and while she was in the hospital, she would refer people so that they could also use the services.

*...I say's cause they have all the channels for you to be able to go through I says cause I know that they have support groups that are there for new born unit mum that you know that you can help out with And I directed them down to the shop cause I always went there and bought my clothes for my son yeah but nah It was awesome to be able to go down there and be able to have that facility there that to go and get free knitting and stuff. I thought that was awesome...*

Family Care/Awhina Whānau<sup>i</sup> was situated as near to the NICU as possible. When this organisation was in operation, its primary function was to provide emotional, practical and educational support. Hine identified the availability of free knitted clothing and accessing graduate parents as an awesome opportunity.

Hine has re-constructed her story through a series of distressing events. She accredits her positive demeanour and her current perspective to the fact that they were life-changing events that have brought about significant changes in her life. The experiences were meaningful for her and she is very philosophical about her future and her children's future.

## Te Whaea o Te Kanakana Rose: *Shanette's korero*

### ***Background***

Shanette identifies her hapū and iwi as being Raukawa, Ngati Kirihika, Ngati Haua, and Ngati Te Oro. She comes from a large whānau, was raised by her grandparents, and as a whangai, considers her aunts and uncles to be her parents. She is 20 years of age and lives in a defacto relationship. Te Kanakana Rose is Shanette's first child and was born at 39 weeks gestation. Te Kanakana is currently five years of age and has a younger brother called Te Kauri who is two years of age.

Part of my consultation process included my whānau networks, and to do this, I visited Te Hauora O Ngati Haua and presented my proposed research to their staff. It was at this time that two staff members came forward as parents of NICU graduates and became research participants. Shanette was the receptionist and felt comfortable having the interview at her workplace in the Te Hauora o Ngati Haua conference room in Waharoa. The space we used had been provided after the consultation and at the time of the interview and Te Kauri was present at the interview while Shanette's daughter Te Kanakana was at school.

### ***Birth experience***

Initially, Shanette felt that her pregnancy was going great, however, as her due date got closer, the doctor kept calling her in for scans. Shanette was at 38 weeks gestation when the doctor decided that since Te Kanakana was not growing they would need to do a medical intervention. Shanette was very apprehensive about the medical procedure that they wanted to do and went to visit her whānau.

*...it was all an induction thing, I went to see one of my uncles in Tauranga and he told me don't let them do it, there'll be a lot of complications, so I was real apprehensive on more of the induction, and then they were like, the midwives here in Matamata don't do it because they'll tell you something and I know a woman that was there for 72 hours before, and I was quite lucky I think I had two sets of gels started at 8.30 in the morning by 9.00pm my daughter was born that night.*

The family's perception and fear had unfortunately been internalised by Shanette with her response being to reluctantly go to the Waikato hospital. Looking back, she feels quite lucky that her induction went smoothly even though her baby was a small 3 pounds at 39 weeks. Shanette had a lot of whānau with her at the hospital, she remembered that her nana, godmother, and tane (partner) were with her when her baby was born and they did karakia and attempted to support her while she fed her baby for the first time. Shanette was shocked at what happened during this time and clearly recalls the event.

*And um straight away you know nana and them put baby on to try and feed her, try and feed her, I was trying to feed her but they (the midwife) growled me, and like just snatched her off us, and raced her up.*

### ***Entering the NICU***

The previous stories are more positive in their descriptions of the transition process into the NICU and signify that their experiences were a result of positive communication and inclusion in the process. Shanette and her whānau were not informed about what was going to happen and the significant needs of such a small baby would involve being rushed off to the NICU once the baby was born, which resulted in a distressing experience. Nor were they aware of any medical problems. A lack of informed consent precipitated the shock that they endured throughout the transition.

*She's like look you gotta hurry up, you gotta hurry up, and then when we got up to the ward to see her. Yeah when I got down to the ward, they were like oh my goodness this child was purple when she came in this morning oh last night, and she was, she was fine but you know just sorta made me feel quite bad really felt like I had done something to her.*

The issues here surrounded being interrupted while the whānau were attempting to assume the normal and natural processes of engaging and feeding the newborn baby. It was at that moment that Shanette and her whānau felt like they had been treated like naughty school children and the relinquishing of control to the medical professionals felt unnecessarily detrimental.

Shanette and her partner had never seen such a small baby, and they spent quite a lot of time asking questions. Te Kanakana was tube fed for the first three days and then Shanette got to breastfeed her baby. Shanette received a lot of support from all her whānau while her baby was in the hospital. However, because the hospital staff seemed unapproachable and the environment was scary, she did not even ask for help with the most basic requests.

*Yeah it was oh even not being in the wards when I was in the wards by myself, no one told me where the showers were, or the towels were, or anything, I just didn't know anything, you know I'm up at five o'clock in the morning, so I wanna get down to where my baby is, and I just didn't know what to do so I was like, should I buzz, will they know, or what you know, and I was more worried about how the nurses were gonna feel, then how I should actually feel myself, so in the end [I would end] up waiting till about seven.*

This quote demonstrates how the previous negative experiences that occurred during the birth of her daughter had impacted on her sense of confidence, which impacted on her confidence to request or access informational support or any other forms of help from hospital staff. Shanette was not familiar with her settings and her concerns over the staff reactions resulted in her sitting and waiting for two hours before staff on the ward started to move about.

There were other issues that arose for Shanette and her whānau that were still significant memories for them after five years. An example was the lack of recognition surrounding the naming of the newborn baby. Te Kanakana Rose was given a name and the NICU staff were asked to use the name given, however, the hospital staff kept referring to her as “*baby of Jack*” or “*baby Jack*” (mother’s surname) which was quite demoralising for the whole whānau.

Secondly, the NICU staff made assumptions about her because she had a big whānau. Shanette was told that only ‘family’ can come into the NICU and she felt that she was constantly defending her definition of whānau.

*We were trying to get like my uncles, because I stayed with my grandparents, I was brought up by my uncles and aunties so yeah and um, and they were like oh you have to be family, and you know my uncle gets pretty irate when it comes to talking*

*family he's like, well I am family, but they couldn't understand, that we were family you know, we don't mean you know extended family, I was like excuse me, that's how we choose to live that's how its gonna be, but yeah nah they're pretty funny about that...*

Shanette was very angry and this was still a painful experience to recall. Growing up, as a whangai with a lot of extended whānau was a reality for her, so when the medical professionals attempted to redefine whom her whānau were because they were attempting to limit the number of people into the NICU, she got angry.

Shanette guided her whānau that came to visit through the processes of what they had to do when they attended the NICU, such as washing your hands and not staring at the other babies. Shanette stayed in Hilda Ross while Te Kanakana was in the NICU, and found this to be a particularly negative experience. Walking from one side of the hospital to the other at half past one in the morning, was quite a frightening experience. Shanette persisted because she wanted to be with her baby.

*I fought and fought and fought to get a room with her, so I could go into the room with her. It wasn't right, it just didn't feel right for me having a newborn baby over there with all these strangers and I just wanted to be there.*

This statement of her experience illustrated her frustration and feelings of powerlessness. Shanette's coping strategy within the domineering environment of the NICU was that she asked to be transferred back to Matamata, and was told that if she chose to go back there she would have to pay for it herself. Once she was in Matamata, she felt more comfortable with her environment and was able to establish breastfeeding with the support of her nan (grandmother) and her aunty. Being from a rural community, she had experienced the friendliness of the Matamata hospital and considered it to be a more homely environment. Shanette had a smooth transition once she had transferred into an environment where she felt supported and she was able to establish breastfeeding and her whānau were made to feel welcome.

### *Support networks*

When discussing what she had been through in the NICU and what she had learnt from those experiences, Shanette reports not accessing services and relying on her whānau to see her through the experience.

*But I don't know whether they took it upon themselves to think that I was alright and I knew what to do and everything.*

Not knowing if there was any support for her led to her feeling homesick and she would ring home upset and wanting to go home. In reflection, she commented that having information would have been really good at the time, or even just having someone to chat with would have helped. Shanette also went on to suggest what she would tell someone else if they were in the NICU.

*Just encourage your whānau to come in, disregard all the signs, and all of that... The nurses would explain things but it was really quickly rushed through, what all these different things were around baby and on baby. If it had not been for my tane, actually persistently asking them all the time, I don't think they would have really answered us properly.*

In the first extract, Shanette's negative past experiences of having limits placed on whānau members that could enter the NICU as support for her, influenced her perspective. Her advice expresses that whānau are a central part of a parents' support network and Māori parents in the NICU should be proactive in having their whānau as support.

The second extract was in response to my question about whether she thought having her whānau with her would have made a difference. Identical to the other mothers' narratives, Shanette confirmed that while she was in the middle of coping with the stresses of the NICU and attempting to understand the magnitude of technological and medical information, having her tane (partner) and whānau there helped.

She began her narrative construction in an informative manner and this developed into her using her experiences as an example for others about to go through the

same process. Shanette's experiences were unnecessarily traumatic and even though five years had passed, those moments were still vivid memories.

## **Te Whānau o Jahvon**

### ***Background***

This narrative represents a whānau hui that captured their experiences at a time when they were still in the throes of developing a whānau experience through shared dialogue.

There were three whānau members that contributed to sharing Jahvon's story at a whānau hui. Mum had gone to full term when she had Jahvon, who was 5 months old at the time of this hui. Mavis (Grandmother) is Hirini's mother and is employed full time as a Māori iwi health worker and Shyanne is Hirini's younger sister. This whānau also lived in Hamilton.

Hirini and I spoke on the phone and she provided me with her mother's contact details so that I could organise a meeting time. After speaking with Mavis, we arranged to have the whānau hui at her home, and on the scheduled day, I rang to confirm. Unfortunately, Mavis had taken ill and forgot that the hui was happening. When I arrived at the house, Mavis was at home recuperating and when I offered to reschedule, she preferred to continue with the hui. Mavis quickly contacted the rest of the whānau by phone to let them know that I was there and within half an hour they arrived. There were other people present at the interview but they chose (as is their right) not to participate.

Hirini was very self-conscious about the tape recorder and it took quite a while before she felt comfortable enough to openly discuss her story. However, she happily participated in the beginning by minimal verbal encouragement such as hmm and used non-verbal actions. The other participants included Shyanne (Hirini's sister) participated by being present to support her sister, but rarely spoke and Mavis (grandmother) felt relaxed and openly shared.

Hirini and Mavis were still developing their shared whānau story, and as I started to ask questions, Hirini's answers were enlightening for her mother Mavis, and also informative for me.

### *Birthing experience*

During the whānau hui, the three areas of questions were covered, and in the initial stages of the discussion, what arose was the fact that the pregnancy and birth of Jahvon was a surprise for all of them. Hirini did not find out she was pregnant until she was 5-6 months pregnant, she then found a midwife and had antenatal care.

*Keri: Oh Ok, so the whānau had time to be notified?*

*Mavis (laughs): We didn't know*

*Keri: About the pregnancy?*

*Hirini: Hmm*

*Keri: Oh Ok*

*Mavis and Hirini: Hmm*

*Keri: Well they knew after baby was born*

*Mavis: Our baby was a wonderful surprise*

During this phase of our discussion, we were discovering new information as Hirini and Mavis shared their collective story. Both of them said that the delivery was fast and took about two hours. It became evident that Hirini and Mavis had previously begun to develop a whānau-birthing story of Jahvon's birth, even though Mavis wasn't there when her daughter went into labour and went to the hospital with her partner. This research was not focussed on the whānau communication and relationship dynamics that were part of why Hirini didn't inform her family of her pregnancy, but it did provide the whānau with an open forum to discuss and listen to each other's experiences.

*Keri: You find out and they basically whipped him away*

*Hirini: Yep*

*Mavis: They didn't tell you why? They didn't say what was going to happen?*

*Hirini: No they just said that they were taking him to the Newborn Unit*

As previously mentioned, Mavis was not aware of her grandson's birth until after he was admitted into the NICU. Mavis was also surprised by some of Hirini's responses because they were the first time that they had been told to her. Finding

out that her daughter had not received enough information to understand what was going to happen to her baby, was alarming for her. Hirini was taken straight into theatre because she needed stitches, while Jahvon's dad went with him to the NICU.

### *Entering the NICU*

Hirini then recalled that Jahvon's dad came down after she came out of theatre and wheeled her up to the NICU in a wheelchair. A nurse then told her that her baby was there because he was a small baby, he was cold, his heart rate was down, and he had respiratory problems. She remembered seeing him enclosed in an incubator and under lights because he was so cold, and then being told that she was not allowed to touch him. She went through a day and night not being allowed to touch her baby.

*Hirini: Yeah it had the lights on or something cause that's where he was. He was cold, but we weren't allowed to open [the door] or touch him.*

*Keri: How long before you actually got your first touch?*

*Hirini: The day after.*

*Keri: So you went through a whole day and night without even being able to touch your bubby.*

*Mavis: That's terrible, aye.*

*Hirini: Ah we went to open [the door to the incubator] and they told us to close it.*

*Keri: Ah, I mean, one little touch...*

*Mavis: Yeah, that could be, for us, touchy feely Māori, that's important.*

*Keri & Hirini: Yeah.*

*Keri: Especially new mums.*

*Mavis: Absolutely...*

This extract presents part of a discussion about the initial entry into the NICU. Mavis and I were surprised to hear that Hirini did not even get to touch her baby.

Hirini and her whānau were aware that my son was a graduate of the NICU. By using a narrative approach, I encouraged the whānau to discuss their experiences, because even though their lived experience deviated from a “normal” birthing

experience, by being able to ask me questions, they became aware that there were certain experiences that were “normal” within the NICU.

- Keri: So when did you get your first cuddle?*
- Hirini: Yeah, the day after, they still had him in the incubator overnight and then put him into the open bed.*
- Keri: Did you do the kangaroo care cuddle?*
- Hirini: No.*
- Keri: Down the shirt?*
- Mavis: (Laughs)Is that how small your bubba was?*
- Keri: No they even do it with the big babies to get the (mother and baby) bonding. It's to get the skin-to-skin contact.*
- Hirini: Yeah...*
- Keri: So it may mean that Mum opens the shirt.*
- Hirini: Dad did it.*

What transpired was that as Hirini began to contribute more to the conversation, it became apparent that Mavis was not aware of everything that her daughter had experienced, so when I asked about whether she (Hirini) had a ‘kangaroo cuddle’, Mavis’s comment showed she was not aware of the practice. Hirini and I started to explain the practice so that Mavis could understand and feel informed about what had happened when Jahvon’s father had a kangaroo care. Mavis is the central part of her whānau, so informing and including her aided the development of a whānau shared story, and as a result, she would be able to incorporate her daughter’s experiences into her story about her grandson’s birth and admission into the NICU.

Jahvon was in the care of the NICU for five days. The day after Jahvon was born, Hirini and her partner went home to tell their whānau and Mavis discussed what happened next.

- Mavis: About five or six days in the newborn unit and of course and when the whānau found out because he was such a wonderful surprise I've got a huge whānau so we arrived*
- Keri: En masse?....*

*Mavis: En masse and you get the nurses thinking, when is this line of Māori going to stop coming in.*

*Keri: (laughs) It doesn't.*

*Mavis: (laughs) No, lucky they have that big room, where you can just kind of congregate while we wait to see baby. They make you feel uncomfortable though, they don't make it, they don't make you feel welcomed in big lots and I suppose they have their reasons for that.*

Hirini saw her main support people as her Mum and her sisters, and Mavis was at the hospital everyday that Jahvon was in the hospital. Hirini and Mavis spoke about how they did not feel supported by the NICU staff while Jahvon was in the NICU, and Hirini said that she didn't even feel that they were talked to, but were just left to do their own thing.

Mavis and Hirini both felt that Hirini was not provided with enough information and tuition to be able to feel comfortable about breastfeeding. She did not feel supported and she believed that if it weren't for her mother, the transition to going home would have been quite stressful. She received breastfeeding support from her Mum (Mavis).

## **Te Whānau o Kaelim-John/Manauri**

### ***Background***

Waihekerangi is 37 years of age and of Ngati Haua descent. She lives in a defacto relationship with Jason whose iwi is Tuwharetoa. Te Ao Marama is Waihekerangi's mother and is a kaumatua of Ngati Haua. Waihekerangi is employed full time as a Māori iwi worker and Jason works as a bakery manager. Waihekerangi and Jason have had seven pregnancies and two live births. Kaelim-John aka Manauri is their first child and was five years old at the time of this interview and Vaughn (brother) was 6 months.

There were three whānau members that contributed to Kaelim-John's story, and they included the Grandmother (Te Ao Marama), Mother (Waihekerangi), and her Partner (Jason). This whānau story has been captured through individual interviews. Kaelim-John's story is one that accounts for all the whānau members involved in the whānau korero that was collected. Waihekerangi works for Te Hauora O Ngati Haua in Waharoa. Her interview was held in their conference room with her youngest child Vaughn present. Waihekerangi allowed other people to utilise the large conference room while we were doing our interview, which meant that others were present although they were not involved in the interview.

The interview with Jason occurred in his and Waihekerangi's home and their youngest son Vaughn was present. Te Ao Marama and I organised to meet at Rukumoana Marae in Morrinsville, where she was involved in a hui but could take time out to talk to me. We positioned ourselves on the mahau (porch) of the wharenuī, which added a spiritual dimension to our meeting and eased the way for a very reflective account of her experiences.

Although this whānau chose to share their experiences individually, what occurred was a shared dialogue and clearly, their narrative had been constructed over time. This narrative has been presented as a composite story because regardless of whether the other people were present during the interview, it was quite evident that they had created a whānau story, and as they individually

reconstructed events through their experiences, their roles within the story emerged.

### ***Birth experience***

Waihekerangi and Jason both began their story by discussing her medical history of miscarriages that they had endured prior to having Kaelim-John, and she spoke about her pregnancy as if it were a whānau experience. She acknowledged that she chose Nicky (her midwife) because she knew that Nicky understood the medical system and they (Wai and Jason) also believed that Nicky would be an excellent advocate, as she had also demonstrated to them that she understood what they wanted and would involve and include their whānau. Waihekerangi's pregnancy was plagued with difficulties and even though she had a midwife, she still needed to access a clinical specialist.

Although Jason's reconstruction of Waihekerangi's medical history was similar to her version, his approach was very different, as he reconnected by using past moments in their life together to establish significant timeframes, such as changes of abode and job changes, to reference the miscarriages and stages that they had gone through before she became pregnant with Kaelim-John. He even discussed how they had considered taking on a whangai (raising one of his brother's children) prior to the birth of Kaelim-John. Jason's use of timeframes helped to establish what had occurred during the pregnancy, such as their choice of a midwife when Waihekerangi was four months pregnant.

Their miscarriages comprised a core element of the birthing story and provided a deeper understanding of who they were prior to the birth of their first baby. Therefore, it was not surprising that Waihekerangi and Jason sought personal control over this birthing experience. They both spoke about how she spent many months in the hospital prior to giving birth. Wai had established a couple of things that helped her to have the experience that she wanted. She engaged the services of a midwife and formed a trusting relationship with her. Her midwife also spent time making her aware of her rights as a patient while in her care and while in the care of the hospital.

*Well Jay and I had already discussed what would happen, if an emergency arrived so we both knew what would happen, and because I had a midwife, an independent midwife, she knew as well, and so we had made sure that the hospital staff, any nurses, or the specialists, they would know what we wanted to happen. (Waihekerangi)*

This extract illustrated how she felt having a really strong advocate in her midwife, particularly during the times when she was feeling unable to communicate her frustrations to NICU staff, to facilitate the birthing experience that she wanted.

Waihekerangi was the dominant author and creator of her own birthing experience. She organised and planned for every situation, so that there would be no surprises. She wanted to be in control of her experience, and it was not surprising to hear that she constructed contingency plans for the different situations that might arise, and told everybody what she expected, what their roles and responsibilities were for all those who were going to be involved in Kaelim-John's birth. Needless to say, even the minute details such as how she wanted the lighting in the room, where the bed would be and when she would get on the bed, being in the bath, and even having her own hot water bottle, were organised.

Te Ao Marama is Waihekerangi's mother and a kaumatua within Ngati Haua. She has eleven mokopuna (grandchildren) and had been present at all but one of their births. Kaelim-John is mokopuna number six. She discussed her whānau experiences with being involved in the birthing situations of her whānau members, and she even spoke about how Waihekerangi had been born premature but had not needed to go to Hamilton. It was not the first time that she had been in the NICU, but Kaelim-John was her first mokopuna that had been in that situation.

*No he's not the first experience that we've had because with whānau we go to all nieces nephews all the whānau and I have had a lot of experiences but he is my first mokopuna being in that situation. I consider all those other births as very close and dear to me because they want their nanny or they want a kaumatua and we go there and have a karakia and that's what I did. I wanted to be there have this karakia and that's what I always do every time the mokopuna comes out when they come*

*out my husband used to do it... when he passed away I just carried on to have that karakia with the water. (Te Ao Marama)*

Reminiscing allowed her to be very philosophical about being in the birthing room. Her reflections about the day Kaelim-John was born were shared in such an affectionate way, that she demonstrated through her words, her love for her family and how important she felt her presence was for Waihekerangi and herself.

*I'll never forget Wai she was just so radiant when she saw me her face just lit up like a ...as if she had already given birth. You know, when I just looked at her she was just so it's like her being a baby again. It was almost going like this (She curls up to show how she thought Wai looked like) and wanted that motherly care and love even though Jason was there her partner giving her that support but she wanted to nestle back into me again and to share it and I can understand where she was at. (Te Ao Marama)*

Te Ao Marama was well aware of the necessity of family rallying around the mother, particularly because of her prior experiences with her whānau. Her comment reflected the strong connection that she had with her whānau.

Te Ao Marama, like Jason and Waihekerangi, shared her experiences of karakia, and said that it was done before the baby left the room. This was a practice that Waihekerangi and Jason had chosen and made their own ipu (carrier) for the whenua (afterbirth) so that it could be taken to Jason's marae in Taupo. They informed the hospital and the nurses that were dealing with them of this, which led Waihekerangi to talk about how the nurses were surprised because she wanted to use her own things, and they hadn't seen an ipu before, and so she spent time educating the nurses of the cultural significance of what it was made of, and what they intended to do with their baby's whenua.

In the birthing room, Jason was there to catch his son, and he proudly spoke about how he was the first to hold him. Te Ao Marama had the task of cutting the umbilical cord and also performed the karakia before he was taken to the NICU. Te Ao Marama also spoke about how Jason had organised with his uncle or his grand uncle to be there so that they could go on to the urupa.

*It's the only one because most of my mokopuna are all buried on our farm. We've got a place there that we take all the afterbirth. With this one it went back and that's fine. Jason asked to take it back... (Te Ao Marama)*

Waihekerangi appreciated the support that her mother provided so that they could follow their tikanga of burying the placenta at Jason's whānau marae. For this whānau, returning the whenua back to paptuanuku not only reconnects their baby with the earth, but also connects their baby to their whakapapa and whānau. They all discussed Kaelim-John's admission into the NICU. As the director of her birthing experience, Waihekerangi had planned and organised people's roles within the birthing process.

*Jason and the midwife were to go with baby and my mum was to stay and help me get showered and all that, ok it wasn't just that, that process that we'd organised, but oh so everything that you had written down was in where he, as in his space or your space, yeah you know you said everything was there the way you wanted it to be... (Te Ao Marama)*

This statement identifies how Waihekerangi went about planning her birthing process. She felt that Jason had not only made a commitment to be with their baby as well, but he was also responsible for writing his own plan. She knew there were times that he would be uncomfortable and she had alternative people available if he decided he could not do it. However, they both decided to do what they were comfortable with and the stress associated with separation was lessened because she knew that he was there in the NICU handling things. When Jason discussed his time being in the birthing room he reconstructed his experience using specific details.

*So yeah I can actually picture everything that went on Nicky went in called for assistance they brought in a little incubator in through the second doors not the doors that we actually used there was another set of doors on the other side of the bed and they opened up and the nurse brought in an incubator on a bed and she said to me 'he's grunting, he's a little bit unwell and we need to take him to ICU. I turned around and looked at Wai and said right she's fine I'm going... (Jason)*

Jason was able to provide a clear descriptive account of the situation and environment, even though five years had passed. Both Jason and Waihekerangi had discussed exactly what would happen if Kaelim-John needed emergency care. He left Waihekerangi to safeguard his son because he knew that she had good medical care while she was in hospital, and that Wai's mother was also there to support her. Jason went with Kaelim-John to the NICU and he was informed about what would happen and was offered the choice of not being in the room when they administered an invasive procedure.

*I was not gonna let my son out of my sight. The only time that I let him out of my sight for the whole seven days he was in NICU was when they put the tubes in. (Jason)*

He chose to not view the procedure, but stayed vigilantly beside his son until Waihekerangi could arrive at the NICU.

### ***Entering the NICU***

While Jason was in the NICU, Waihekerangi was cleaned up in the delivery suite and then was taken to the ward. She waited until she felt ready to move and therefore, did not see her son for five hours. Waihekerangi had been in the hospital environment prior to the birth and planned for an emergency event by organising the people around her. However, she had not seen the NICU prior to Kaelim-John's arrival, and when she entered the unit, she recalled that she freaked out.

*When I finally got to the newborn intensive care, I absolutely freaked out. Initially it was just seeing all the incubators and the machinery even though before I had gone down, my midwife was telling me what to expect. But to walk in there and see the room with all the babies in there, that was what really shocked me. (Waihekerangi)*

When she first arrived at the NICU, it was all a blur, and recalling what she did is still a struggle as she was not able to cuddle him when she arrived in the NICU. However, Jason talked about how he had over the years, reminded Waihekerangi that she was able to put her hand in the incubator. They were a family that had prepared themselves for the NICU. Yet it remained an overwhelming experience

irrespective of their preparedness. When I asked Te Ao Marama about her experience in the NICU, she talked about previous experiences with other whānau members that had been extreme examples of life and death situations. So during the time that her mokopuna (Kaelim-John) was in the NICU, she felt that he was in the best place because of the specialised care that he was receiving.

Waihekerangi's initial reaction to the NICU was an unpleasant or distressing experience, where the trauma of just being there was horrible. The ways in which staff approached her, their professionalism and support, helped her develop a much needed sense of trust in the staff, and she ended up feeling very differently about her NICU experience in the end.

*The staff were excellent, they didn't do anything without giving us reasons, of why they had to do the things they allowed us to make his incubator thingy as comfortable and non-threatening as we wanted it to be, they understood the value, the importance of why, if my family turned up in, and they all wanted to go in, not all together, but if they all wanted an opportunity to go in, they knew why it was important for me, Jason, and for baby...*

Waihekerangi thought it was fantastic when she received a book that was a resource that she could use to document all the changes that baby went through. The exercise book allowed her and the NICU staff the availability to record everything in it. She felt that the book really helped. The ability to hold onto those moments by recording each milestone provided them with a sense of connectedness, and the chance to fill it in during those quiet moments in the hospital while sitting beside their baby's bed, were really precious. Generally, at Waikato hospital, a book is given to parents of an infant that will be in hospital for a long period time, such as a low birth weight and premature baby. The nurses also make notations in the book (with parents permission) when the parents are not there, so that the parents can remain informed about how their baby did during that time that they were not there. These notations are usually written in a non-technical and parent friendly manner.

*...they were pretty thorough pretty quite thorough with us what they were going to do, the treatment Kaelim-John was receiving, where we stood as parents we were so strong being included having that time up in NICU I didn't feel like they*

*were imposing on us or Kaelim- John's wellbeing...*  
(Waihekerangi)

Te Ao Marama had been in the NICU before, and she validated Waihekerangi and Jason's story by acknowledging that it was a huge experience for them as first time parents, because the whānau as a whole, was dealing with an unknown situation. She then went on to say that she felt there was nothing that she could say; all she did was go with the flow.

*They leaned on that very day? they took in every word that the doctors were saying and my guidance that's what it was just guidance. (Te Ao Marama)*

When talking about the NICU she had commented that she felt that all she could give was guidance, because a lot of practices used these days were very different to when she had a baby. *"The greatest lesson that I had previously was that sometimes, deaf people don't hear me"* (Waihekerangi). Waihekerangi was aware that her verbal requests did not necessarily get put into practice and this was one of the examples she discussed.

*When I first gave Kaelim-John a bath, I had strictly requested that I did not wanna use any soaps, because it strips him of his oils, that's how I said it so I when and I asked for them, had a look at them, they had made me, they had written in my notes, like I was cooky or something, you know really nutty, coz I didn't want to bath him with soaps or anything, I requested, just water, and um she had not put down the reasons for it one of the nurses in the ward, had not put down my reasons, just saying no soap, you know and i was really, coz that was the first time, I'd ever fully understood that um it doesn't always [mean people understand]. (Waihekerangi)*

Waihekerangi had attempted to be as thorough as possible when communicating her request to the nursing staff. She was well aware of her rights as a mother of an NICU infant. She promotes having a midwife who understands the medical system and protocols, and whose willing to be an advocate for the whānau, which was very empowering when she facilitated the birthing process.

*Waihekerangi: Yes, it definitely helped facilitate the process, there was that, and it was also, I had a strong*

*advocate, my midwife was a very, very strong advocate*

*Keri: Ok*

*Waihekerangi: Yeah, so we, we spent a lot of time talking about how you know, um what are my expectations of her how do I want things to work in the hospital, and we spent a lot of time discussing my rights, as a patient and, and you know the expectations of me as a patient in the hospital, so I was very, very clear about my entitlement as a person who was using the health services and things like that...*

Waihekerangi discussed the importance of having an advocate who understands the institution that they were dealing with. She recognised that the information that her midwife shared, enhanced the communication processes within the hospital, and eased the stresses associated with being in an unfriendly environment.

Kaelim-John stayed in the hospital for a week, and once he was reunited with his mother in the wards, she needed help to become successful with breastfeeding.

*They were just keeping us under observations, seeing how I was feeding. I think I only breastfed for maybe a couple of days and then I needed help, I couldn't even express (breast milk) anymore, just was not enjoying it. (Waihekerangi)*

During her time when she was able to finally spend the night staying in a room with her son, she put him into bed with her and benefited from having him close to her so that she could feel his heart beating.

### ***Support networks***

Waihekerangi identified the differing support systems that were available to her during her pregnancy, birth, NICU experience, and once she was home. Firstly, during her pregnancy there was her whānau that consisted of her mum, partner, sisters, aunties, nieces, nephews, and midwife that educated her on her rights and empowered her to establish a birthing plan that involved the whole whānau. During her NICU and hospital admission, her midwife also functioned as her advocate in the hospital, and the whānau were regular visitors so that she would

know that they were supportive. Waihekerangi summarised her whānau support in the following way.

*While we were in hospital they were at home getting things ready for us, and my family turned up with everything that I possibly needed, there wasn't a thing that I didn't have. So it was about the things that they were, you know... it wasn't just about the support, but about just being there in person. It was about the provisions that came with [being whānau] and then there was the organising of the afterbirth. (Waihekerangi)*

When Jason was asked to discuss support people, he immediately referred to the medical staff. Jason's experiences placed him in a position where he had a lot of contact with the doctors and nurses. He found them to be very positive, encouraging and representative of a family friendly environment.

*Definitely the supporting doctors and the supporting nurses... This is the doctor. She is going to be on hand for your baby and they did give us the attention which was good. I didn't feel like we were taken away from the control and the input that we had with our son as time went on they'd say to us this tube is coming out because he had quite a few tubes... (Jason)*

When Te Ao Marama and I discussed support during the time in the NICU, she reflected on the fact that she was there for her daughter (Waihekerangi), and acknowledged that she felt that Jason would have loved to have his mother and family there as support people. She went on to discuss how she believed that since they were in an NICU environment, having the professional formal support was the the most important source of support necessary, as they were available to give that specialised help and guidance, and progress information that they (as first time parents) needed at the time.

### ***Transition to home***

This family was in the NICU for seven days and during that time, they were able get their heads around having a child, and felt that the time in the NICU allowed them to do that because it was their first child.

*We weren't instructed on how to care for him but Nicky said she would call in from time to time. With our midwife because she was such a strong advocate for the mother and the child*

*that we were able to do that and we felt comfortable in taking him home... (Waihekerangi)*

When Waihekerangi and Jason took their son Kaelim-John home, they felt empowered and informed about what they had been through, what to expect, and they felt supported. Waihekerangi felt very supported by the people around her; those being her whānau and her midwife. She chose to put Kaelim-John on the bottle because she had the practical support of her younger sister.

*She stayed with me till I got home and Jason was one of those dads, that has no problems with changing stinky bums and doing that extra stuff so that all I had to do, is just feed the baby. (Waihekerangi)*

Jason then ended his story by talking about the fact that Kaelim-John suffered from asthma, and ended back in the hospital the second night after they first arrived home. Jason and Waihekerangi would stay at the hospital for almost up to 9-10 hours a night, and then Jason would go to work in the morning and come back in the evening, and this was ongoing for the first 3-4 years where things didn't change until they moved to Napier. They are now living in Waharoa and Kaelim-John is doing well.

### ***NICU reflections***

The interactions of this whānau with the NICU developed into a meaningful relationship that occurred because Waihekerangi had planned for the event. She demonstrated through her story, that she valued pre-planning, and had successfully created a plan that catered to every scenario that they could think of, hence, when asked if she had any advice for someone who might be in this situation, Waihekerangi suggested having a plan. While she acknowledged that it may not make the experience easier, it really helped her feel that she was in control. Another suggestion that she put forward was that you should use your support people, as she felt that having her midwife as an advocate was really important. When reflecting on how she felt as a Māori woman in the NICU, Waihekerangi's views were similar to that of Carianne's experiences, in that she started by focussing on her overall perceptions of how the staff treated her and her whānau. Waihekerangi further explained how she perceived NICU service

delivery and the quality of care that her son received. Her experiences and observations were that all the infants received the same excellent quality of care, she had formed positive relationships with the NICU staff, and was well assisted by her midwife because she knew the medical institute and the way in which the systems work.

## CHAPTER FOUR: ANALYSIS

This chapter presents an analysis and discussion of the key themes and similar experiences that were identified across six whānau shared narratives, about their experiences of being in the Neonatal Intensive Care Unit (NICU) at Waikato Hospital. The reconstructions of their experiences cultivated unique insights into their personal and whānau narratives as parents and whānau members.

For the analysis process, I chose to focus on participants' current understanding of those events as they storied their experiences (Murray, 2000). Each whānau member was offered the time to tell their story in its entirety, and every effort was made not to fragment their lived experiences. It was a strategic intention to refrain from pathologising participants' experiences by using a narrative approach. In this way, I could listen and record their narratives as participants constructed their stories from their own understandings. Each whānau narrative was told when the whānau were at differing stages of understanding their experiences, which offered a unique opportunity to research how they went about constructing their story. These differing stages also provided the opportunity to gain insight into how the participants developed a meaningful understanding of the significant moments that occur for the whole whānau. This also allowed them to reconstruct their stories in a way that made sense for them (Bruner, 1991; Bury, 2001; Frank, 1995; Murray, 2000).

The illness narrative literature reinforced the view that informing others of the impacts, suggesting differing approaches, and warning people of the pitfalls, was an empowering way for the lay person to make sense of their experiences while helping others (Bury, 2001; Frank, 1995; Lawton, 2003). The research process that I engaged allowed the relationship between myself as the researcher, and parents as the researched, to develop into a parent-to-parent connection. This process enabled the participants to be reflexive in their experiences, and engage with the research process, so that it could be a meaningful experience for themselves and others who read their experiences (Crotty, 1998; Etherington, 2004; Hodgetts et al., 2004).

This analysis chapter is structured to present the narratives as collective experiences to draw out the similarities that occurred across the differing whānau narratives. The findings represent the participants' birthing experiences, transitions through an NICU to home, and the key relationships that were utilised during these transitions.

## **Birthing experiences**

All the mothers were invited to begin their narrative by discussing their pregnancy and birthing experience. The birth of a baby is an experience that is unique to each whānau (Ellis, 1998; Rimene et al., 1998). The following section provides discussion on the mothers' birthing experiences by offering two examples from mothers that did not receive antenatal care, and the impacts they they experienced. This section also presents two examples from mothers who did access antenatal care and the benefits they experienced. Two of the participants discuss how they incorporated cultural birthing practices into their birthing experience. The section ends with a discussion of the benefits that the mothers and whānau experienced when whānau were involved in the birth of their baby.

### ***Antenatal care***

Two of the participants interviewed were young mothers. Both discussed how they were surprised to find out that they were pregnant. Jade, aged 19 years, was in premature labour when she was first informed that she was pregnant. Hirini, aged 17 years, was 5-6 months pregnant when she found out, and then accessed a midwife. Both of these young mothers experienced high levels of stress when they first entered the NICU because they were unprepared for the birth of their babies.

Waihekerangi and Carianne had miscarriages prior to the birth of their babies. These womens' narratives identified their previous miscarriages as indicators that they were more likely to be at risk of developing health issues during their pregnancies. To reduce any health problems that could occur during their pregnancy, both of these mothers sought and received antenatal care throughout their pregnancy. Pre-existing and concurrent personal and family factors such as

the loss they were experiencing with their miscarriages is a stressor acknowledged in the research (Holditch-Davis & Miles, 2000). Expressions of joy can be coupled with fear and anxiety for the impending birth (Talmi & Harmon, 2004). Utilising antenatal care lessened these mothers' anxieties about their impending birth. Waihekerangi and her whānau also directed her antenatal care and birthing plan so that they would be prepared for an NICU admission.

Jade and Hirni's stories highlight the importance of having accessible sexual health education for youth. The stories of Waihekerangi and Carianne highlight the importance of accessing good antenatal care during pregnancy. Positive outcomes for Māori in prenatal services necessitate that policy founded in providing best practice for Māori (Ministry of Health, 2002a) and family centred care (Ministry of Health, 2002b), translate to culturally safe practices that ensure a strong healthy start for new whānau members. The implications suggest that Māori mothers, young and old, and their whānau, are more likely to feel in control and empowered when there is positive communication and inclusion in the birthing process, regardless of any medical interventions that may occur.

### ***Cultural birthing practices***

Two of the mothers were explicit about the Māori cultural practices that were incorporated into their whānau birthing plans. These included traditional cultural practices of karakia (prayer), and use of an ipu (clay pot) for returning the whenua (afterbirth or placenta) to papatuanuku (earth) (Rimene et al., 1998; Te Huia, 2005). What follows are two different examples of how Waihekerangi and Shanette incorporated these practices into their birthing plans, and their subsequent experiences.

Waihekerangi and her whānau employed practices of karakia, use of ipu, and retaining of the afterbirth into their birthing plan, because it was a cultural and whānau tradition. She was able to retain control of their birthing experience because she had developed a whānau birthing plan with her whānau, midwife and hospital staff. The result for her was that they were able to maintain their whānau rituals that had been a part of their history, and with pre-planning, they were able

to continue the family tradition regardless of the disruption with their baby being transferred into the NICU.

Shanette's birthing experience story also involved cultural practices. Shanette's nan did karakia and was attempting to help Shanette bond and feed her baby for the first time when they were interrupted by the midwife. In Shanette's narrative, she discusses the the distress that her and her whānau experienced because of the disruption to their natural whānau practices. The resulting negative impact for this whānau and a lack of informed consent about what was going to happen precipitated the shock they endured throughout the transition to the NICU.

### *Whānau involvement*

Because of the varied circumstances during the birthing experience, only some of the mothers were able to have their whānau members present as support people. In those instances where whānau were present, the narratives reflected the emotional, cultural, and spiritual connectedness that they experienced by having whānau with them. Some mothers identified that they were unable to have their whānau present during the births of their babies for varying reasons. Their stories reflected participants' feelings of loss with not being able to have their whānau as support people.

## **Transitions through the NICU**

When I spoke to participants, each whānau narrative represented their individual whānau journey into, and through, an NICU. This section discusses the similarities across the groups and provides examples to reflect their stories. Areas addressed in this section includes: their whānau narratives of how they entered the NICU, being separated from their babies, and their coping strategies. Separation and breastfeeding are discussed and examples are provided. Also, how mothers adjusted to the transitions through the NICU, and successful bonding practices are discussed. All the findings were consistent with the breadth of research that exists about mothers experiences of an NICU environment.

The mother and whānau narratives within this research reinforced that there are many different reasons associated with an infant's admittance into an NICU

(Bradford, 2000; MacArthur & Dezoete, 1992). Infants like Te Hinairo (Jade's son) born at 27 weeks gestation, and Matai (Hine's son) born at 26 weeks, were considered to be *very* low birth weight (less than 1500g/3.5 pounds) and at least 3 months premature (O'Brien et al., 1995). Due to their prematurity and low birth weights, both were at risk of primary complications of immature development of major organs. Jayton (Carianne's son) and Te Kanakana Rose (Shanette's daughter) were considered to be low birth weight because their infants were less than 1500g (3.5 pounds). However, Te Kanakana Rose (Shanette's daughter) was not considered premature because she was born after 37 weeks gestation (O'Brien et al., 1995).

Research has shown that there are mothers who have felt unsupported while adjusting and progressing through the differing transitions associated with the infant's medical well-being (Franck et al., 2005; Griffin et al., 1998; Jackson et al., 2003). The mothers in this research reported that their initial experiences in the NICU included feeling shocked or overwhelmed by the environment and technology in the unit, with some of the mothers experiencing physical manifestations of their shock by feeling dizzy or nauseous. The initial shock that all the mothers experienced when entering the NICU environment and being separated from their infant, was similar to those experiences already documented (Franck et al., 2005; Heermann et al., 2005; Holditch-Davis et al., 2003; Holditch-Davis & Miles, 2000).

### ***Mother and infant separation***

All the participants' narratives identified how the differing stresses affected their natural processes of being a new mother attempting to bond with their new-born infants' admission into the NICU.

Jade, Shanette, Hine, and Waihekerangi were not from Hamilton. All of these mothers were from rural communities within the Waikato and Thames/Coromandel regions. Hence, the overwhelming setting of the NICU and being forced to stay in a foreign city compounded their initial shock of being separated from their babies. A clear example of how being separated from their babies affected the natural process of bonding was manifested in Jade's anxiety

combined with her homesickness, which increased her psychological and emotional stress. Parallel to this, was separation after birth due to their child's need for admission, and the medical interventions essential for the infants well-being. Waihekerangi's shared whānau story also provided another example in which they had prepared themselves for the NICU. However, the reality of the situation remained an overwhelming experience, irrespective of their preparation (Harrison & Kositsky, 1983; Madden, 2000). Examples in the mothers' narratives highlighted other factors in the NICU, such as the incubator as a barrier to touching; delayed holding; and the mothers' proximity to the infant, which further delayed the bonding process (Franck et al., 2005; Griffin et al., 1998).

### ***Coping with mother and infant separation***

The findings showed that as the participants reflected on their experiences, they were able to identify some of their initial coping strategies. Some of the mothers and whānau members adjusted faster to the NICU environment because they were orientated into their environment by nurses who were able to take time to explain what was going to happen, and what would happen to their newborn. Examples of some of their initial coping strategies are discussed below.

Carianne and Hine recalled how they were informed of their babies' conditions and showed pictures of their sons. It is common practice for the NICU staff to provide a mother with a photo of the newborn to a mother who is unable to be moved due to their medical trauma (Griffin et al., 1998). Having a picture can help mothers feel connected to their baby while they heal and ease their stress (Griffin et al., 1998). Carianne was unable to go and see her baby in the NICU for two days, so having a picture of her son helped her to be connected with her son. Hine also used her picture to stay connected with her son until her whānau could arrive.

Waihekerangi discussed how when she first arrived at the NICU, it was all a blur. She recalled the struggle she experienced by saying she was not able to cuddle him when she arrived in the NICU (Franck et al., 2005; Griffin et al., 1998). Her partner, Jason, talked about how he had reminded Waihekerangi that she was able to put her hand in the incubator. So during the time that her son (Kaelim-John)

was in the NICU, she felt that he was in the best place because of the specialised care that he was receiving. Research supports the findings that delivering early is a confusing experience, and not surprisingly, research supports this finding also (Griffin et al., 1998).

### ***Separation and breastfeeding***

Research proposes that separation from an infant can intensify the negative stresses and have a negative effect on the ability to breastfeed (Bartle, 2004; Jaeger et al., 1997; Spangler, 1995). Mother and infant separation, and the demanding nature of the NICU can make feeding extremely difficult for mothers to initiate and sustain breastfeeding and expressing milk (Bartle, 2004; Callen & Pinelli, 2004; Jaeger et al., 1997; Spangler, 1995).

Four of the participants discussed their adversities and barriers when they were attempting to breastfeed in the NICU. Jade had difficulties trying to build and maintain her milk supply, while also attempting to travel home so that she could be with her whānau in Taumarunui. Hine also experienced homesickness from being separated from her whānau, which resulted in her milk supply running out. Hirini and her mother discussed how they did not receive any support or information to help Hirini breastfeed. Shanette spoke about waiting to return to her hometown so she could have whānau to support around her while breastfeeding. It is clear that mothers that have adversities and barriers when attempting to breastfeed a neonate, require support (Davanzo, 2004).

### ***Successful breastfeeding in an NICU***

Providing an holistic environment can be influential for positive experiences of expressing milk and breastfeeding (Bartle, 2004; Latto, 2004). A key factor discussed in three of the mothers' success stories of breastfeeding involved having whānau support.

Shanette described how she was able to breastfeed once she was back in her hometown, with her nan and her aunt supporting her to feed her baby. Hirini also received support from her mother to breastfeed. Waihekerangi sought support from the nurses in the hospital to become successful with breastfeeding. These

findings highlighted that mothers can successfully feed their babies through expressing or breastfeeding, when positive experiences and supports are put into place that meets their needs (i.e whānau support). Although the natural process of breastfeeding can be compromised when entering an NICU, it does not necessarily mean that the experiences need to be negative.

### ***Successful bonding practices***

All the mothers acknowledged that being separated from their infant by the incubators and technical equipment that housed their babies were significant barriers, yet the practice of kangaroo care was recognised by all the parents to be a source of enjoyment that promoted bonding.

Kangaroo care (KC) is a common practice used within the NICU at Waikato hospital, and the benefits are well documented (Davanzo, 2004; Ludington- Hoe & Golant, 1993; Roller, 2005). The need for skin-to-skin contact for the infant and the mother is more than just medical; mothers are provided with a way of getting to know their baby's likes and dislikes, and it increases bonding tenfold (Ludington- Hoe & Golant, 1993; Roller, 2005). Research shows that a mother supported by the nurses to partake in KC is provided with benefits that extend beyond the essential physical gains that happen for the infant and comforting experience that occurs for the mother. The synergistic interaction of skin-to-skin contact with an infant provides an important means of developing and strengthening maternal identity, while getting to know their infants patterns and preferences (Ludington- Hoe & Golant, 1993; Roller, 2005).

## **Relationships in the NICU**

This section discusses the differing types of relationships that the participants utilised while they transitioned through the NICU. The NICU staff, which includes the doctors, nurses, and affiliated staff, are discussed. Particular attention is given to the nurses relationships with whānau members. The importance of whānau relationships and the types of support that whānau provide are discussed. This section ends by recognising the other types of support, such as parent-to-parent support.

Parents are not visitors, and feeling like an unwelcome guest can induce feelings of inadequacy, anxiety, and fear (Davis, Edwards, Mohay et al., 2003; Heermann et al., 2005). Parents want interaction and communication that is respectful of their vulnerability (McGrath, 2005), and they are aware of the power and control that medical personnel have because of the control over their environment (Hurst, 2001). However, when professionals show indifference, families can feel isolated (Talmi & Harmon, 2004). Research supports that parents want to be communicated with openly and honestly, in a dignified way that respects their vulnerability (Griffin et al., 1998; McGrath, 2005).

### ***Relationships with NICU staff***

It is obvious to all my participant families that the staff of the NICU have control over their environment. As such, being perceived positively by NICU staff, as indicated in research by Hurst (2001), positively equated to having an insurance policy for their baby.

In Shanette's narrative, her perceptions were that NICU staff were not approachable, and that there were incidences when she and her whānau were treated like naughty school children when they relinquished control of their birthing situation to the medical professionals. This is a more extreme example of the parents' perception of who had control of their baby. Tilokskulchai, et al. (2002) had research participants that would wait for the nurse's permission to touch their babies rather than be chastised by the on-duty nurse. The measure by which Shanette and her whānau were indoctrinated into the NICU was an experience of feeling disempowered, uninformed, and even uninvolved in the decision making process. Feelings of stress are heightened for the parent when inadequate communication creates uncertainty regarding the norms of the NICU.

Parents want help in understanding what is happening to their infant (Griffin et al., 1998; Talmi & Harmon, 2004). Waihekerangi discussed the importance of having an advocate who understands the NICU. Her midwife acted as her advocate, and enhanced the communication processes within the hospital and eased her stresses associated with being in an unfriendly environment. Parents

need to know that they are heard, as trust includes being listened to in a sensitive and responsive manner (Henry, 2004).

A large proportion of literature focuses on the medical and technical advancements that have occurred within the neonatal field (March of Dimes, 2005b). Throughout all the stories, the participants never reported any doubts about the medical expertise and technological advances within the NICU. On the contrary, some of the participants spoke openly about their appreciation of the medical expertise, and in some cases, their silence in this area actually articulated their satisfaction with their infants' medical treatment, and allowed them to focus on constructing a narrative that allowed them the scope to discuss their experiences in the NICU.

The role of a parent is fundamentally important to the health and well-being of the infant and their whānau. Research has acknowledged that when mothers are consistently well informed concerning their infants' hospitalisation, they feel empowered and included, and can cope more effectively with the stress (Bartle, 2004; Davis, Edwards, Mohay et al., 2003; Griffin et al., 1998; Holditch-Davis & Miles, 2000; Roller, 2005; Tilokskulchai et al., 2002; Wepa, 2004).

### ***Relationships with NICU nurses***

All the participants in this research discussed nurses as a vital source of support for themselves and their whānau in the NICU. Parents are aware of the power differentials that exist that position nurses as the 'expert' (Hurst, 2001). All of the participants in the whānau interviews reported on their interactions with the nurses. As such, there was agreement throughout their reflections, that the role of the nurses was deemed to be of utmost importance. Similar to the comments made in research, nurses were considered to be the key communicators of information and primary facilitators of care during the period of hospitalisation (Bartle, 2004; Davis, Edwards, & Mohay, 2003; Griffin, 2006; Holditch-Davis & Miles, 2000; Roller, 2005; Wepa, 2004).

Working collaboratively with the nurses is the ideal situation for the parents to be able to learn and be supported in understanding how to care for their baby

(Holditch-Davis & Miles, 2000). When a parent is shown how to move from being a nervous observer to an active participant, then they are more likely to claim their baby as their own (Heermann et al., 2005). Two of the participants gave examples of how they moved from being nervous observers to actively caring for their baby in the NICU. Jade spoke about how the nurses helped her understand the medical equipment that kept her baby alive. The nurses also praised her when she did her baby's care routines, which made her feel more comfortable within the NICU. Carianne gained confidence with being shown how to care for her baby. This confidence increased her willingness to actively care for her baby. Parents and families that are respected and encouraged to be part of a partnership that nurtures a relationship of reciprocity, creates a more affective environment (Davis, Edwards, Mohay et al., 2003; Holditch-Davis & Miles, 2000). Jason's experiences in the NICU supports the literature in this regard. Jason felt that his whānau were respected and able to retain parental control while in the NICU.

The boundaries between the parent and nurse at times, can become blurred, because of the specialised equipment and roles within the NICU that can render the families feeling powerless under the restrictions of what they are allowed to do, especially for a mother wanting to be with her baby (Griffin et al., 1998). Shanette, Hirini, and their whānau members all experienced feelings of frustration and powerlessness. These feelings were exacerbated by the cultural miscommunications that they experienced in their stories. Cultural differences can be a barrier for parents to be able to fully understand all the information being communicated (Talmi & Harmon, 2004). Nurses are, to a large extent, the primary source of advice and information regarding the infant, and research has shown that it is crucial that nurses communicate to parents in a respectful manner (Davis, Edwards, Mohay et al., 2003; Griffin et al., 1998; McGrath, 2005).

### ***Efficacious communication***

It has been documented that although parents start off being passive receivers of information, they can only evolve into active seekers of information when staff create a positive and effective environment (Heermann et al., 2005; Hummel, 2003). Efficacious communication for the purpose of this research has been

defined as the ability of the support people (formal and informal) to produce positive results through effective verbal and non-verbal communication. Another critical component of efficacious communication with Māori requires the communicator to be culturally responsive, so that the recipient feels empowered and supported (Henry, 2004; Ministry of Health, 2002a; Ramsden, 1993).

The participant accounts provided clear examples of efficacious communication with nurses. Some examples below illuminate the participants' experiences when communication is used to produce positive results. When parents are informed, this can generate a positive environment and extinguish the overwhelming anxieties that a mother has regarding their infant's caregiver (Talmi & Harmon, 2004). Carianne gained more confidence in her maternal ability, by having a nurse teach her the skills that she needed to be part of the NICU. Allowing more responsibility and control over her baby's environment increased Carianne's confidence in her own ability to mother her infant in a foreign environment (Tilokskulchai et al., 2002). Waihekerangi thought it was fantastic when she received a book that was a resource that she could use to document all the changes that baby went through (Griffin et al., 1998).

### ***Relationships with whānau***

All of the mothers expressed how their whānau were extremely important support people during their time within the NICU. There is a sparse amount of research regarding family experiences, and the majority of these experiences focus on the mothers (Doucette & Pinelli, 2004; Jackson et al., 2003). Focussing solely on the mothers leads to fathers being underrepresented and other family members not being included at all (Doucette & Pinelli, 2004; Jackson et al., 2003).

I intentionally developed this research to be inclusive of fathers and other whānau members, to allow for the shared dialogue that naturally happens within whānau. The findings acknowledged the way in which whānau were able to share their experiences. For example, the whānau hui with te whānau o Kaelim-John/Manauri included the father's perspective (Jason), and a grandmother's point of view (Te Ao Marama). Their whānau narrative had evolved over time, hence their individual narratives were compiled to represent their shared story. The

other whānau hui with te whānau o Jahvon included a grandmother (Mavis) and an aunt. Their whānau narrative hui revealed that their whānau story was just beginning and captured their experiences at a time when they were still in the process of developing a whānau experience through shared dialogue. The importance of responding to these naturally occurring and interactive elements within their shared narratives, produced composite stories of their experiences and made it meaningful for them. This process also allowed the father and other whānau members involved in this research, the opportunity to discuss their role in their whānau birthing experience and NICU admission.

Whānau and friends are valuable sources of support. Participants stories were congruent with past research show that parents within an NICU tend to seek emotional support from sources that they can identify with, such as their family members and friends (Griffin et al., 1998). Whānau and friends become even more important when parents are in a foreign and scary environment, such as the NICU (Franck et al., 2005; Griffin et al., 1998; Tilokskulchai et al., 2002).

### *Whānau support*

There were a range of ways in which whānau members provided support for the mothers and/or parents of neonates. Support requirements of mothers who lived outside of Hamilton differed to the mothers who lived in Hamilton. A major source of distress for the out-of-town mothers involved having to be separated from their babies because they had to stay in alternative accommodation, such as the Hilda Ross premises at the hospital. These mothers were not familiar with their environment and had less preferred support systems (whānau) available to them.

Jade and Hine were mothers that were not from Hamilton, and their infants had to remain in the NICU for an extended period of time, due to their prematurity and high medical needs. These mothers travelled back to their hometowns regularly so that they could seek support from their whānau. This strategy of ‘cultural time out’ (Ritchie, 1976), enabled them to cope within a stressful environment with little or no whānau support available on a daily basis.

The whānau of Shanette and Waihekerangi are a normal representation of the diverse realities and complex relationships that Māori live in (Durie, 2001). Both of these mothers had ongoing whānau present at the hospital to support them. Shanette's negative experiences of being questioned on the legitimacy of her whānau created unnecessary stresses, and was not congruent with the Ministry of Health (Ministry of Health, 2002b, 2004b) best practice guidelines that support culturally safe practices (Ramsden, 1993). Due to negative treatment that she and her whānau experienced throughout her transitions in the NICU, her narratives have remained negative, even after five years. To regain ownership of her experiences, Shanette positively discussed her transition to home in Matamata, where her whānau were welcomed into the small maternity ward, and could provide her with the support she needed.

Waihekerangi's whānau supports, particularly her partner Jason, were at the hospital on an ongoing basis throughout her baby's NICU stay. All members of her whānau were aware of the NICU environment and were able to provide the support she needed when she needed it.

### ***Relationships with other support people***

Parents who are going through a traumatic experience find it helpful when they are given a chance to meet others with similar issues, or others who can empathise with the circumstances of the situation/event (Ireys et al., 2001; Purk, 2004). Jade discussed how she liked meeting and talking to other mothers while she was in the NICU. Jade and I had met when she came into the Family Care/Awhina Whānau office looking for someone to talk to. Talking to others lessened the stresses of being away from her whānau.

All the participants were given the opportunity to share any suggestions that they may have had for other mothers and whānau in the future who may go through similar experiences. One of my participant's provided suggestions during their narrative. Waihekerangi suggested two things: firstly, the importance of having a birthing plan. Secondly, she suggested that a mother in the NICU would benefit from having a support person that could act as an advocate, such as she had with her own midwife.

## Chapter summary

The analysis of the combined narratives revealed how parents make sense of their own experiences. Key events and experiences that emerged across the participants' stories included their birthing experiences, the transitions through the NICU to home, and key relationships that they utilised. The findings showed that being prepared (ie, antenatal care during pregnancy and a birthing plan), can lessen the impact of any medical interventions that may occur. The findings also showed that initial shock and confusion that occurs during the transitions through an NICU are reduced when parents are informed and supported throughout their infants' admission. The coping strategies utilised by the mothers and whānau members involved their key relationships with NICU staff, and more specifically, nurses. Staff support was vital for positive experiences. Efficacious communication within their relationships was considered ideal for positive outcomes. The mothers' narratives also confirmed that having whānau support was considered to be the most valuable source of support for mothers in an NICU. Where whānau were unable to be there to support, other support people such as parents who had similar experiences, were helpful in lessening the stresses of being away from their whānau.

## **CHAPTER FIVE: CONCLUSION AND REFLECTIONS**

The core focus of this study was to contribute meaningful insights into understanding regarding how Māori whānau members construct their experiences of childbirth that leads to a Neonatal Intensive Child Unit (NICU) experience.

My findings brought to light three levels of implications. Firstly, the participants' narratives and their experiences provided a range of coping strategies for future Māori parents and their whānau who enter an NICU. Secondly, there are implications for NICU policy, particularly when supporting Māori in an NICU environment. Lastly, the narratives shared by the participants contribute to filling gaps in literature at local, national and international levels about understanding Māori and family experiences of an NICU.

The findings revealed that the effective coping strategies did not remove the sources of stress but rather, lessened their impact. In situations where sources of stress were unable to be removed or reduced, participants perceptions of ineffective coping translated into narratives of negative perceptions of the NICU and birthing experience. To increase the chances of having a positive experience, irrespective of the transitions through the NICU, the findings revealed that there are key events and therefore key strategies that can lessen the impacts of any stresses.

The birthing experience is a key event. Therefore, being prepared for the birth through antenatal care, and having a birthing plan was a key strategy employed by the mothers who discussed positive birthing experiences in conjunction with medical interventions. Other key events were the initial experiences of an NICU and transitions through an NICU to home.

The complexities involved in coping within the NICU environment produced a wide range of coping strategies, involving formal and informal support systems. Relationships with NICU staff and in particular, nurses, were vital for participants. Also seen as a key strategy was the ability to have access to a support person to act as an advocate on behalf of the mother and her whānau. Positive

results occurred and stresses were lessened when staff used efficacious communication. Understanding the NICU environment and being supported to undertake and maintain as many mothering duties that increase successful bonding was important for the mothers' wellbeing and increased their ability to cope with the transition to home. This is reinforced by literature which states that providing information assists the parents to become confident and supported with their transition to home (Bartle, 2004; Holditch-Davis et al., 2003; Hummel, 2003).

All of the participants discussed the importance of being with whānau. Whānau members and whānau support were considered to be central to the health and well-being of the mother (Durie, 2001; Ministry of Health, 2002a; Wepa, 2004). Whānau support was compromised when understanding of the whānau by the NICU practitioners differed to the needs of the mothers. This finding highlights the importance of creating whānau/family friendly environments with culturally safe practices (Ministry of Health, 2002a; Ramsden, 1993; Wepa, 2004; World Health Organisation, 2005a).

Secondly, the findings have implications for nursing, medical and other health care professionals working in the NICU. Understanding the nature of stress for Māori and their coping abilities is vital for professionals providing support to whānau.

Māori whānau participants had been in the NICU at differing times, yet the experiences revealed comparable issues across the narratives. Overall, their experiences revealed that the negative experiences that they had were unnecessary, and that positive experiences were possible if medical and nursing staff understood the nature of stress that Māori experience, coping abilities, and preferred supports. Parents responded positively to nurses when they were:

- Friendly
- Approachable
- Informative
- Educative
- Family orientated
- Culturally safe

When nurses work collaboratively with parents and take time to orientate new mothers and their whānau into the NICU, there are benefits for the health of the infant, mother, and well-being of the whānau (Davis, Edwards, Mohay et al., 2003; Griffin et al., 1998; Holditch-Davis & Miles, 2000; Jackson et al., 2003; McGrath, 2005; Ramsden, 1993; Wepa, 2004), and these findings have implications for NICU policy, and nursing best practice.

Thirdly, the core focus of this study was to contribute meaningful insights about understanding how Māori whānau members construct their experiences of childbirth and an NICU experience. The research successfully created a space for the mothers and their whānau members to share their stories. The range of narrative reconstructions stemmed from their current experiences, to events that had occurred five years prior to these interviews. Current experiences revealed that their birthing story was under construction, and that making sense of their experiences contributed to the individual and shared story. Stories at two and five years provided more lucid and clear descriptive accounts in comparison to those that had occurred earlier. Their narratives also made available a composite story that displayed their shared experiences that had developed into coherent and meaningful experiences that they all shared.

As a researcher, listening to the participants' stories and presenting them in a way that would be respectful of their individual circumstances, was an important part of the research process. The way in which these Māori participants constructed their individual and shared stories, has implications for the way in which people understand the support needs of Māori. The sharing of stories with others is commonly used within illness narratives (Bury, 2001; Frank, 1991, 1995; Williams, 1984), and reinforces the view that talking with others to share experiences, pitfalls, and strategies is empowering for the both listener and speaker. The closure of Family Care/Awhina Whānau was a disappointing event. This research highlights the necessity of Māori whānau in these situations, and the support of an organisation and its empathetic workers that provide culturally appropriate support.

Finally, understanding other Māori parents and their whānau narratives was a personal journey. This thesis topic originally emerged from my personal experience of having a premature baby in the NICU at the Waikato hospital. I found out that just like me, these mothers, and other whānau members, constructed narratives that were meaningful accounts to be shared with others. This thesis provides one mechanism by which these participants' stories can be shared.

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## APPENDIX: INFORMATION SHEETS

### Appendix 1: Information sheet



#### *Whānau experiences of a Neonatal Intensive Care Unit*

#### INFORMATION SHEET (Parent interview)

*Tēnā rawa atu koutou*

*He mihi mahana ki a koutou katoa i tēnei wā.*

*Ko Keri Thompson tāku ingoa. Nō Te Whare Wānanga o Waikato.*

#### ***What is this study about?***

This study aims to explore Māori whānau experiences of having a premature or special care baby in the Neonatal Intensive Care Unit at the Waikato Hospital. The study will look at the coping strategies that individuals and family members employ; their support systems within the hospital environment, and when they go home; and how they cope/adjust in their environment. It is hoped that this study will offer insights, raise awareness, and provide some practical and advantageous suggestions towards the area of supporting Māori whānau members in the NICU at the Waikato hospital.

The project is being conducted by Keri Thompson and is supervised by Dr Darrin Hodgetts and Bridgette Masters from Waikato University.

#### ***What am I being asked to do?***

You are being invited to take part in an interview about your experiences of having a premature baby in the Waikato hospital Neonatal Intensive Care Unit. I am interested to know your story as a parent of a premature baby. How you coped/adjusted to the environment, what support systems you utilised, while in the NICU and once the baby was home, who your support people are, What you made of your experiences, what was missing from the experience.

The interview will take about one hour of your time. It will be organised at a time and place that is suitable for you. The interview will be audio-taped, although you are free to ask for the recorder to be turned off at any time.

#### ***What will happen to my information?***

All the information that you provide will be used in the study to find commonalities and differences in what Māori whānau member's think about their

experiences. The information provided will also help me write storylines about those experiences, processes, and challenges of having a premature baby that can be used to enhance the area of support to Māori families who have a premature baby.

***Will other people know who I am?***

Anonymity is your choice, if you would like a pseudonym (false name) can be put in place of your name, if any brief quotations are used from the discussions to illustrate common concerns that people have, and if you would like a particular pseudonym then that will be possible too. A summary report of the interview will be made and these will be made available to review (if requested). At the end of the study, the tape-recordings will be destroyed. And I will send you a summary of our findings at the end of the study

***What can I expect from the researcher?***

If you decide to participate in this project, the researcher will respect your right to:

- ask any questions about the study at any time during participation;
- decline to discuss any particular issue in the focus group;
- withdraw from the study up to the end of the focus group discussion;
- ask for the audio-tape to be turned off at any time during the discussion.

***Who can I speak with about my participation in this project?***

If you have further questions or concerns, please contact Keri Thompson or my supervisors Darrin or Bridgette

Their contact details are below:

Keri Thompson, Department of Psychology, University of Waikato, Private Bag 3105, Hamilton. Phone: (07) 838 4466 ext 6456 Email: kat@waikato.ac.nz

**Supervisors**

Darrin Hodgetts, Department of Psychology, University of Waikato, Private Bag 3105, Hamilton. Phone: (07) 838 4466 ext 6456 Email: dhodgetts@waikato.ac.nz

Bridgette Masters, Department of Psychology, University of Waikato, Private Bag 3105, Hamilton. Phone: (07) 838 4466 ext 6456 Email: bridge@waikato.ac.nz

*Noho ora mai i raro i te manaakitanga o te Atua. Pai marire.*

**Na Keri Thompson**

## Appendix 2: Background information sheet

### *Background information*



#### *Demographic Details*

Name \_\_\_\_\_

Iwi/Hapu \_\_\_\_\_

Maritalstatus \_\_\_\_\_

Gender \_\_\_\_\_ Age \_\_\_\_\_

#### *Children's details Name and DOB of children*

##### **NICU Infant**

Name \_\_\_\_\_ DOB \_\_\_\_\_

Gestation \_\_\_\_\_

##### **Name and DOB of other children**

Name \_\_\_\_\_ DOB \_\_\_\_\_

Name \_\_\_\_\_ DOB \_\_\_\_\_

Name \_\_\_\_\_ DOB \_\_\_\_\_

Name \_\_\_\_\_ DOB \_\_\_\_\_

#### **Contact Details**

Address \_\_\_\_\_

Town \_\_\_\_\_

Phone \_\_\_\_\_ Email \_\_\_\_\_

## Appendix 3: Discussion areas



*I would like to hear about your experiences in the Neonatal intensive care Unit?*

The focus of any of the stories that you share during the interview and/or the whānau focus group discussions will revolve around four key areas.

### *1. Adjusting to the NICU*

**The first area of questions will involve finding out about how you as a parent/ whānau member adjusted to the NICU after your baby was born.**

Eg: What have been some of the significant factors that have impacted on you as a parent/whānau member while being in the NICU?

### *2. Support People*

**The second area of questions will entail finding out who are/ or were the people or whānau members that supported you and your baby while in the NICU?**

Eg: Can you tell me how you utilised your whānau while in the NICU?

### *3. Support Services*

**The third area of interest is finding out what (if any) support services you accessed while in the NICU? For example: any organised support like Hospital support Social worker, or Parent support groups**

Eg: Can you tell me how you utilise the support services while in the NICU?

### *4. Adjusting at home*

**The fourth key area of questions involves hearing about how you as a parent/ whānau member adjusted to your home environment with your baby after the NICU.**

Eg: Can you tell me about your experiences as a parent in adjusting at home after having your baby in the NICU?

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