DEVELOPING PALLIATIVE CARE MODELS IN NEONATAL NURSING:
AN INVESTIGATION OF BARRIERS AND PARAMETERS FOR PRACTICE

by

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Thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy in the Department of the Institute of Health and Biomedical Innovation, Queensland University of Technology
Statement of Original Authorship

“The work contained in this thesis has not been previously submitted to meet requirements for an award at this or any other higher education institution. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made.”

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ABSTRACT

The neonatal intensive care unit (NICU) is frequently occupied by newborns who are marginally viable, or critically unwell, and could be considered terminally ill. It is a busy, highly technical environment with an arsenal of life-saving medical equipment at its disposal, and advances in technology used in this field stretch the boundaries of viability. Despite technological advances, increases in the margins of viability and highly skilled healthcare delivery, some newborns will still die in the NICU. In recent years, palliative care for the neonatal population has become increasingly topical and part of the lexicon of contemporary neonatal practice. Evidence-based protocols are available to inform this model of care, yet in reality, provision of palliative care to newborns is ad hoc. The reasons why implementing a palliative model of care have been problematic are unclear.

The purpose of this study was to identify the barriers and facilitators to palliative care practice in neonatal nursing, and to develop policy recommendations to improve this area of practice. This exploratory research was conducted to answer two research questions:

1) What are the barriers and facilitators to palliative care practice in neonatal nursing?

2) How can the identified issues be addressed to inform policy and clinical guidelines in the practice environment?
Phase one of this investigation developed, pilot tested, and administered an instrument to identify the barriers and facilitators to practice. Data analysis identified three subscales that indicated facilitators and barriers to palliative care practice. The second phase of this study used a translational research approach, utilizing interpretive methods to explore and contextualise the population study findings to inform policy development to improve palliative care practice in neonatal nursing.

This research has identified that the facilitators that do exist for palliative care practice are subject to caveats that impinge markedly upon these facilitators. Furthermore, the barriers that were identified pose threats to the integration of a palliative model of care into Australian neonatal nursing practice. Thus, the overall results from this research have lead to a composite understanding of the barriers and facilitators to palliative care practice in Australian neonatal nursing, which may account for the gap between support of palliative care for marginally viable and critically ill newborns, and the application of this model of care in clinical practice. Translating the survey findings into policy directives that are applicable to the clinical environment has resulted in the development of recommendations that are aimed at improving palliative care practice in the NICU.
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CHAPTER 1 - Introduction

‘If we are able to improve quality at the end-of-life for patients and families, it is our obligation to do it. After all, their hopes and dreams for the future die with their infant, their memories should include the knowledge that their baby was comfortable and well cared for until the end.’


1.1 Background

The neonatal intensive care unit (NICU) is frequently occupied by newborns who are marginally viable and critically ill. It is a highly technical environment with an arsenal of life-saving medical equipment at its disposal. These technological breakthroughs have had a profound affect on neonatal nursing practice, creating a practice environment fostering the attitude that technology can care for and save even the smallest, sickest of newborns (Raines, 1994b).

Whilst such technological imperatives have been implemented to improve survival, the development and influence of technology has never been more apparent than in today's health care setting. This is particularly apparent in the nursing and midwifery professions, resulting in a shift of emphasis whereby many technological devices have altered from being one of supporting clinical practice to that of being an essential requirement in treatment delivery. Neonatal nurses are at a stage that without the use of the many available devices, procedures could not be carried out safely. This continued development however, may be a double-edged sword.

The escalation of technology and medical advances have been responsible for an increase in neonatal survival in recent decades, yet these advances have been followed by an increase in later disabilities. Due to this expansion – including antenatal corticosteroids and postnatal surfactant treatment (Walther, 2005) – treatment options for newborn infants have increased, thus enabling neonatal nurses to provide care to newborns who previously would not have been intubated, or were presumed to be dying (Pierucci, Kirby, & Leuthner, 2001). Advances in life-sustaining medical technology present ethical concerns with a strong emotional component. Many of these newborns are born within the so-called ‘grey zone’ of
gestation of approximately 23–25 weeks (Keogh et al., 2007), and this may result in situations where healthcare professionals feel ‘held hostage’ by these technological imperatives (Hefferman & Heilig, 1999; Muraskas et al., 1999). This growing discomfort with technological imperatives has led some healthcare professionals in the NICU to hesitate about whether they would have their own extremely premature newborn in the NICU (van Zuuren & van Manen, 2006). Despite technological advances, increases in the margins of viability, and highly skilled healthcare delivery, some newborns will still die in the NICU, often as a result of extreme prematurity and other complex medical problems (Yam, Rossiter, & Cheung, 2001). This has given rise to many new ethical issues, including when it is appropriate to withhold or withdraw intensive care therapies, and what the needs of marginally viable and critically ill newborns, their families and caregivers, such as medical and nursing staff, actually are (Walther, 2005).

In recent years, palliative care for the neonatal population has become increasingly topical and part of the lexicon of contemporary neonatal nursing practice. An evidence-based protocol (Catlin & Carter, 2002) is available to inform this model of care, yet in reality, provision of palliative care to newborns is ad hoc (Cignacco & Zeitschrift-Für, 2004; Maginnes, 2002), and components of this protocol difficult to implement (Carter & Bhatia, 2001). The reasons why neonatal nurses have had difficulty engaging in a palliative model of care are unclear, as these questions have not been tested before. Furthermore, although the literature alludes to barriers to this practice, neither these barriers, or facilitators, have been well described in neonatal nursing.

Ethical concerns regarding the treatment of marginally viable and critically ill newborns resonate throughout the western world. In the majority of NICUs within developed countries, any newborn weighing more than 500 grams or a gestation of 24 weeks is likely to be offered intensive care (Yu, 2005). Throughout some of these countries, guidelines are being developed for the treatment of extremely preterm newborns. However, according to research from the EURONIC group – a research group to explore neonatologist practices in NICUs across Europe – marked variations have been emphasized in neonatal ethical issues between these countries (Arlettaz,
Mieth, Bucher, Duc, & Fauchère, 2005). Given this, ethical treatment dilemmas are endemic to most NICUs (Purdy, 2006) and appear to be driven by the issues already identified, and are related to advances in technology and pharmacology. This has resulted in increasing numbers of newborns presenting to the NICU, and the literature is saturated with escalating controversy over whether this type of healthcare is in the best interests of these newborns (Hack, Friedman, & Fanaroff, 1996). Each of these babies pose the same question to healthcare staff: How can we decide in his or her best interests (Baumann-Holzle, Maffezzoni, & Bucher, 2005).

Complicating these ethical concerns is the notion that the death of a newborn in this highly curative environment is a failure of medical science (Lo, Quill, T., & Tulsky, 1999). Whilst this highly technical environment saves the lives of newborns, healthcare needs to provide for the needs of newborns who will die before they leave the hospital. Newborns and infants have the highest death rate in the paediatric population (Pierucci et al., 2001), yet there is a paucity of data relating to palliative care for this population (Carter et al., 2004; Pierucci et al., 2001). Due to a lack of coordinated interdisciplinary services, dying children are often deprived of the benefits of palliative care (Carter et al., 2004), yet evidence of an increasing societal demand for palliative care provision to the neonatal population is reported in the literature (Conway & Moloney-Harmon, 2004; Maginnes, 2002; Romesberg, 2003).

Australian perinatal data indicate that the neonatal death rate was 3.1 per 1,000 live births, and the perinatal death rate 10.5 per 1,000 births in 2003 (Australian Institute of Health and Welfare, 2003). Data from the United States reports an overall newborn mortality rate of 6.7 per 1,000 live births in 2004 (Dept. of Health and Human Services., 2004), with 20,000 newborns born each year with conditions considered incompatible with life beyond the first year, and are essentially ‘born dying’ (Glicken & Merenstein, 2002). These data suggest that neonatal palliative care should be increasingly relevant, yet palliative care principles are inconsistently applied, and in the past two decades there has been growing recognition of the importance of palliative care for newborns with unviable outcomes (Sumner, 2006). Furthermore, inconsistencies in palliative care practice may evolve from the
historical association of palliative care with oncology or geriatric patients – not newborns and infants.

In 2002, Catlin and Carter (2002) in conjunction with a 101 member international Delphi panel, created an innovative neonatal end-of-life palliative care protocol. The goals of this protocol were to provide a dignified, pain free, family and staff supported death for newborns who were not expected to survive. The protocol was also intended to provide assistance to the healthcare team that lacked formal ethical or clinical training for providing palliative care to newborns. There are ten comprehensive principles that underpin these guidelines, yet since the introduction of this protocol, palliative care delivery to this patient population has remained arbitrary. Glicken (2002) states that whilst this protocol was a good starting point, palliative care provision to newborns remains ‘virtually non-existent’ (Maginnes, 2002 p 77).

Resistance towards accepting a neonatal palliative model of care may occur when health professionals enter the healthcare arena to cure illness and improve quality of life. Changing from a curative to a palliative model of care is a difficult adjustment (Glicken & Merenstein, 2002). Job satisfaction in healthcare is frequently derived from witnessing the recipients of care recovering from illness. Neonatal nurses are no exception, especially when models of care are focused primarily upon curative care, and life saving measures (Yam et al., 2001). Providing palliative care in an environment that is technically driven towards curative care is an emotive issue, and often presents a challenge to the healthcare team in making the transition from curative to palliative care (Prior & Poulton, 1996). Neonatal nurses may be torn between the competing ideologies of curative versus palliative care, perceiving that there is a need to preserve life, yet at the same time, minimize unnecessary pain and suffering for the newborn (Yam et al., 2001).

In summary, there may be issues related to neonatal nurses engaging in a neonatal palliative model of care which may be significant, ranging from attitudinal, educational and institutional in origin (Carter & Levetown, 2004). Furthermore, these issues may prevent newborns and children from receiving the care that they
deserve (Moro, Kavanaugh, Okuno-Jones, & VanKleef, 2006). The implementation and utilization of palliative care may be besieged by issues including ineffective pain assessment and management, a lack of continuity of care, unclear diagnosis, prognosis and treatment explanations (Moro et al., 2006). However, the actual reasons for inadequate palliative care delivery to this fragile population are unclear. Given this, exploratory research is necessary to acquire a composite understanding of the barriers and facilitators to palliative care practice and delivery in neonatal nursing.

1.2 Defining neonatal palliative care

‘Delivery room resuscitation is an unusual team sport in which the only player who never swings the bat is also the only one who can strike out’ (Finer & Barrington, 1999)

To explore palliative care practice in neonatal nursing, it is first necessary to examine the operational definitions and commonly used terminology in this field. Throughout this thesis, the terms ‘palliative care’ and ‘end-of-life care’ will be used synonymously. Although end-of-life care encompasses palliative care, some commentators do not interpret these terms as synonymous (Field & Behrman, 2003). Palliative care has been interpreted as an element of end-of-life care, focusing more upon the management of the end stages of a medical condition whilst preparing for death. However, these subtle differences in nomenclature are acknowledged.

Merriam-Webster (2004) define palliate thus: ‘to reduce the violence of (a disease)’ or ‘to moderate the intensity of something’. From the Latin term ‘palliates’ (meaning to ‘conceal’), palliate is defined as alleviating symptoms without curing. The tenets of palliative care are seemingly straightforward, serving to enhance quality of life, relieve symptoms, and provide bereavement support to families. This includes maintaining an interdisciplinary approach to assist the newborn and family with physical, psychological, social, emotional, and spiritual support (Romesberg, 2004). The World Health Organisation (2002) described palliative care as an approach which improves the quality of life of patients and their families facing life-threatening illness, through the prevention, assessment and treatment of pain and
other physical, psychosocial and spiritual problems. The goal, therefore, is to facilitate a so-called ‘good death’. A ‘good death’ is defined as one that is ‘...free from avoidable distress and suffering for patients, families, and care-givers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards’ (Institute of Medicine of the National Academies., 2003 p 39)

When defining palliative care, it is necessary to include discussion about hospice principles also. Perinatal hospice is defined as a service that supports parents through their grief when their baby dies and takes full advantage of the opportunity for mourning (Calhoun, Reitman, & Hoeldtke, 1997). Although there is strong support in the literature for perinatal hospice, there is also the suggestion that these services are rarely provided or available either as an adjunct to palliative care, or as a treatment option within the perinatal period (Calhoun & Hoeldtke, 2002; Calhoun, Hoeldtke, Hinson, & Judge, 1997; Calhoun, Napolitano, Terry, Bussey, & Hoeldtke, 2003; Calhoun, Reitman et al., 1997; Hoeldtke & Calhoun, 2001; Ramer-Chrastek & Thygeson, 2005).

In summary, withholding, or not initiating, intensive support does not equate to withdrawal of care. Palliative care involves active treatment aiming to assure that newborns receive care in a comfortable environment, free from pain and distressing symptoms, with emotional and practical support for both parents and healthcare professionals. When the decision to withhold resuscitation, discontinue resuscitation, or forgo other life-supporting treatments are made, compassion for the family and their needs become paramount. This humane and compassionate care should include careful handling of the newborn, maintaining warmth, avoiding invasive procedures, and unobtrusive monitoring—such care is sometimes called ‘comfort care’ (MacDonald, 2002) and this term is used synonymously with palliative care by some authors.
1.3 Locating palliative care in contemporary neonatal practice

The purpose of this section is to examine how neonatal palliative care is situated in contemporary neonatal practice. However, to engage in objective and balanced discussion, it is first necessary to address the assumption that palliative care is inherently beneficial for all patient populations who may require it. Some literature offers a critique of the palliative approach, arguing that the emphasis of palliative care should not be on extinguishing the denial of death but on the relief of suffering (Zimmermann, 2004). Such philosophical debate argues that the palliative approach may result in the ‘social death’ of a person before their actual death. This results in the ideal of ‘living until you die’ being unfulfilled (McKechnie, MacLeod, & Keeling, 2007). McKechnie et al (2007) argue that whether a dying person experiences a ‘good death’ or not is determined not only by the management of the dying process by health professionals, but also by the way in which the dying person is perceived by others. The palliative approach may be interpreted as being somewhat prescriptive, yet there are no guidelines for the dying role; everybody dies differently and individually (McKechnie et al., 2007). Such debate suggests that healthcare professionals should be mindful of the palliative approach leading to the ‘social death’ of a dying baby prior to its actual, physical death.

In the remainder of this section, an argument will be presented as to why there is a need for a neonatal palliative model of care, and therefore why research such as this is necessary. Death is a part of life in any NICU, and any healthcare service provider associated with labour and delivery and the care of newborns would inevitably experience perinatal death and bereavement (Leuthner, 2004). Furthermore, there is a neonatal population that would benefit from this model of care, recognised under three broad categories: newborns born at the limits of viability; newborns born with a lethal anomaly and/or malformation; and newborns who have received intensive care in the NICU but for whom this model of care has become inappropriate. These categories of newborns have low rates of survival and high morbidity on the occasions that they do survive, and palliative care may be the best approach (Carter, 2004).
Despite this, palliative care principles are difficult to apply to neonatology, and there may be several plausible explanations for this. Foremost, the death of a newborn is considered a life that has ended too soon: illness and death are unexpected for a newborn and are devastating and life-altering events for the family. Society in general does not know how to respond to the death of a newborn, and therefore have few established social norms to help a family cope with such loss (National Association of Neonatal Nurses www.nann.org, 2005). The social stigma of denying neonatal death coupled with the paradox of providing palliative care in a curative setting present a compelling research problem. However, it is possible for palliative care to coexist with curative treatment modes because palliative care has become an area of expertise within many other health disciplines, such as in adult intensive care. Yet, advances in palliative care have not yet been integrated effectively into standard paediatric/adolescent clinical practice, and even less so into neonatal clinical practice. Therefore, the precepts of palliation should be a basic component of the attitudes, knowledge base and practice skills of all health care professionals (National Association of Neonatal Nurses www.nann.org, 2005). The previous section suggests that the clinical application of palliative care should be seemingly straightforward. However, when one explores these clinical ideologies in the context of contemporary neonatology, the notion of neonatal palliative care raises a myriad of issues and controversies.

Whilst it is noted that there have been remarkable achievements in newborn survival and these advances have increased the possibility of sustaining life, more newborns die in the neonatal period than at any other time in childhood. Despite this, there is much that is unknown about both the needs and the care of these critically ill newborns (Field & Behrman, 2003). To illustrate, 34% of all childhood deaths occur within the neonatal period (Carter, 2004). It would be a reasonable assumption, then, that when death becomes inevitable for a marginally viable and critically ill newborn, that decisions to prolong suffering be reassessed and a transition to palliative care at least be considered (Carter, 2004). Again, such a rationale is not straightforward. This notion necessitates that aggressive, curative treatment be withheld, or withdrawn: yet how does this translate into actual practise. When is it appropriate to
withhold or withdraw curative care and, in doing so, what are the needs of the dying newborn, the family, and the staff to provide a humane and compassionate death. The literature suggests that confusion exists about what palliative care constitutes, and when – if ever – it is appropriate to withhold aggressive, curative care. In Catlin’s (1999) research of neonatologists’ resuscitation practices of extremely low-birth weight (ELBW) preterm newborns, one fourth of participants stated that withholding resuscitation attempts wasn’t an option for them. Emotive terms such as ‘executing’, ‘killing’ and ‘pulling the trigger’ were used to describe the practice of ‘doing nothing’ (Catlin, 1999 p 271). Attempting resuscitation even on the smallest ELBW fetal-newborns was described as a neutral action for which they were simply trained to do: there was no training in terms of when ‘not to do’. One neonatologist recalled: ‘there’s no one telling you the rules, because there aren’t any rules’ (Catlin, 1999 p 271).

There is often difficulty in accepting a palliative model of care in contemporary healthcare. There is a focus upon curative treatment regimens, with a drive to offer aggressive interventions. This may be because the serious nature of disease is still evolving or perhaps to postpone the acceptance that death has become inevitable. Healthcare needs to consider when no potentially curative intervention exists, or their benefits have become exhausted. This can lead to a feeling of hopelessness that there is nothing left to offer the newborn (Craig & Goldman, 2003). There is a notion of curing at all costs, and it is stated that in acute care settings the purpose of treatment is generally to cure, and it is for this reason that facing the death of a patient and providing palliative care can be ‘uncomfortable’, and engender a sense of failure (Davies et al., 1996; Hartline, 2002; Lo et al., 1999).

In some countries, such as the Netherlands (Moro et al., 2006), euthanasia of certain newborns is considered a viable option for marginally viable and critically ill newborns in countries. Discreetly practiced active euthanasia, although technically illegal, has been tolerated in countries such as the Netherlands for over 30 years. There is no mention in the law of active euthanasia for newborns and small children, which remains illegal. However, in the Netherlands neonatal and infant deaths preceded by the deliberate administration of life reducing medication are known to
take place, although infrequently (Cuttini et al., 2004). This research does not seek to advocate or condemn such practices, however in order to locate palliative care in contemporary neonatal care, such discussion is necessary.

In a study by Provoost and Cools (2005) a death-certificate audit was performed for all deaths of newborns and infants in Flanders over a 12-month period. With a response rate of 253 (87%), 121 (69%) of the 175 neonatologists also responded to a series of attitude questions. An end-of-life decision was possible in 194 of the 253 deaths studied, and such a decision was made in 143 cases. Lethal drugs had been administered in 15 cases among 117 early neonatal deaths and in two cases among 77 later deaths. Furthermore, the attitude study demonstrated that 95 of the 121 neonatologists reported that their professional duty at times included the prevention of unnecessary suffering by hastening death and 69 of 120 supported legalization of life termination in some cases. This research reported that within its sampling frame, the majority of neonatologists favored the legalization of the use of lethal drugs in certain cases.

The EURONIC study (Arlettaz et al., 2005) demonstrated that the administration of lethal drugs with the aim of terminating life was reported in the Netherlands and France, in contrast to other European countries. This report reasoned that the prevention of suffering at times justifiably demanded the use of lethal drugs and that non-treatment unnecessarily prolonged suffering. The study found that most of the neonatologists participating in the research supported a change in the law, permitting the termination of life (Provoost & Cools, 2005). However, these guidelines, known as the Groningen Protocol, relate to newborns who would continue to survive after the withdrawal of medical care. Under the auspices of such a protocol, the decision to terminate the life of a newborn is based upon perceived intractable suffering (Verhagen & Sauer, 2005) and in this decision-making process, the prognosis, the expected outcome of treatment in terms of quality of life, and the burden placed on the patient by the treatment (pain, discomfort and physical limitation) play an equal role (Arlettaz et al., 2005).
In summary, intensive care can be an unpleasant, uncomfortable experience for newborns even when it is appropriate. As stated by Yu (2005) a ‘proactive policy to initiate intensive care must take into consideration that a decision to withdraw intensive care might have to be made in selective newborns at a later stage in the course of the newborn’s treatment. In the event that the newborn’s subsequent clinical course indicates that further curative efforts are futile or lack compensating benefit, intensive care should be discontinued and palliative care, which provides symptomatic relief and comfort, should be introduced’ (Yu, 2005 p 746 - 747).

Given this, the initiation or continuation of treatment which is considered futile is unlikely to be in the best interests of the newborn. Even so, many healthcare professionals find it difficult to accept that palliative care may be a more appropriate course of action (Craig & Goldman, 2003). The NICU environment has changed dramatically in past decades and continues to do so into the new millennium, with advances in technology and prenatal screening. These advances mean that many newborns who might once have died are now surviving (Handley, 2003). Therefore, the concept of providing palliative care to newborns is an emerging one, but as argued, it is a concept that is proving difficult to incorporate into contemporary neonatal care. The following section will provide a chronological perspective of how marginally viable and critically ill babies have been supported in recent decades, and the issues that have contributed to the growing support for neonatal palliative care in contemporary practice.
1.4 A chronological perspective

"My hope is that it won't be the epitaph of our generation that people will say: 'Here was a community which developed the most amazing, dazzling fields of science and yet proved themselves so indifferent or incompetent, that they didn't address the serious social and ethical consequences of what they were up to’"

‘What rules for embryology?’


Historically, neonatology arose from an era where the focus on healthcare was curative – survival was the ultimate outcome, with little concern for morbidity (Hartline, 2002). The role of medicine was to seek out illness and ‘conquer it with technology’. A cure was winning – and death was the ultimate loss and failing. The late Dr. William Silverman (Anspach, 1993; Nolan, 1987; Penticuff, 1988; Silverman, 1981, 1992, 2002, 2004) pioneered many of the life saving initiatives associated with this field of medical science. However, Silverman became a supporter of neonatal palliative care, publishing prolifically on this subject since retirement, and voicing the excesses of neonatal resuscitation upon newborns who would benefit from a palliative approach. Silverman’s outspoken opinions about the care of marginally viable and critically ill newborns have been criticized, and offended elements of the medical fraternity (Kattwinkel & Boyle, 2004). In the 1940s, when Silverman was a paediatric house officer, he was informed: “We don’t attempt to save newborns weighing less than 1 kg because they are pre-viable” (Silverman, 2004 p 402). This was frequently witnessed as newborns weighing less than 1 kg were left unwrapped, placed in a cold corner of the delivery room and ignored until they expired. Parental consent was never sought; the dying baby was baptized, and the outcome of the pregnancy was recorded as ‘stillborn.’ Silverman stated that the turning point came from an anesthesiologist, Virginia Apgar. Apgar purportedly stated that: “No one ever stops breathing on me” (Silverman, 2004 p 402). Apparently horrified that marginally viable and critically ill newborns were allowed to die without any rescue effort, Apgar launched a campaign to change the culture of the delivery room. The ordinal scoring system that documented and categorized the status of all newborns at 1 minute of age (the APGAR score) was developed in 1953 (Apgar, 1953). This essentially meant that the labeling of babies as ‘stillborn’ was permanently erased. To illustrate, Silverman recounted:
“This minute infant was apneic and pulseless. The anesthetist asked for a scalpel, he opened the chest with one stroke, he began to squeeze the heart directly and he yelled for someone to intubate the infant immediately. Before this, no one ever dreamt of using open chest cardiac massage for the resuscitation of a baby. Needless to say, this dramatic intercession had an electrifying effect on the crowd of open-mouthed young people in the delivery room. This was a very loud signal indicating how far resuscitative efforts were now prepared to go. The fact that this infant died a few hours later was dismissed as an irrelevant detail” (Silverman, 2004 p 402).

By the 1960s, neonatology as a recognized specialty field of medical science exploded. Neonatal doctors (now called neonatologists) became the guardians of the rights of borderline newborns. The technology progressed quickly, leading to statements such as: “with the skills we have developed, (we) can bring a peach back from death” (Silverman, 2004 p 403). The collective forces of these changing attitudes, technology and unlimited resources saw neonatal mortality rates plummet to lows unprecedented in human history. Another significant social event occurred in 1963 and changed the direction of neonatal intensive care – the death of a premature newborn from hyaline membrane disease (respiratory distress failure) – the son of the late John Fitzgerald Kennedy, Patrick. Born on the 7th of August, 1963, he lived just two days before expiring. It took the death of the son of the then American President for neonatologists of the day to declare that this could never happen again. The first continuous positive airways pressure (CPAP) machines were developed, and the race to push back the edge of newborn viability began. Ethical questions momentarily took a backseat: How young could these newborns be saved? Who would be the smallest? (Simpson, 1999b).

In the 1970s, quality of life concerns began to be raised. Increasingly, parents expressed concerns about not being involved in decision-making for their babies. Neonatologists were accused of ‘playing God’, and amidst this controversy, the first survivors of this brave new world of neonatology began to emerge (Romesberg, 2003). In 1973, Duff and Campbell (1973) questioned whether marginally viable
and critically ill newborns should be allowed to die if their condition was futile, causing worldwide controversy. The purpose of this seminal research was to shed light on neonatologist behavior in end-of-life decision-making. Publications and revised legislation ensued, for the most part disparaging neonatologists for ‘playing God’ in the nursery (Tyson, 1995). This heralded the beginnings of the concept of palliative care replacing aggressive curative care to marginally viable and critically ill newborns (Glicken & Merenstein, 2002). Around 25 years later, Duff & Campbell’s research was replicated by Todres et al (Todres, Guillemin, Catlin, Marlow, & Nordstrom, 2000). Neonatologists’ approaches towards active intervention for critically ill newborns had remained static. This was considered a landmark study (Wall & Partridge, 1997), precipitating debate about the limits of viability for marginally viable and critically ill newborns. Palliative care has become increasingly topical in contemporary neonatal practice in the decades since Duff and Campbell’s research.

Another major turning point for marginally viable and critically ill newborns occurred between 1982 and 1984, when the late President Ronald Reagan initiated strict regulations preventing medical decision-making and restricting what families could decide for their newborns if the decision might allow an earlier death. Made in conjunction with the Surgeon-General at the time, this became known as the ‘Baby Doe’ law (Kopelman, Irons, & Kopelman, 1988). The ‘Baby Doe’ law emerged from the 1982 case of Baby Doe, an infant born with Down syndrome and oesophageal atresia. After hearing contradictory prognoses for surgery to repair their baby’s malformed oesophagus, the parents refused consent for the procedure. Paediatricians filed a lawsuit citing neglect, but state courts disagreed. Before the U.S. Supreme Court could hear the case, Baby Doe died. The controversy intensified with the 1983 birth of Baby Jane Doe, who was born with spina bifida and other complications and whose parents, also facing conflicting medical advice, opted against treatment. This lead to US Congress voting to add the denial of fluids and nutrition for newborns with birth defects to the federal definition of child abuse in 1984. This law has withstood, and has subsequently yielded vague limits on what treatments can be refused; although parents can deny care that is considered by them to be ‘futile’, but nowhere is futility in this context specifically defined. Outcomes
are often uncertain, and defining futility can make decisions about withdrawing or withholding treatment vague (Muraskas, 2005).

The issue of medical futility is an age-old debate. Early Hippocratic doctors noted that ‘dreadful diseases demand dreadful remedies’ (Chadwick & Mann, 1950), and observed that doctors should ‘refuse to treat those overmastered by their illness’ (Jecker, 1991). This Hippocratic tradition was paternalistic and anticipated that neonatologists alone would decide when treatments should be offered or withheld. Futile care refers to treatment that either prolongs suffering, does not improve the quality of life, or fails to achieve a good outcome for the patient (Romesberg, 2003). Futile means ‘useless for something’ (Kopelman, 2005), and it has been stated that ‘futile’ in neonatal terms means ‘futile in terms of survival of the infant’ (Kopelman, 2005). ‘Futility’ may not be specifically defined within the parameters of the law, but in Wall and Partridge’s (1997) survey of neonatologists, it was cited in 74% of cases as the documented reason for limiting life support. The perception of futility and its medical application in neonatal practice has been the subject of considerable controversy and debate in recent years, and the definition of medical futility remains ambiguous at best (Muraskas et al., 1999).

The plight of parents of marginally viable and critically ill newborns came to the fore in 1983, when a controversial book was published, ‘the Long Dying of Baby Andrew’ (Stinson & Stinson, 1983) by parents Robert and Peggy Stinson. This book chronicled the life and demise of their premature son, and their monumental struggle to obtain reliable information on his condition from the attending neonatologists. Although devastating cases such as Andrew Stinson made international headlines, fostered memoirs, and influenced public opinion, most NICU dilemmas are less black and white, as are their solutions: "I'm afraid my baby is going to die. I'm afraid my baby is going to live," Peggy Stinson stated.

Given this public outcry, it is difficult to extrapolate what impact, if any, the documented plights of grieving parents had on legislation, but the latest version of the ‘Baby Doe’ regulations state that life-sustaining treatment for a newborn may be withheld if treatment would be futile in terms of the survival of the newborn, perhaps
meaning that treatment would be virtually futile in terms of the newborn’s survival and the treatment itself would be inhumane. Unfortunately, it is difficult to interpret exactly what these regulations mean. Before the application of the ‘Baby Doe Regulations’, the decision to treat (or not treat) marginally viable and critically ill newborns were often made behind closed doors between the neonatologists and parents. Once the Baby Doe regulations were applied, however, they created a strong presumption that a newborn should always be treated, regardless of whether the treatment was not considered to be in the baby’s best interests (National Association of Neonatal Nurses, 1999). In 1986, the ‘Baby Doe’ regulations were ruled ‘unconstitutional’ because State autonomy was deemed to have been violated. Furthermore, the Rehabilitation Act did not extend insofar as to apply to marginally viable and critically ill newborns who were handicapped. However, the Baby Doe laws continue to permeate contemporary neonatal practice, and allowing newborns to die has become extremely difficult and controversial as a result of ‘Baby Doe’.

In 1997, the American Academy of Paediatrics funded a study to investigate neonatologist decision-making for end-of-life care in newborns born severely premature (Catlin, 1999). The purpose of this research was to explore the perceptions of neonatologists making delivery room decisions regarding resuscitation of ELBW newborns born at marginal viability. The design of this research was descriptive, using naturalistic inquiry. The sample was a convenience sample obtained in 1996–1997 of 54 neonatologists in five perinatal subspecialties who resuscitated ELBW newborns. This study found that despite prior knowledge of the high morbidity and mortality of this patient population, 96% of neonatologists offered resuscitation to all ELBW newborns in the delivery room. Six major themes emerged from the study’s transcripts: role expectation, uncertainty, awareness, internal and external forces, burden, and continuing quandaries. In conclusion, it was suggested that the American Academy of Paediatrics’ Neonatal Resuscitation Protocol needed to revise the ethical criteria for resuscitation (Catlin, 1999).

This research coincided with public hearings across several states in the US to discuss recommendations about the future of intensive care technology for newborns and palliative care options. In particular, the Neonatology and the Rights of Families
(NaRoF) support group, headed by the parent of a premature newborn, Helen Harrison (Harrison, 1993), began to advocate themes such as ‘children should be allowed to die when extremely premature’. The NaRoF forum and mailing list were established to give a voice to the families raising impaired NICU survivors and to parents and professionals critical of current practices in neonatology. In other settings, such voices are often discouraged and suppressed. Parental concerns included lack of information, exclusion from decision-making, over-treatment of newborns, and under-treatment of pain. This lead to the notion of palliative care for marginally viable and critically ill newborns gathering momentum. Nurses and neonatologists began to work together to plan studies and to provide mutual support. This was further buoyed in 2000 when a study regarding end-of-life care and newborn withdrawal from ventilatory support (Abe, Catlin, & Mihara, 2001) found that many newborns did not receive any pain relief or relief of symptoms when removed from a ventilator to die, and some had lived up to ten days before their demise.

In 2002 the Baby Doe regulations and Emergency Medical Treatment and Labor Act (EMTALA) represented a landmark historic legislative attempt to regulate treatment decisions made by neonatologists. In the United States, this lead to the Born-Alive Infants Protection Act of 2002 becoming Public Law No. 107–207 on August 5, 2002. This law stated that "infants who are born alive, at any stage in development (and regardless of the circumstances of their birth), are persons who are entitled to the protections of the law" (Boyle, Carlo, Goldsmith, Halamek, & Singhal, 2003 p 680). The law further defined an infant who is born alive as one who "at any stage of development, is expelled from the mother’s body and displays any of several specific signs of life—breathing, a heartbeat, and/or definite movement of voluntary muscles" (Boyle et al., 2003 p 680). However, in the opinion of the American Academy of Paediatrics the Act was interpreted as not being intended to affect the approach to resuscitation of extremely premature newborns, and decisions regarding viability needed to continue to be re-evaluated at the time of delivery (Romesberg, 2003).

In summary, it has been over three decades since Duff and Campbell (1973) created controversy with their suggestion that technological intervention could be withheld
in the nursery, yet these views have gradually gained acceptance. In 2002, Catlin and Carter (2002) created an innovative neonatal end-of-life palliative care protocol, yet despite the availability of an evidence-based protocol, the actual delivery of neonatal palliative care is largely ad hoc. Given the rapid growth of the science of neonatal intensive care, and the subsequent ethical concerns and questions that have been raised as to the appropriateness of a palliative care service for newborns, palliative care has undergone surprisingly little analytic evaluation (Pierucci et al., 2001), and still little is known about facilitators and barriers to palliative care practice, or the attitudes of neonatal nurses towards this area of nursing practice.
1.5 Aims of the research

The overall aims of this study were to develop a knowledge base about palliative care practice in neonatal nursing by identifying the facilitators and barriers to practice, and; to draw upon these findings to develop policy recommendations to improve neonatal nursing practice. These aims inform two research questions:

- What were the barriers and facilitators to palliative care practice in neonatal nursing?
- How could the identified issues be addressed to inform policy and clinical guidelines in the practice environment?

This research incorporates a predominantly non-experimental exploratory design with a less dominant qualitative aspect. The first step (Phase One) in this investigation is to apply the findings of a comprehensive literature review to inform the content of an instrument to investigate the barriers and facilitators to palliative care practice. Prior to administration to a population sample of Australian neonatal nurses, this instrument will be subject to face and content validity testing by involving the input of an Expert Panel, and reliability testing using test-retest procedures. Data reduction techniques will be used to describe the subscales of this instrument, and to identify the barriers and facilitators to palliative care practice. This will answer the first research question.

The second phase of this research uses a translational research approach, utilizing interpretive methods to conduct focus group interviews. These interviews will explore and contextualise the population study findings to develop policy to improve palliative care practice in neonatal nursing. This will address the second research question.

Addressing these research questions will lead to a composite understanding of the barriers and facilitators to palliative care practice in Australian neonatal nursing, and the development of research findings that have direct application to nursing policy in the NICU.
1.6 Structure of the thesis

The literature review following this introductory chapter will present the theoretical and empirical context for this research. Specifically, the literature review will capture the empirical and sociological perspectives of providing care to marginally viable and critically ill newborns. It will present a review and critique of contemporary literature and health research that has already been conducted in this context to clarify what the present study will add. It will also capture the significant sociological discourse that permeates the attitudes to caring for these babies in contemporary healthcare.

Chapter three will discuss the theoretical framework that underpins this research – EM Rogers Diffusion of Innovations (Rogers, 1995). Chapter four will discuss the methodology of this research. Chapters five to six will present the findings from the population study and the interpretive phase in separate chapters. The quantitative and qualitative findings from this research will be combined to culminate in a discussion chapter where the barriers and facilitators to palliative care practice will be discussed. In this chapter, the theoretical framework used to guide this research will be revisited to conceptualise how Diffusion research can assist in the interpretation of the research findings. In the final chapter of this thesis, the main conclusions that can be drawn from this research will be presented. Recommendations to inform nursing policy will be made based upon the findings of this research, and recommendations for further research in this area will also be made.
CHAPTER 2 - Literature Review

2.1 Introduction

The purpose of this chapter is to explore the literature and provide a comprehensive overview relating to the care of marginally viable and critically ill newborns. The primary themes identified from this review were used to inform the content of an instrument to ask neonatal nurses about palliative care practice to identify the barriers and facilitators.

The approach towards this literature review encompassed broad search terms, the aim being to convey a thorough overview of a research domain about which little is known. Therefore, there was no implicit inclusion criteria for this review. The search terms were quite specific to begin with, and as the findings from the literature review were critiqued, this generated further search terms. In the preliminary search of the literature, research papers were preferentially sought, responding to the search terms of ‘neonatal nursing’ and/or ‘neonatology’; (and) ‘end-of-life care’; (and) ‘palliative care’. However, a lack of research papers were identified, hence the search was broadened to include narrative and opinion papers. The search was also broadened to incorporate sociological aspects, which included ‘grey’ literature such as websites and newspaper sources.

This literature review involved a systematic search of databases, including CINAHL, Medline, PsycInfo and PsycArticles. There was no time limit imposed upon this search. Significant articles were also hand-searched for relevant references, which were then retrieved and included in the literature review if considered relevant. The internet search was conducted using the Google search engine, identifying websites and other media relating to neonatal palliative care practice. The search then extended to personal libraries which were explored to identify literature relevant to this review.
A systematic search of the literature produced 121 items of literature ranging from research papers to websites and newspaper articles that were reviewed and categorised according to the constructs identified: given the exploratory nature of this research, all of these papers were included in this literature review. This search identified a significant social discourse that permeated this literature, and these influences will be discussed in the final section of this chapter. Previous research conducted within this area of nursing practice, including evidence based guidelines that are available to guide palliative care practice will also be discussed.

The primary constructs that were identified by this literature review included: support for parents; the experience of caring for marginally viable and critically ill newborns upon caregivers (grief, stress and moral distress); resources to support palliative care practice (protocols, guidelines and infrastructure); support and training for caregivers; decision making on behalf of marginally viable and critically ill newborns, and; the social discourse of caring for these babies.

2.1.1 Support for the parents of dying babies

This section of the literature review identifies the needs of parents of marginally viable and critically ill newborns in the NICU. The parents and families of babies who are admitted to the neonatal unit are exposed to a variety of stressors, and may face extremely difficult decisions in unique situations (Fowlie & McHaffie, 2004). It has been suggested that the parents of babies admitted to the NICU need to be empowered to facilitate bonding, attachment and care-giving skills. Neonatal nurses play a pivotal role in the empowerment of parents, but often find this aspect of their role difficult due to the lack of clarity on how to accomplish it (Herbst, 2006).

In Harrison’s (1993) discussion paper about the needs of parents of marginally viable and critically ill newborns, many parents expressed gratitude for the skilled staff and technological interventions that fundamentally saved their children. Conversely, other parents were reported as voicing concern and anguish over the way they and their babies were cared for in the NICU. In particular, parents reported difficulties in acquiring accurate information about treatments, and prognoses; of their exclusion from medical and ethical decision-making; of the over-treatment of marginally viable
and critically ill newborns and the under-treatment of pain; of their concerns about
the unyielding NICU environment and the use of inadequately validated therapies; of
the pointless obstacles to the nursing and nurturing of their babies in the NICU; and
of their frustration over inadequate discharge planning, follow-up, and services for
NICU survivors (Harrison, 1993).

The ‘unyielding environment’ of the NICU as portrayed by Harrison (1993) is
supported by other authors (McHaffie, 1991, 1992a). Babies requiring intensive care
is a traumatic experience for parents and families, yet rigid policies such as visiting
guidelines do little to support the needs of families. Although most units have openly
expressed policies relating to whom visits the NICU, these policies are not based on
systematically gathered information of what families want. A recommendation of
McHaffie’s (1992b) survey research was that parents themselves should decide who
is able to support them in the period of their baby's hospitalisation. Unmitigated rules
dictating who may visit and what they may do denies the parents' rights and in some
circumstances adds to their stress. This research also concluded that these ‘rules’
impact negatively upon grandparents also (McHaffie, 1991).

The needs identified by these earlier authors were addressed by other authors such as
Gale and Brooks (2006), who developed comprehensive clinical guidelines on how
to best address the needs of parents and families in the NICU. This research
developed and implemented a palliative care program to meet the needs of families
and staff caring for dying infants and their families. Whether this program can be
replicated in other organisations is a creditable component for future research. As
suggested by Gale & Brooks (2006), support for parents and family members of
marginally viable and critically ill newborns needs to include such aspects as
cultural, spiritual and practice needs, prenatally, at birth and in the long term, a
suggested supported by other authors (Catlin & Carter, 2002).

As well as addressing these needs, the literature also reports considerable stressors
for parents, such as predicting the length of time it might take for a newborn to die
when curative care is withdrawn. This is another cause of conflict and anxiety for
parents and the healthcare team, and is well described in the literature (Chiswick,
2001). Although such predictions should be avoided, parents require information about what the process of dying might be like for their baby. Authors such as Chiswick (2001), Carter (2004), McHaffie et al (2001), Cranley-Grass (2002) and Leuthner (2004) have reported the difficulties of such dialogue, in particular estimating how long it might take the baby to succumb. These concerns centre around the conflict and anxiety between parents and NICU staff in terms of the estimation of what death will be like, or how long it might take. Such estimations are frequently based upon clinical judgment, so the margin for error is high. If this stage is misjudged, the likelihood of the newborn suffering a protracted death after extubation, and the decision to withdraw intensive care needing to be reversed when it becomes apparent that the newborn's condition is not terminal. This is considered a situation that may be too difficult to contemplate for the attending healthcare team (Chiswick, 2001). Furthermore, although it may be agreed that a newborn is dying, this consensus is not always straightforward. Consensus should always be reached, however, when there is no sound reason to continue with aggressive treatment for marginally viable and critically ill newborns, but compassion, comfort and sensitive nursing care remain very important and must be upheld (Cranley-Grass, 2002). Parents need to be assured that if their baby takes a long time to die, a poor prognosis is not altered. Healthcare professionals also need to address the internal conflict experienced by parents at this time of wanting their child to live, yet wanting them to die quickly and painlessly (Leuthner, 2004).

Most often, when newborns are on assisted ventilation, the time taken to die is relatively swift (typically minutes to hours). With other conditions, such as metabolic, chromosomal or neurodegenerative conditions, survival may continue for a long period after life sustaining measures have been ceased. An environment for these newborns might be within the home, or with home-hospice service (Carter, 2004). In McHaffie et al’s (2001) research, parents described their distress when their newborn made unpleasant sounds or struggled to breathe unassisted. Colour changes (cyanosis) were unexpected when ventilation was ceased, and this was distressing. McHaffie et al (2001) have described some parents as being hysterical or terrified, and unable to look at their newborn. There is a possibility that these situations could be assuaged somewhat if parents were well informed, and prepared
for what might happen in the process of dying. Preparing parents for death is an approach advocated by Carter and Leuthner (2003). When the infant ceases to urinate, death can soon be anticipated, and usually occurs within several days from the commencement of anuria. It is also reported that sleep periods increase, and the newborn will eventually not awaken again. Parents will often describe the event of death as occurring comfortably in the infant’s sleep (Carter & Leuthner, 2003). This emphasis on a comfortable death is not only a concern for parents, as Barr (2007) indicated. In a survey asking neonatologists to speculate that if there were no laws inhibiting them from doing so, would they consider it more compassionate and humane to purposefully hasten death if medical treatment was deemed therapeutically non-beneficial. This research reported that there had been occasions when neonatologists had considered expediting death as it was the most sensible way to alleviate the infant’s pain and suffering (Barr, 2007).

Catlin’s (1999) research of neonatologist resuscitation practices also identified this source of trauma for parents regarding newborns who did not immediately die when life support was withdrawn. Some neonatologists (16%) described their decision to withdraw life support, then the obligation they experienced to resuscitate when the newborn who was deemed nonviable failed to succumb within an hour. This lead to the distressing and unenviable position of knowing that this decision was ‘wrong’, but not knowing what else they could do (Catlin, 1999).

To avoid the distress of a lingering death, parents need to be prepared that their newborn may not die immediately, or even within a few hours of ceasing life support. Instead, there should be a focus on information about compassionate care, as suggested by Chiswick (2001) and McHaffie et al (2001). Parents need to be reassured that a protracted death is not necessarily associated with pain and suffering. If appropriate arrangements have been made, parents can take advantage of this time to be with and to love, nurture and hold their newborn (Chiswick, 2001). When a newborn expires quickly after cessation of life support, this may confirm to the parents their wisdom in making the decision to cease treatment. However, when the death of the newborn is protracted, inevitably, doubts may be raised. The need for parents to be adequately prepared for what may happen after treatment withdrawal is
supported by literature, as in McHaffie et al (2001). Historically, it is often believed that newborns who are destined to die will do so early. However, the median day of death of extremely low birthweight newborns has steadily increased, from 2 days to almost 10 days after birth, increasing the potential for both neonatal and family suffering (Meadow & Lantos, 2003). This research supported the findings of Chiswick’s (2001) retrospective qualitative study of parents, where it was found that when life-support was withdrawn with parental consent, almost one quarter of parents expressed their distress at how long it actually took for their babies to die (time range 3 – 36 hours). Research concluded that parents had not been adequately prepared for the possibility of this. Again, this was also identified in McHaffie’s (2001) research, with more than a fifth (13/59, 22%) of parents reporting the length of time it took their newborn to die as a significant source of distress. This research considered this an irony given the deteriorating condition of the baby coupled with a poor prognosis, leading to an expectation that death would be swift and merciful, yet this didn’t necessarily happen. McHaffie et al (2001) gave an example of parents expecting the death of their newborn to be immediate when life support was withdrawn, and were completely unprepared for the 21 hours they had with their newborn. The time these parents had with their newborn wasn’t necessarily positive, as none of the parents in this research harboured regret about a rapid death as this served to reinforce the accuracy of the medical prognosis, and the wisdom of the parents decision was confirmed. When the newborn took a long time to die, this was interpreted as the newborn ‘putting up a fight’, and these delays caused parents to question their decision to stop treatment, as in McHaffie et al (2001 p F11): “If the newborn was fighting so hard to live should they give him/her every chance? Was he or she trying to tell them that they wanted to live?”

In summary, parents require compassionate care when an infant is dying/dies. Neonatal nurses can provide such care and possibly facilitate grieving, yet often have inadequate preparation in bereavement/end-of-life care. Education on bereavement/end-of-life care could affect nurses’ comfort with caring for families of critically ill and/or dying infants (Engler, Cusson, Brockett, & Cannon-Heinrich, 2004). In Contro et al’s (2004) research using structured interviews, families emphasized the need for support during their child’s illness and death and for follow-
up contact after the death. In this research, interviewers reviewed the parent’s responses and discussed the most salient themes. Themes that appeared to occur frequently were grouped into categories, including relationships with hospital staff members, pain management, and quality of support. Contro emphasized the need for follow-up care, reporting that parents often regarded hospital staff as their ‘second family’, and perceived the lack of contact after their child’s death as a secondary loss (Contro, Larson, Scofield, Sourkes, & Cohen, 2004).

2.1.2 The effects of caring for marginally viable and critically ill newborns upon caregivers

2.1.2.1 Stress

The literature is replete with research about caregiver suffering and stress when caring for marginally viable and critically ill newborns (Armentrout-Richey, 1988; Astbury & Yu, 1982; Ewing & Carter, 2004; Farrell, Bennett, & Dixon, 2000; Gribbins & Marshall, 1982, 1984; Jacobson, 1978; Marino, 1998; Raeside, 2000; Sortet & Banks, 1996) and it has been reported that nurses caring for these types of babies rate the experience as stressful (Raeside, 2000). Stress can be defined as the disruption of homeostasis through physical or psychological stimuli. Stressful stimuli can result in mental, physiological, anatomical or physical reactions (Rippetoe-Kilgore, 2006).

The practice of providing end-of-life care to dying patients has been identified as a major stressor and a protagonist of unresolved grief for the nurse. Benica (1992) identified professional nursing as the seventh most stressful of 130 occupations surveyed. Lee (2003) corroborated this finding, stating that dealing with death and dying resulted in significant job stress in nursing. Marino (1998) argued that the source of stress associated with working with dying patients could be either organisational (work related or inherent to the work environment itself) or psychosocial (inter- or intrapsychic).

There are several studies that have examined the impact of stress and grief upon the neonatal nurse when caring for marginally viable and critically ill newborns, such as
Engler et al (2004) and Yam et al (2001). Prior to these studies, Jacobson’s (1978) quantitative (survey methods) study developed an instrument to examine neonatal nurses’ responses to patients’ deaths, and identified stress as a major response. In this multisite study (7 NICUs in 3 US states, N = 87) it was reported that sudden death or the clinical relapse of an infant and the nurse coping with parental grief were considered significant stressors for neonatal nurses. The instrument used in this research (the Anecdotes About Nursing Stresses) was not described in any detail, therefore its validity and reliability could not be evaluated. Despite this lack of analysis, in an Australian study, further research was conducted based upon Jacobson’s work by Astbury & Yu (1982) four years later. This research used structured interviews to elicit responses from a sample of 29 neonatal nurses in Australia about the stressfulness of the situations previously identified by Jacobson as stressful. These findings were replicated, with the sudden death or clinical relapse of a newborn, ranking as the most intense stressor, coupled with nurse/doctor conflict and nurse/nurse conflict.

The findings of these researchers were supported by Gribbins and Marshall (1982) who developed an instrument – the Neonatal nurse Stress-Coping Assessment Inventory – that also identified infant deaths as a significant stressor for neonatal nurses. In this research, nurses who were new to the clinical area expressed concern about ‘handling the many problems raised by the death of one of their patients’. This study, like Astbury & Yu (1982) and Jacobson (1978) was conducted over two decades ago, and for a quantitative study had a small sample size (N=24) from a single NICU. Although this research developed an instrument, the authors did not evaluate the validity and reliability of the scale and therefore these findings cannot be reliably used to inform other studies.

In 1988, Armentrout-Richey (1988) extended these findings by using survey methods to investigate the attitudes and beliefs of neonatal nurses towards caring for fetal-infants. The instrument developed by this research was an attitudinal assessment questionnaire. The sample was obtained from a subscriber list to a neonatal intensive care nursing journal, which was also a limitation of this research. This can be argued because nurses subscribing to such a journal have a more proactive and
scholarly interest in their own professional development. Furthermore, the validity and reliability of the instrument were not reported. Participants were asked what ‘feelings’ caring for fetal-newborns were conjured: for example, ‘caring for these fetal infants makes me feel discouraged; hopeful; depressed; rewarded; angry or satisfied’. These findings were similar to those of Jacobson (1978), Astbury & Yu (1982) and Gribbins & Marshall (1982). However, Armentrout-Richey’s (1988) research also asked a series of moral/ethical questions using a Likert scale including which laws impacted upon the management of these newborns, and the impact technology had upon caring for them. This study reported 6 major findings, including that there were greater positive than negative feelings towards caring for marginally viable and critically ill infants (Armentrout-Richey, 1988).

A qualitative study in 1995 (Todd, 1995) investigated why neonatal nurses rarely discussed the use of, removal of, or the withholding of life support for marginally viable and critically ill newborns. Neonatal nurses were asked to discuss their ‘fears, heartaches, and despair’ when caring for these newborns. This research culminated in a book entitled ‘Journey of the Heart: Stories of grief as told by nurses in the NICU’ (Todd, 1995). This research discussed the feelings reported by nurses caring for newborns for whom technological support was considered futile, and echoed the findings from other researchers reported in this section. However, in further research using an informal survey informed by Todd’s (1995) research, neonatal nurses reported sources of workplace stress, their preferred methods for dealing with stress, and suggestions for employer-based assistance (Ewing & Carter, 2004).

Survey methods were used in Downey et al (1995) with a sample of 59 neonatal nurses. Again, participants described feelings of ‘helplessness’ and ‘intense sorrow’ when providing care to marginally viable and critically ill newborns. The nurses reported psycho-emotional responses of chronic fatigue, decreased interest in exercise, irritability, becoming overly critical in their work, and becoming ‘difficult to work with’. The results, however, were inconclusive due to a low response rate of 35% from a small, homogeneous sample (all white, married females) and the study was therefore insufficient to extrapolate any meaningful conclusions.
In 2000, a study by Raeside (2000) reported similar findings to other researchers in terms of stress, and for many neonatal nurses, the period of compassionate care before the death of a newborn was considered the most stressful period. In Raeside’s survey research (N=59, 78% response rate), the most prevalent responses of nurses included sadness, intense sorrow, and a feeling of helplessness, supporting the findings of Downey’s et al’s (1995) survey research. In Raeside’s study (2000), the responses/coping mechanisms of neonatal nurses were identified. Fifty-nine nurses in an upper US mid-western state participated in this study, in which respondents reported feelings of irritability, headaches, being overly critical, weariness, over activity, emotional lability, tearfulness, inability to concentrate, and ‘feeling low’. There were limitations to this research also, such as a member of the NICU staff conducting the research in their own unit, and a small sample size (N = 59) for a quantitative study.

In 2001, Yam (2001) utilised qualitative methods to conduct structured interviews with ten neonatal nurses in Hong Kong about their experiences in caring for marginally viable and critically ill newborns, in particular their attitudes to palliative care. This research used content analysis to devise eight themes which included disbelief; ambivalence and helplessness; emotional protection; providing physical care to the infant and emotional care to the parents; expressing empathy; a lack of skill in communication and counselling and conflicting values in care. This research demonstrated that the cultural upbringing, socialisation of the nurses’ training and the environment of their workplace all contributed to moral distress in this area (moral distress will be discussed in section 2.1.1.3 of this literature review). Furthermore, it was reported that the ‘bureaucratic rules’ of the organisation made the experience for the family of the dying newborn ‘dehumanising’. In part, this was due to the lack of an appropriate area – or even a ‘multipurpose room’ – so that palliative care could be administered. Although this research provided insight into issues related to palliative care practice, the findings were limited because the research was conducted in a single setting and the issues identified may have been endemic only to that organisation. In addition, the interviews were conducted in
Cantonese, and translation into English may have lead to some differences in the interpretation of the data.

In another study from Hong Kong, Chan et al (2003) used survey methods (N=110, 88% response rate) to determine nurses’ attitudes toward perinatal bereavement support. The sample was obtained from an obstetrics-gynecology unit in a single public hospital using a structured questionnaire. The majority of participants reported positive attitudes toward end-of-life care for dying babies. Attitudes were significantly more positive among nurses who were older than 40, who had greater seniority, more than 5 years experience, and who had received training in palliation. This linear relationship between increasing clinical experience and a decrease in the experience of stress for nurses has been identified in other studies (Gribbins & Marshall, 1982; Sortet & Banks, 1996): that more experienced nurses may be better equipped to deal with stress due to established communication mechanisms with colleagues. However, the relationships of ‘stress’, ‘experience’ and ‘coping with death in the NICU’ requires further research attention. In Chan’s (2003) research, the attitudes of the nurses positively correlated with the need for training in palliative care ($r = 0.53$) and support from hospital policies ($r = 0.55$). This research had several limitations: senior Nurse Unit Managers distributed and collected the questionnaires (which may have lead to participants feeling obligated or coerced to participate), and the reliability and validity of the instrument was not adequately described.

The literature identified that the organisation in which the nurse operates may contribute to caregiver stress (Marino, 1998; McDonnell, Johnston, Gallagher, & McGlade, 2002). In McDonnell’s (2002) quantitative study of general palliative care nurses, the nurses’ perspectives of providing palliative care in a general hospital setting were explored. This research was substantial in terms of sample size (N = 263) and included registered nurses randomly selected from the duty rosters of 18 wards in four district general hospitals in Northern Ireland. A pre-piloted questionnaire was developed using Likert scale items that had been adapted from a previous questionnaire measuring community staffs’ educational needs in palliative care. The results identified serious issues in providing palliative care in a hospital.
setting. These included a lack of appropriate training and education; work pressures and a lack of support, including staff shortages, and the lack of an integrated multidisciplinary approach. The results indicated that more evidence was required regarding the quality of palliative care provided in a hospital setting, and suggested that radical reform was necessary. A major theme identified was that holistic, palliative care was not embraced within the hospital setting due to the identification of issues such as a staff shortages and a lack of support. It also raised doubts regarding the nurses’ ability to remain objective in an environment fraught with conflict due to the chronic deficiencies (staffing and physical resources) within the healthcare system (McDonnell et al., 2002). The sum of these studies raised many issues in caring for marginally viable and critically ill newborns that require further empirical investigation beyond the scope of the research presented in this section.

2.1.2.2 Grief

Several studies have identified grief as being a common experience amongst caregivers (Davies et al., 1996; Doka, 1989; Downey et al., 1995; Ewing & Carter, 2004; Farrell et al., 2000; Hammer, Nichols, Armstrong, & Rose, 1992; McIntosh & Eldridge, 1984; Papadatou, 1997; Raeside, 2000; Romesberg, 2004; Ross, 1992). Grief is a multi-faceted response to loss. Although conventionally focused on the emotional response to loss, it also has physical, cognitive, behavioral, social and philosophical dimensions. The grief experienced by neonatal nurses is seldom recognised, leaving nurses with a sense of despair and bewilderment (Farrell et al., 2000). Doka (1989) describes this inability to acknowledge or gain support for this type of grief in the workplace as ‘disenfranchised grief’ – often seen in unacknowledged, personal, work-place related loss - as a type of grief that is experienced when a loss, such as the death of a newborn, is not openly acknowledged, discussed, socially sanctioned, or publicly shared. This may lead to moral distress, which will be discussed in the following section.

Survey research was used to develop a paediatric palliative care program in Papadatou’s (1997) research. This research identified aspects of grief in ‘personal perception data’ collected from the nurse participants. Following the survey phase of
Papadatou’s research, the nurses participated in a training program. Participants reported that the knowledge and skills gained in providing palliative care to dying children was very useful from each of the didactic units provided and indicated specific ways it helped them in their everyday clinical practice. In addition, all participants reported that the effects of training were highly positive in the development of a deeper understanding of their personal beliefs, feelings, and attitudes toward death, dying, and living. Papadatou’s research offered a rationale as to why grief is so prevalent in contemporary end-of-life nursing. Papadatou argued that an assumption centres around the theme that in the Western world, the death of a child is relatively rare, and paradoxically, nurses are directly confronted and affected by childhood death. This may be because an increased number of children die in hospital, usually after extensive efforts and heroic measures are undertaken to save them. This research hypothesises that this may be perceived by nurses as a triple failure: firstly because they did not have the skills to save the child, secondly because in their social role as adults they were unable to protect the child from harm and thirdly, because they felt they betrayed the parents who trusted them with the most valuable thing in their lives (Papadatou, 1997). A limitation of this training program was the lack of a control group which would have tested the reliability and validity of these results.

In Davies’ et al (1996) qualitative research of paediatric palliative care nurses, it was reported that nurses respond to grief in a variety of ways. Following content and thematic analysis of interview transcripts (N= 25), this study found that nurses who were able to express their sadness when a child was dying were better psychologically equipped to manage their distress. These ‘healing conversations’ commonly occurred between colleagues. Other nurses in Davies’ research responded to grief by separating professional tasks from personal emotions. Previous research suggests that when multiple deaths occur – as in a hospice situation – ‘bereavement overload’ may occur, or ‘cumulative grief’. Some of the more obvious effects of cumulative grief is a total denial of grief so that the nurse does not realise they are grieving. This can lead to a preoccupation with death and exaggerated grief (Hammer et al., 1992). In Davies’ (1996) research, paediatric palliative care nurses withdrew both physically and emotionally due to the impact of caregiver grief. In
withdrawing emotionally, the nurses admitted to blocking their sadness and distress in dealing with dying children. Others responded by becoming increasingly task-oriented due to the fear that expressing themselves emotionally would negatively impact upon their nursing competence (Davies et al., 1996).

Most of the research identified in these sections is dated, and/or fails to contextualize the origins of caregiver stress and grief in the NICU environment. This is because stress may not stem from actually caring for marginally viable and critically ill newborns, but more from a perceived or real lack of support from colleagues and the loss of control over practice (Farrell et al., 2000). Several of these studies have developed instruments, but reliability and validity data have not been adequately described. Updated research is warranted in this area using a validated, reliable tool.

2.1.2.3 Moral distress

Moral distress is described as a manifestation of the prevention of translating moral choices into moral action (Rushton, 1992). This is a serious issue in contemporary nursing, and is often described in the literature regarding caring for marginally viable and critically ill newborns. Moral distress in this literature review was also explored with reference to nursing disciplines that routinely provide care to dying patients. The nurse may respond to this by experiencing anger, resentment, guilt, frustration, sorrow or powerlessness. When moral distress is not addressed, the nurse’s self-worth is jeopardized, affecting personal and professional relationships. Ultimately, the quality of patient care may also suffer (Rushton, 1992).

Moral distress has been identified as being experienced by nurses (Armentrout-Richey, 1988; Downey et al., 1995; Hefferman & Heilig, 1999; Miya, Boardman, Harr, & Keene, 1991; Todd, 1995), and medical staff(Carter, 1993; Catlin, 1999; Doron, Vaness-Meehan, Margolis, Holoman, & Stiles, 1998; Muraskas et al., 1999; Sanders, Donohoe, Oberdorf, Rosenkrantz, & Allen, 1995; Simpson, 1999a) when caring for marginally viable and critically ill newborns. It has been associated with stress, burn-out, and the decision to leave the nursing profession altogether (Fry, Harvey, Hurley, & Foley, 2002; Gutierrez, 2005). Research indicates that moral
distress is a causative factor in high nursing turnover, and ‘burnout’ (Gutierrez, 2005).

Survey research of neonatal nurses (N = 115) and residents (N = 164) by Janvier et al (2007) found that 35% of nurses and 19% of residents were frequently confronted by ethical dilemmas in the NICU, which may have attributed to moral distress. The literature further identifies that failure to control pain when caring for marginally viable and critically ill newborns often results in moral distress for caregivers. Furthermore, opioid use for these newborns has been a controversial subject for many years, and healthcare professionals have often argued about the infant's ability to experience pain (Partridge & Wall, 1997). There is compelling evidence that concludes newborns, including premature infants, are able to manifest both behavioural and physiologic responses to nociceptive stimuli. Despite this evidence, little is known about the infants' experience of pain and discomfort during routine handling and non-invasive procedures (Partridge & Wall, 1997).

Moral distress has been identified in nursing personnel who perceive the death of a patient as a personal failing (Davies et al., 1996; Hartline, 2002; Lo et al., 1999; McIntosh & Eldridge, 1984; Papadatou, 1997; Pierucci et al., 2001). It has also been described by healthcare professionals who are affected by what they perceive as the unrealistic demands of parents of dying babies (Nolan, 1987; Silverman, 1981, 1992, 2002, 2004; Wocial, 2000). The impact of technology in the clinical area has also been alluded to as a causative factor in moral distress with the literature reporting staff as being ‘held hostage’ by increasing technology in the NICU arena (Catlin & Carter, 2000; Kain, 2007a; Muraskas et al., 1999; Simpson, 1999b; Stevenson & Goldworth, 1999).

As this section of the literature review has identified, there is a paucity of research on moral distress and providing care to dying babies in neonatal nursing. Much of the research that has been undertaken in the area of moral distress in and nursing practice is in the form of small, qualitative studies. Contemporary research, particularly in the area of neonatal nursing, fails to accurately describe how moral distress and its resulting emotional, physical, and economic effects influence the nurse and patient.
care outcomes. Further research is necessary to seize the opportunity to identify and measure moral distress, thus providing a key to developing the strengths and skills to assist neonatal nurses to move beyond moral distress and towards moral action (Kain, 2007a).

2.1.3 Resources to support a palliative model of care

2.1.3.1 Protocols and guidelines

Although evidence based protocols (Catlin & Carter, 2002), clinical practice guidelines (Gale & Brooks, 2006), and published Australian standards (Palliative Care Australia, 2005) are available to guide palliative care practice, palliative care provision to the neonatal population is interpreted as ad hoc in reality (Maginnes, 2002). The existence of a palliative care protocol for the neonatal population (Catlin & Carter, 2002) developed in conjunction with a 101 international Delphi panel has provided a major contribution to the promotion of palliative care in neonatology. In practice, however, these guidelines have been difficult to implement (Carter & Bhatia, 2001). The reasons for these difficulties are unclear (Maginnes, 2002), and require further investigation by empirical research. Furthermore, it is not known whether such protocols inform guidelines in use in Australian NICUs, and if such guidelines exist, it is not known if they have an evidence base. Ciccarello (2003) identifies the lack of a protocol to guide critical care nurses when caring for patients at the end-of-life as a barrier to providing such a model of care. A protocol could guide the expert critical care nurse to deliver appropriate palliative care in the clinical area to dying patients.

It is suggested that most NICUs have at least some approach to managing newborns at the end-of-life (Stringer, Shaw, & Savani, 2004), yet these processes may not take the form of evidence based guidelines. However, an evidence based protocol, argued Catlin & Carter (2002) is essential, as it allows team members to become familiar with implementing palliative care, and guides them in their support of the patient and symptom management. Catlin and Carter (2002) stated that it is neonatologists who have expressed the most concern about the lack of a structured palliative care protocol. Such a protocol would provide consistency and a useful model for teaching.
In Catlin’s (1999) research of neonatologist based decision-making, it was reported by neonatologists that a lack of policy and guidelines contributed to uncertainty in practice. For example, incongruities were found to be commonplace in terms of what the minimum requirement for resuscitation should be. There has been concern expressed by neonatologists that if they fail to develop their own guidelines for end-of-life care, guidelines might be dictated by managed care organisations. It has been suggested, therefore, that based upon their previous experiences, neonatologists should be involved in guidelines, protocols and policy to provide guidance and direction to both families and nurses involved in care (Simpson, 1999b).

Davies et al (1996) emphasized the importance of clearly establishing a palliative focus of care. Protocols that address criteria such as making the child comfortable, free from pain and ensuring the family are satisfied with care make coping with the situation easier for those involved (Davies et al., 1996). Such a protocol should contain elements of clinical and ethical training in areas such as alternatives that allow the infant to die from their condition; principles of transition from life extending care to palliative care and familiarity with various pain assessment tools. The needs of the family should also be incorporated, and should consider five major elements: the patient’s best interests; the family through open dialogue; the staff who all require support in dealing with these cases; the institution and society (Carter & Bhatia, 2001; Catlin & Carter, 2002). Furthermore, it is suggested that general palliative care protocols and guidelines already in existence could also be reassessed and adapted for neonatal use (Maginnes, 2002). This includes, as suggested by Engler (2004), the American Association of Colleges of Nursing (Competencies Necessary for nurses to Provide High-Quality Care to Patients and Families During the Transition at the End-of-life), the principles of which would be of value to the neonatal population. Although primarily addressing palliative care for the elderly, useful aspects include communicating effectively and compassionately with the patient, family, and health care team members about end-of-life issues and recognizing one’s own attitudes, feelings, values, and expectations about death and the individual, cultural, and spiritual diversity existing in these beliefs and customs (Engler et al., 2004).
The “Standards for Providing Quality Palliative Care” protocol developed by Palliative Care Australia (2005) is another example of available resources that could be adapted for neonatal use. These guidelines incorporate 13 standards, and were developed for use by specialist palliative care services and other health care services that care for people with life limiting illnesses. The standards have been based on a number of core values, assumptions and beliefs, and range from decision-making and care-planning; acknowledging caregiver/s and family needs regarding decision-making and care planning, and; ensuring that staff are appropriately qualified for the level of service offered whilst demonstrating ongoing participation in continuing professional development. These standards also recognize special needs populations, including children with a life limiting illness. Although they do not extend to the highly specialized needs of neonates, the core values that underpin these standards are relevant to the neonatal population also, and could be adapted for this purpose.

Gale and Brooks (2006) developed clinical guidelines to better meet the needs of families and staff caring for dying infants and their families. Prior to these guidelines, marginally viable and critically ill newborns received standard care led by the neonatologist supported by nursing, social work, and pastoral care in the research setting. Although this approach was mostly effective, the limited availability of leadership support overnight and at weekends impaired the consistency of providing palliative care. The Palliative Care Pathway was adapted and described seven phases of care of the dying infant that progressed from pre-resolution of an infant's potentially nonviable status through death and bereavement. By having a pathway to guide palliative care, the family's adjustment to the infant's prognosis and changing needs was promoted. Furthermore, decisions regarding limiting or withdrawing life-sustaining care occurred in collaboration with parents. The efficacy of the program was only anecdotally reported by staff, but it did indicate that increasing the speed and availability of grief support reduced moral distress for staff. Informal feedback was obtained by parents, suggesting that the palliative care support they received was helpful to them and their families (Gale & Brooks, 2006). This initiative illustrated the philosophy that palliative care and intensive care are not mutually exclusive. The pathway developed by Gale & Brooks frames the infant and family’s care needs at each phase of the dying process. It highlights important patient
observations, expected outcomes, and providing essential discussion points to frame discussions with families. The pathway also identified nursing considerations for nutrition and pain control. The pathway provided rational suggestions for anticipatory guidance and support for families who may be simultaneously celebrating a birth while struggling with the death of their infant. Furthermore, the authors described an environment where healthcare professionals are encouraged to explore their personal values, to seek spiritual counsel, to debrief as a team, and to create peer support systems and ‘safe havens for healing’ (Gale & Brooks, 2006).

2.1.3.2 Infrastructure

The literature demonstrated a lack of resources to facilitate a palliative model of care. This included the physical environment. The literature available on this subject was mostly polemic. It is recommended that the best environment in which to provide palliative care in the NICU is one that allows privacy and comfort for the family (Catlin & Carter, 2002; Fauri, Ettner, & Kovacs, 2000; Wyatt, 1999; Yu, 1997). Providing such an environment requires policy changes, such as relaxing visiting restrictions and providing infrastructure such as multipurpose rooms to ameliorate some of the stresses placed upon grieving families (Yu, 1997). The chaos of a busy, open, and public NICU is not the place for palliative care to take place (Conway & Moloney-Harmon, 2004). The literature reported that some positive developments have occurred (Peterson, 2005), but it is the mindset of the staff that is far more important than the physical space. The attitude of the healthcare team and their willingness to care for marginally viable and critically ill newborns and their families, skills in accurate observation and the ability to support the process are considered far more important than simply providing the optimal physical environment (Catlin & Carter, 2002).

2.1.4 Support & training for caregivers

Most healthcare professionals practising in areas that are likely to encounter death receive little formal education or training in palliative care, and as few as 2% of undergraduate nursing and medical training curricula in the United States is related to end-of-life topics (Maginnes, 2002). Despite the paucity of formal preparation
(Contro et al., 2004), neonatal nurses and neonatologists are expected to deal with complex end-of-life decisions and are expected to do so as a team, performing in unison, despite their individual opposing beliefs and opinions (White, Payne, & Patel, 2001).

Contro et al’s (2004) research developed a paediatric palliative care program that highlighted the need to improve education and support for staff members when caring for dying children. This research used a mixed method approach: a survey of staff and family interviews aimed at improving paediatric palliative care. Four hundred and forty-six healthcare professionals responded to a survey regarding their personal comfort and expertise in delivering palliative care to dying children. Sixty-eight family members of 44 deceased children were also interviewed regarding treatment, the transition to palliative care, and bereavement follow-up contact. In the survey phase, Contro reported healthcare professionals’ inexperience in communicating with patients and families about end-of-life issues, the transition to palliative care, and ‘Do Not Resuscitate’ (DNR) orders. Additionally, in the structured interviews, families described their distress caused by the ‘uncaring’ delivery of ‘bad news’ and ‘careless remarks’ made by staff members. Healthcare professionals also reported their inexperience in symptom and pain management, describing occasions when pain management ‘could have been better’. Fifty-four percent of staff members reported that there was inadequate support for those who care for dying children.

In 2004, Engler et al (2004) conducted a quantitative study using an instrument (a 55-item instrument, the Bereavement/End-of-Life Attitudes About Care: Neonatal Nurses Scale (BEACONNS) based upon parental needs for compassionate care when their baby had died. It was hypothesized that although nurses had the potential to provide compassionate palliative care they often had inadequate preparation in bereavement/palliative care. This study was of particular interest to the current research: although the focus was upon parents, it began to ask questions about how neonatal nurses’ attitudes may impact upon providing care to marginally viable and critically ill newborns. Specifically, this study asked nurses about what factors influenced their involvement with families of marginally viable and critically ill
newborns, and what influences education, their professional role, and educational level have (Engler et al., 2004). The BEACONNS consisted of 104 items, and was revised on the basis of content review and pilot testing with a convenience sample of 24 neonatal nurses. This research used a cross-sectional, descriptive, correlational mailed survey design (N=190 completed data sets from 125 hospitals; response rate 52%). Following evaluation of the scale for clarity and redundancy, the final 55-item instrument contained 4 sections:

- The nurses’ comfort with bereavement/palliative care (comfort scale – to obtain the degree of comfort the nurses experienced with various aspects of bereavement/palliative care, for example, allowing parents to hold the dying infant),
- The nurses’ roles with families (roles scale – to assess the nurses’ perception of their roles with families of critically ill and/or dying infants, for example, explaining the technology to family members and providing support),
- The nurses’ involvement with families (involvement scale – to gather the nurses’ ratings of the importance of various factors relative to the participants’ involvement with patients’ families, for example, a busy Unit or a receptive family),
- Demographic characteristics of the NICU and participant.

Reliability was acceptable for all scales for both the pilot study and the main study. The ‘roles scale’ correlated with both the ‘comfort scale’ and the ‘involvement scale’ (Engler et al., 2004). This research had some limitations, however. Firstly, the participants were selected by their Nurse Unit Managers as being the most knowledgeable about bereavement/palliative care in the NICU. Therefore, the nurses’ expertise may have made them more comfortable with these aspects of care in the first place. Secondly, parents were not surveyed in this research, thus did not allowing for a comparison between nurses' and parents' perceptions to be made, a notable exception considering the research was centred around parental needs. This research concluded that education about bereavement/palliative care could affect nurses' comfort with caring for families of critically ill and/or dying infants (Engler et al., 2004).
The literature reports that there is little training in the skills needed to effectively communicate with families about issues related to death and dying (Levy, 2001) and most healthcare professionals often learn how to do so ‘on the job’ (Blank, 1998) and by ‘trial and error’ (Hilden et al., 2001). However, much like common sense, end-of-life issues, are not easily taught (Muraskas, 2005). The importance of training in communication skills at the end-of-life, however, is a prevalent theme in the literature (Ferrell & Borneman, 2002; McDonnell et al., 2002; Miya et al., 1991; Rogers, Karlsen, & Addington-Hall, 2000; Vachon, 1995; Wilkinson, Roberts, & Aldridge, 1998; Wyatt, 1999) and general palliative care nurses have reported a lack of confidence in discussing death and dying with their patients and their families (McDonnell et al., 2002). Communication can make the difference between parents agreeing with a decision that has already been made by the healthcare team, versus obtaining enough information to participate actively in the decision-making process and thus give ‘truly informed consent’ (Becker & Grunwald, 2000 p 66). A need for specialist training in communication is important when one considers that effective communication between parents and healthcare professionals in the NICU is an integral part of collaborative decision-making regarding treatment plans, and these ethical components of decision-making need to be made collaboratively with parents and health care professionals (Ward, 2005).

In summary, the literature suggests that training in the basic principals of palliative care is mostly neglected in nursing curricula. In Engler et al’s (2004) study based on parental needs for compassionate care when their baby died, 63% (n=119) of nurse participants indicated that their basic nursing education programs had included content on bereavement/palliative care. Of these, only 42% (n=50) reported that the content was satisfactory for their clinical requirements. Engler concluded that although education and training have the potential to affect neonatal nurses’ comfort with bereavement/end-of-life issues, it was uncertain if the perceptions of their roles and involvement with families were likely to be affected. Nevertheless, Engler reported that providing further education and training in bereavement/palliative care could amplify the nurses’ comfort in dealing with difficult topics, such as autopsy and organ donation. Contro et al (2004) states that for such palliative care programs to be effective, it must encompass a broad education and training basis for all
healthcare professionals who provide care to children and their families in the palliative phase.

2.1.5 Decision making on behalf of marginally viable and critically ill newborns

As this literature review has emphasised, technological improvements and increases in the skills of healthcare professionals have altered the face of neonatology. As a result, survival rates have enhanced dramatically, but with these improvements, new dilemmas have occurred as a result. For babies who are born at the margins of viability, or are critically ill, McHaffie (1997) argued that the question now is not so much can healthcare, but should healthcare, save the infant’s life. These are significant and overwhelming decisions for healthcare personnel as well as parents to face. These arguments, as well as research regarding these issues, will be presented in this section.

McHaffie and Fowlie (H. McHaffie & P. Fowlie, 1998; 1998) cited several sources of conflict when it comes to decision making, including conflicting values/religious beliefs and the differing interpretations of selective non-treatment to marginally viable and critically ill newborns. When decisions are being made about whether or not treatment is in the newborn’s best interests, some tension may be inevitable (McHaffie, 1998a). However, opinion in the literature stresses the importance of using best interest principles as a standard for decision making in the care of neonates (Spence, 2000). The context in which decisions are made has evolved in ways that have made treatment decisions more, rather than less, difficult. Legal, health systems, and technological factors all form this social context for resolving decisions about withholding or withdrawing treatment for fragile newborns (Becker & Grunwald, 2000).

Parents often have to face ethical decisions when making decisions on behalf of their babies (Pierce, 1998). They have both the authority and obligation to make decisions that are in the best interests of their child, yet parents of babies in the NICU report experiencing ‘numbness’ as they struggle to decide what is right for their child, and the family (Anderson & Hall, 1995). In a prospective observational study (Hentschel, Lindner, Krueger, & Reiter-Theil, 2006) conducted over a 30-month
period, newborns for whom restriction of ongoing intensive care were indicated were studied. This research utilised a standardized form which recorded the newborn’s medical condition, the type of restriction of intensive care that was decided upon, the parents' wishes (when known), and the information they had received to support their decision. In general, parents were well informed; however, their wishes concerning restriction of ongoing intensive care were unknown in 25% of cases. The desire for restriction of ongoing intensive care or ‘humane treatment’ prevailed over wishes for ‘maximum therapy’, but there was a significant number of parents who opted against restriction of ongoing intensive care when first presented to them. This study reported that it was the task of the neonatologist to explain the background of the team’s decision to the parents. In a similar study reported by this research team, it was claimed that parents were ‘involved in making 79% of decisions’, but this was only the interpretation of the neonatologist and was not verified by an interview with parents (Hentschel et al., 2006).

Historically, it has been reported that parents are not adversely affected by participating in decision-making (Benfield, Leib, & Vollinan, 1978), and more recent literature (McHaffie, Lyon, & Hume, 2001; McHaffie, Laing, Parker, & McMillan, 2001) suggests that this remains so, and furthermore that parents express satisfaction at being involved. These issues were clarified by two empirical studies conducted in Scotland by McHaffie et al (2001). The combination of these collaborative studies used in-depth interviews with 176 medical and nursing staff and with 108 parents of babies for whom there was discussion of treatment withholding/withdrawal. The data generated by these studies on both the decision making process and the management of these cases provided a wealth of information. These studies reported that both staff and parents believe that parents should be involved in treatment limitation decisions on behalf of their babies. However, whilst many doctors and nurses consider the ultimate responsibility too great for families to carry, McHaffie’s (2001) research found that the majority of parents maintained their wish to be the final arbiters. Earlier empirical research also supported that the final decision was the responsibility of the doctor in clinical charge of the infant yet supported a team approach to decision-making (Campbell & McHaffie, 1995). With reference to the two studies conducted in 2001, parents identified two important factors which
minimised parental anxiety and doubt: full and honest information and tangible evidence of a poor prognosis. The majority of parents expressed the desire to be active in decision making on behalf of their baby. These studies also concluded that including parents in decision making did not appear to have adverse consequences. Furthermore, McHaffie et al (2001) suggest that dissatisfaction can be reduced if parents are given time and evidence to help them absorb the reality of each stage.

In an opinion paper, Harrison (1993) supported McHaffie’s (2001) suggestion that parents require ‘time’ and ‘evidence’, and argues that there is no excuse, however well-intentioned, for withholding important clinical information about a baby’s condition or prognosis from their parents. Parents, stated Harrison, have a right to know about relevant differences of medical or ethical opinion among healthcare professionals or within the medical community. In neonatology, it is the parents and families who are consumers, by proxy, of palliative care (Rogers et al., 2000). Handley (2003) stated that although parents have the right to decide by proxy what treatment their child should receive, and that such decisions be made in the newborn’s best interests, these so-called ‘best interests’ were subjective. However, the views of the parents should take precedence when acting in the child’s best interests, because they are obligated to act in their child’s best interests. Cranley-Glass (2002) reiterated this notion, stating that parents have the unique ties of affection and concern for their children – albeit an assumptive authority over their welfare – and it could therefore be assumed that they would most likely act in the child’s best interests. In the last decade, the literature has emphasized the importance of parental involvement in the decision-making process (Arlettaz et al., 2005) yet parents initiate end-of-life discussions in only 13% of cases (Buus-Frank, 2006).

Making decisions regarding withdrawing life support and limiting resuscitation efforts for marginally viable and critically ill newborns are among the most difficult, heart-rending and traumatic decisions faced by parents, neonatologists and the healthcare team (Jellinek, Catlin, Todres, & Cassem, 1992). Furthermore, a decision to withdraw life support or limit resuscitation efforts tests the trust between the parent and the neonatologist. The basic fundamentals of trust are based upon the neonatologist’s honesty, medical experience, warmth, ability to listen, empathy, and commitment to the family. This trust supports the parents through the painful
process of facing loss, supporting decision-making and the beginnings of grieving (Jellinek et al., 1992).

Despite evidence that parents wish to be involved in decision making about their babies, there is much debate about the extent and/or appropriateness of their involvement. Historically, parents are considered the natural surrogate decision makers for the care of their children primarily on two not necessarily related grounds (Arlettaz et al., 2005). The first rationale is that the decision ‘properly belongs to those who bear responsibility for the infant: the parents’. The second is that the parent is best suited to advocate for the well-being of their offspring and best suited to choose a treatment plan that best protects the child’s interests. In most circumstances, it would appear that parents are the ones most likely to make decisions on their children’s behalf that are legally accountable, given that no one else is as familiar with their needs, or as likely to cherish them (Nolan, 1987; Pinkerton, 1997).

A qualitative study by van der Heide et al (1998), reported that when decisions are made to either accelerate the death of a baby, or not to prolong life, they are generally made following discussion with the parents. However, this study also found that such discussions did not take place when it was known that parents might disagree. This research found that there were several situations in which end-of-life decisions simply weren’t made because of a lack of parental consent, including complications of prematurity (24%) or perinatal asphyxia (40%). The paediatricians interviewed often expressed feelings of unhappiness about the situations they had encountered where there had been disagreement between themselves and parents. In this research, it was considered that the principle of preserving life was abandoned by paediatricians only when they were sufficiently certain that the parents would agree that such a course of action was in the best interest of the child (van der Heide et al., 1998).

Because families bear the emotional and financial consequences of the birth of an extremely preterm newborn, it is essential to inform prospective parents regarding the expectations for neonatal survival and outcome and the risks and benefits of various
approaches to care (MacDonald, 2002). Furthermore, Stevenson and Goldworth (1999) argued that although parental decisions are based exclusively on self-interest for the newborn, the life of their child is so intertwined with theirs that it is idealistic to propose that they can choose for the newborn without choosing for themselves. After all, it is the parents, not the neonatologist, who endures the major burdens of long term care should the newborn survive (Stevenson & Goldworth, 1999). However, many parents do not wish to be burdened by having the final word for their children. The weight of such a decision may lead to guilt, but parents do want to be informed and taken seriously in the decision-making process (Brinchmann, Forde, & Nortvedt, 2002). Qualitative research by Brinchmann et al (2002) concluded that parents value the communication they have with healthcare professionals regarding life and death decisions about their premature newborns more than their autonomy and right to choose (Brinchmann et al., 2002).

Deciding when to withhold or withdraw curative treatment for marginally viable and critically ill newborns, however, is an intricate and emotionally disturbing task. It was argued that was not possible draw up a definitive framework which could be used as a ‘cookbook recipe’ (McHaffie, 1998b). However, such an approach to decision making has been advocated in a qualitative study conducted in 2005 (Baumann-Holzle et al., 2005). This study devised a framework to facilitate structured decision making in the NICU. This framework aimed to integrate the best interests of the newborn and their parents, the possibilities of high-tech interventions, and the perspective of the nurses and doctors. This framework was evaluation utilizing an external evaluation of 84 sessions over a three year period. The evaluation sessions demonstrated a beneficial effect on the quality of the decision-making process itself and on the quality of teamwork in the unit. Survival time of the newborn was shorter (median 2 days, interquartile range 1–7 days) in the 26 infants that died after structured decision making compared with the 26 controls matched for gestational age, malformation and intracranial haemorrhage (median 7 days, interquartile range 4–15 days). This study concluded that the introduction of the framework for structured decision making involving doctors and nurses improved the quality of teamwork. It also shortened futile intensive care, and thereby alleviated suffering for both the newborns and their parents (Baumann-Holzle et al., 2005).
In summary, it can be argued that healthcare has much to learn from parents who have lost newborns in the NICU, because it is parents who have survived the painful experience of marginally viable and critically ill newborns who can teach healthcare the most - it is therefore crucial that healthcare providers listen. Maginnes (2002) states that parents who had benefited from palliative care had much to teach the healthcare team, and that lessons could be learnt from their experience of the decision-making process. Parents who have been in this unfortunate position may challenge healthcare to revisit current practices and ask whose interests they are really serving in protracting inevitable deaths, as suggested by McHaffie et al (2001).

2.2 The social discourse of caring for marginally viable and critically ill Newborns

The purpose of discussing the social discourse in this section is to identify and decontextualise the strong societal voice that is entrenched in this field of research. This includes identifying the expectations, values and beliefs of society and the pivotal role these issues play in the care of marginally viable and critically ill newborns. Caring for these babies is an emotionally loaded subject, and in developing policy and clinical guidelines to inform a palliative model of care, research must deliver guidelines that are sensitive to the population it serves. This section will address how the social literature is constructed and how it represents a significant voice in the research paradigm. The literature for this section was identified from within the search strategy used for the literature review, and also from media resources such as newspapers, books and internet searches.

2.2.1 Society’s expectations of caring for marginally viable and critically ill newborns:

Opinion in the literature suggests that society perceives medicine as entering an age of ‘miracles’ and ‘wonder’, and this is all upon public display in the NICU (Levy Guyer, 2006; Tisdale, 2003). As an example, there are internet sites that espouse this notion of so-called ‘medical-miracles’, an example of which being the Children's Hospital at The Cleveland Clinic (http://www.wkyc.com/miracles/about/breakthroughs.asp, 2007) when discussing their 17 bed NICU. Given these influences, parents often
have unrealistic expectations with what can be offered to their child in terms of medical intervention. This may lead to the belief in the ‘medical miracle’ to explain a technological solution for everything (Levy Guyer, 2006; Paris, DeLisser, & Savani, 2000). Extremely premature newborns have survived, and so there is an unsound basis for parental requests that everything possible be done to ‘save’ their babies. Due to reports of these so-called ‘miracle babies’ (The Age., 2007) the public may expect more from the NICU now that some newborns born at 22 weeks gestation have survived. It is expected that modern medicine can save every newborn born beyond this milestone (Levy Guyer, 2006; Paris et al., 2000). This expectation is captured in the following newspaper article:

*Miami, February 20, 2007.*

Baby Amillia Sonja Taylor was just 24.1cm long and weighed less than 285 grams when she was born just under 22 weeks of pregnancy. The world’s most premature living baby, born at 21 weeks and six days, is headed home after spending four months in a NICU, Baptist Children’s Hospital in Miami announced today. No baby born at less than 23 weeks was previously known to have survived, according to the University of Iowa, which keeps a record of the world’s tiniest babies.

"She’s truly a miracle baby," said William Smalling, a neonatologist at the Baptist Children’s Hospital. He said caring for Amillia in the past month was like navigating uncharted waters.

"We didn’t even know what a normal blood pressure is for a baby this small," Smalling said.

The American Association of Paediatrics indicates that babies born at less than 23 weeks of age and 400 grams in weight are not considered viable.

"It may be that we need to reconsider our standard for viability in light of Amillia’s case," said Smalling. "Over the years, the technology that we have available to save these premature babies has improved dramatically. Today, we can save babies that would have never survived 10 years ago," he said(The Age., 2007).

In a television series aired on an Australian commercial network entitled ‘Saving Babies’ (Quail, 2007), examples of apparently ‘futile’ cases were ‘saved’, further fostering the notion that all newborns can be saved, no matter how futile their condition may appear. The notion of unrealistic expectations is supported by the literature that the influence of the media has allowed many parents to think that the path of newborn problems can be altered and corrected (Catlin & Carter, 2001). Facing the wrath and anger of parents often resulting from these expectations can be one of the most difficult aspects of caring for marginally viable and critically ill newborns. Parents cannot blame their baby, who may have been born with
anomalies or on the verge of death, and therefore, their anger is often displaced onto staff (Jellinek et al., 1992). This anger and frustration is powerfully highlighted in a parent’s rejoinder (Horn, 2004) to an editorial (Kattwinkel & Boyle, 2004) published in a medical journal:

“David ... was snatched from his mother’s womb 11 years ago at 24 weeks gestation and weighing one pound ... David has cerebral palsy, mental retardation and daily multiple seizures. He cannot toilet or dress himself. We ‘selfish’ parents were handed a life sentence of hell without ever being given the proper info or choice that we now know was available, but was purposely withheld by the experimenting, revenue generating NICU. Some exact quotes from our NICU doctors and doctor’s assistants: “It’s a grade III brain bleed. Often these things resolve themselves.” Another exact quote after the too-late discovery of the brain bleed, which I, as a civilian, now know normal people call a stroke. “He may be a little behind.” Exact quote. Why did they sugar coat and outright lie? So they would have a cooperative parent. I realize in retrospect I was psychobabbled and socially engineered by the NICU staff to keep me in the dark. So much for healers.

All we parents of damaged super preemies ask is that we be given the choice. Why is it you perform amniocentesis, ultrasounds and other tests on foetuses to see if there is a malformation? Isn't the point to let the parents know and make a choice? Why was I denied that same choice, instead of given a life sentence. Did my health insurance have something to do with it? The hospital got half a million dollars for our four and a half month stay. All we got was sleepless nights, no vacations and financial burdens. My wife is David’s 24 hour nurse, administering meds and managing endless doctor’s appointments. Oh, I get it, you keep ‘em alive so there’s a constant stream of follow up income. Nice. Cynical you say? Come wipe the poop off David for a whole week and I’ll exonerate you. Perhaps some parents would say yes to a severely damaged super preemie. Let them have their choice and let me have mine” (Horn, 2004).

As this example indicates, despite the successes championed by the media, there are also failures, and contemporary neonatology may be either a blessing or a curse (Fine, Whitfield, Carr, & Mayo, 2005). Part of society’s unrealistic expectations of neonatal care may stem from an inability to accept death. Romesberg (2004 p 162) quotes death as ‘a mysterious stranger at a costume ball, whose mask conceals the face beneath’, arguing that neonatal care is expected to ‘cure’, and how this has led to healthcare providers inadvertently denying that death may be the ultimate outcome for some patients. Romesberg’s work in understanding neonatal death states: ‘we are a nation that has forgotten how to die, forgotten how to grieve, and is in danger of losing our ability to care for the dying’ (2004 p 162). She further quotes a suggestion
that society considers the death of an infant to be: ‘weird, unbelievable, and in bad
taste’ (2004 p 162). These social attitudes may play a major role in the management
of newborns who are not expected to survive. There is a societal view that newborns
are not supposed to die (Romesberg, 2004) and the death of a child is considered
unnatural (Contro et al., 2004). It is suggested that parents harbour unrealistic
expectations, considering that overall, it is denied that children die. Maginnes (2002)
theorizes that when one considers that the English language contains words such as
‘orphan’ or ‘widow’ to describe those who have lost their parents or spouse, and that
no word defines parents who have lost a child that it is possible that neonatal death
becomes easier to deny overall.

Conflict may result from the differing opinions about decisions on behalf of
marginally viable and critically ill newborns between staff are parents. When the
expectations and opinions of parents differ from staff opinions, parents may perceive
that they have no control (Cisneros-Moore, Coker, DuBuisson, Swett, & Edwards,
2003) as this BBC news quote (BBC, 2006) illustrates,

**Quote from: BBC News online, “Don't let baby die’, pleads father.**

**The father of a seriously ill premature baby has pleaded with the High Court not to allow doctors to let her die.**
Charlotte Wyatt weighed just one pound when she was born 11 months ago and has
serious heart and lung problems. Doctors want permission not to revive her if she
stops breathing, saying it is not in Charlotte's best interests.
But Darren Wyatt, 32, from Portsmouth, said she was a ‘fighter’ and everything
should be done for her. The judge has reserved judgement until Thursday. During the
second day of the hearing on Friday, Mr Wyatt said: "When you get to the stage
when you grow to love someone, you can't just throw them away like a bad egg and
say you will have a different egg." With his wife, Debbie, 23, in tears, he told the
judge about how they had held their daughter recently.
"I held Charlotte's hand and she gripped my finger. She knows who we are and that
we are her parents." And Mr Wyatt, a committed Christian, added: "If the man
upstairs says this person should live, then this person should live." He conceded that,
if the time came when the baby was really suffering, he would have to change his
mind. He also told the court one of his three older children from a previous
marriage was a nine-year-old boy who was disabled by having suffered from
tumours. Despite his problems, he could walk and talk and went to school, said Mr
Wyatt. He said he appreciated Charlotte would be much more disabled, but she
should be able to have some life. But the medical staff treating her say it is not in
her best interests to resuscitate her if she stops breathing again. She has already
stopped three times.
However, one expert medical witness has said treatment should continue until the parents agreed with doctors. The consultant paediatrician said parents in such awful situations often agreed to the withdrawal of life support after realising that prolonging life was futile. The doctor, who has been given anonymity like all the medical witnesses in the case, said Charlotte should be ventilated by way of a tracheostomy - the insertion of a breathing tube through the throat - so further discussions could take place between parents and doctors. Mr Wyatt said he was willing ‘to sign a contract’ to the effect that he and his wife would let Charlotte go if, at the end of five days following a tracheostomy, there was nothing more that could be done. Charlotte was born when her mother was 26 weeks pregnant, has never left hospital and is fed through a tube as she cannot suck from a bottle. She also needs a constant supply of oxygen. David Lock, counsel for the hospital, part of the Portsmouth Hospitals NHS Trust, said a doctor had said she was ‘living in a plastic box’ and that her life would be ‘dominated by pain and suffering’. Mr Lock summarised the trust consultants' findings by saying: "They are of the view that Charlotte has life-limiting conditions and that, despite their best efforts, she has no feelings other than continuing pain. "Her quality of life is both terrible and permanent and they cannot see a way in which it would significantly improve." Portsmouth Hospitals NHS Trust says that while parents can decide what treatment is given to their child, they cannot insist on inappropriate treatment which would bring more suffering than benefits. The couple have stressed that they maintain a good relationship with the trust, even though they disagree with its views. The hospital pledged that, if Charlotte needs emergency ventilation before the judges gives his verdict on Thursday, she will receive it”.

In summary, nursing research in the area of caring for marginally viable and critically ill newborns needs to be conversant across the multiple paradigms and perspectives that inform this research field. This includes an understanding of the psychological, social, cultural, ethical and political dimensions of caring for marginally viable and critically ill newborns. This approach generates breadth of knowledge and a depth of understanding of both nursing and societal perspectives of caring for these babies. The social discourse of these perspectives makes an important contribution to the development of this burgeoning knowledge. As described, the context of providing care to marginally viable and critically ill newborns is emotive, and controversial. Regardless of decisions made on behalf of these newborns, and by whom, there are a myriad of stakeholders affected by these decisions. Ultimately, these stakeholders are represented within society as parents and families, and are buoyed, influenced and even encumbered by the greater influences of societal mores, public opinion and the media.
2.3 Summary

This literature review concludes that there is a multitude of issues to consider when caring for marginally viable and critically ill newborns. The literature critiqued provides some insight into the ethical and moral challenges faced by caregivers, as well as the challenges for parents. Furthermore, the majority of the literature reported in this review is clinical or ethics based, and while such literature is useful, there is a need for more research to better understand the needs of marginally viable and critically ill newborns and the psychosocial and emotional needs of caregivers, parents and families (Kain, 2006). There appear to be no universal standards for treating newborns at the end-of-life, and the literature reveals that there is variation in the medical care these newborns receive. There was a lack of validated instruments identified to understand these issues, and therefore the contribution of this research to a knowledge base about palliative care is negligible because the outcomes cannot be tested.

A neonatal palliative model of care is a tentative one, but what appears to be evolving from the existing literature is the presence of barriers that may be social and emotional, but also organisational and may undermine the nurses’ ability to provide this model of care. Furthermore, the facilitators to this model of care have not been identified by the published literature. Understanding the facilitators has equal importance in gaining a composite understanding of the parameters of palliative care practice. This literature review highlights the importance of palliative care in the neonatal environment, yet clearly there is a dearth of research in this area. To further complicate the acquisition of a composite depiction of neonatal palliative care, the loss of a newborn is still often unacknowledged by the public and care providers. Thus, research needs to identify the barriers and facilitators to palliative care practice to better understand these issues, to formulate how best to deliver effective palliative care, and to design and implement effective nursing clinical guidelines and public policies.
CHAPTER 3 - Theoretical Framework

“Getting a new idea adopted, even when it has obvious advantages, is often very difficult.”
(Rogers, 1995)

3.1 Introduction

Everett M. Rogers Diffusion of Innovations (1995) model is the theoretical framework that underpins this research. Diffusion of Innovation theory explains how a new idea—a palliative model of care, for example—is spread throughout the population of interest, in this case, the NICU. Furthermore, this framework describes the processes by which a change in practice—an innovation—is communicated—or diffused—within a social system. Diffusion research accomplishes this by exploring the attributes of the social system into which the innovation is to be diffused and gives context as to why different practices are adopted, or why they are rejected. Rogers’ model also provides a synopsis of successful and unsuccessful strategies to promote the dissemination and utilization of available knowledge. This framework can provide valuable insights into why neonatal nurses adopt some evidence-based innovations, and not others. According to Rogers’ definition of an innovation, a palliative model of care for marginally viable and critically ill newborns is an example of this.

Diffusion research has increasing appeal to scholars, students and practitioners. Firstly, the diffusion model is a conceptional approach that has relevance to many disciplines, particularly nursing. Diffusion research has a multidisciplinary nature that cuts across various scientific fields. Examples of where diffusion research has been used in various scientific fields includes communication (Ascroft, 1969), education (Abdella, 1981; Allan & Wolf, 1978), public health (Banta, 1980; Becker, 1970) and agricultural economics (White, 1968). Diffusion research has also been widely used to study contemporary nursing practice (Barta, 1995; Castle, 2001; Dobbins, Ciliska, Cockerill, Barnsley, & DiCenso, 2002; Funk, Champagne, Wiese, & Tornquist, 1991a; Kirchhoff, 1982; Lia-Hoagberg, Schaffer, & Strohschein, 1999; Mallik, 1998;
Retsas, 2000; Romano, 1990; Siddell, 1995; Taylor-Piliae, 1998; Zerwekh, Thibodeaux, & Plesko, 2000). Secondly, the diffusion approach assists in connecting evidence-based innovations with the potential adopters of such innovations, thereby overcoming and addressing barriers to adoption. Thirdly, diffusion research assists researchers to re-examine their empirical findings into high level generalisations of a more theoretical nature. Given the exploratory nature of the current study, the diffusion model is particularly appropriate.

According to diffusion research theory, the process of diffusion of a new model of care in a nursing context is theoretically influenced by: (1) characteristics of the nurse, such as education, skills and values; (2) organisational characteristics, including infrastructure and support; and (3) characteristics of the innovation itself. What is less clear is how these influences interact, and their relative importance and impact upon the research field. In context of the current research, palliative care practice in neonatal nursing has received scant research attention, and despite evidence-based protocols (Catlin & Carter, 2002) and a clinical pathway (Gale & Brooks, 2006) to support this practice, palliative care practice remains ad hoc (Carter & Bhatia, 2001; Glickcn & Merenstein, 2002; Hylton-Rushton & Catlin, 2002; Maginnes, 2002). The reasons why palliative care uptake for this patient population is sporadic are unclear as these questions have not been asked. This theoretical framework will guide the structure of this research to answer these questions. For the purposes of this research, Roger’s model will be used to explain the adoption of, and barriers to, palliative care practice in neonatal nursing.

### 3.1.1 The Diffusion of Innovations

Rogers describes diffusion as the process by which an innovation is communicated through certain channels over time among the members of a social system. Rogers’ theory is grounded in the perspective that most innovations require a lengthy period, sometimes years, from the time when they become available for clinical use to the time when they are widely adopted. The model has a theoretical underpinning in the premise that new ideas, even when they have obvious advantages, are often difficult to accept and adopt into practice. This may be due to uncertainty about the innovation itself, or due to the characteristics of the potential adopters within the
social system, or social system of an organisation. These theories will be explained in this section.

Diffusion theory is not one well-defined, integrated, and comprehensive theory. Many theories, from various disciplines, each focus upon different elements of the innovation process, and combine to create a ‘meta-theory’ of diffusion. While a number of factors interact to influence the diffusion of an innovation, the four major factors are:

- The features of the innovation;
- How information about the innovation is communicated;
- Time, and;
- The nature of the social system into which the innovation is to be introduced.

Diffusion research investigates how these major factors, and a multitude of other factors, interact to facilitate or impede the adoption of a specific practice among members of a particular adopter group. These components can be identified in all areas of diffusion research and these will be discussed in context to the current research.

3.1.1.1 Innovation:

The innovation refers to an idea, practice, or object that is perceived as new by an individual or other unit of adoption. Rogers argues that it matters little, in terms of human behavior, whether or not an idea is ‘objectively’ new as measured by the lapse of time since its first use. The perceived newness of the idea for the individual determines his or her reaction to it. If the idea seems new to the individual, it is considered an innovation. In context to the current research, the neonatal nurse may be aware of palliative care as an option for marginally viable and critically ill newborns but has not developed a favourable or unfavourable attitude toward it, nor has adopted or rejected it. Therefore, knowing about an innovation is different from adopting it.
3.1.1.2 Communication Channels:

Rogers defines communication as the process by which participants create and share information with one another in order to reach a mutual understanding of it. In terms of diffusion, it is a particular type of communication in which the information that is exchanged is concerned with new innovations. This communication channel is the means by which messages get from one individual to another, this may be in the form of a protocol, or new research. Rogers suggests most individuals do not evaluate an innovation on the basis of its scientific merit. Instead, most depend upon a subjective evaluation of an innovation that is conveyed to them from other individuals like themselves who have previously adopted (or rejected) the innovation.

3.1.1.3 Time:

Time is an important element in the diffusion process. In fact, time is an observable aspect of any communication process. Rogers states that time does not exist independently of events, and considers it an aspect of every activity. In context of the current study, the time taken in adopting a palliative model of care has been protracted, and generally, palliative care delivery has not been widely accepted with the same rigour and enthusiasm as more technologically driven, curative models of care.

3.1.1.4 The social system:

Rogers defines the social system as a set of interrelated units that are engaged in joint problem solving to accomplish a common goal. In the context of the current research, this applies to the social system of the healthcare team involved in caring for marginally viable and critically ill newborns in the NICU. All members of the healthcare team cooperate to at least some extent of seeking to solve a common problem in order to reach a mutual goal. This sharing of a common objective binds this system together. Understanding the social system of the NICU is integral to understanding how the innovation of a palliative model of care will be diffused. The relationships within this social system affects all diffusion processes that occur within it. Rogers describes several issues when considering the diffusion process within the social structure: social structure and diffusion; system norms
and diffusion and opinion leaders and change agents. These issues are especially important when considering a palliative mode of care in the curative environment of the NICU.

In terms of system norms, Rogers defines patterns of behavior that are entrenched in any social system. These behaviours are within a range of tolerable behaviours that serve as a guide for members within that social system. The norms within any given system can, in fact, become a barrier to innovation. Rogers describes certain roles played out by individuals in a social system which effect diffusion: opinion leaders and change agents. Rogers describes opinion leaders as those individuals who are able to exert influence over other’s attitudes. This is a type of informal leadership and does not necessarily reflect the individual’s formal position or status in that particular system. The position of opinion leader is earned by that individual’s technical competence, social accessibility and conformity to the system’s norms. If the system in which the opinion leader operates is oriented towards change, the opinion leaders tend to be innovative and more likely to be in favour of an innovation; but when the cultural norms of the system are opposed to new innovations, the behaviour of the opinion leader reflects this cultural norm. In the context of palliative care practice, if the social system of the NICU is geared towards aggressive, curative care, a palliative model care may rarely be considered as a treatment option. The opinion leaders within that Unit will tend to reflect the cultural norm and also be less inclined to be sympathetic towards this innovation. In theory, then, the collective forces of these cultural variables are powerfully persuasive as to whether an innovation such as the seamless transition to a palliative model of care will be adopted.

Change agents operate quite differently to opinion leaders within the social context of the social system. By Rogers’ definition, change agents’ ability to influence innovation is motivated by their educational preparation and social status within the social system. The change agent may use the opinion leaders in the social structure as deputies to change in the innovation process to expedite adoption. The change agents within the social structure of the NICU may be nurse practitioners, or clinical nurse specialists whose academic preparation assist them in facilitating change and assisting the innovation process. Their pivotal role as change agents could therefore influence opinion leaders in the diffusion process, if the innovation is considered desirable.
Rogers defines five categories of the characteristics of the adopters of an innovation. These are conceptualisations of the potential adopters that guide diffusion research efforts and serve as a framework for the synthesis of innovation diffusion. The five categories of adopters include:

- **The innovators** (representing 2.5% of potential adopters) – the innovators within the social context are described as ‘venturesome’; they are keen to try new ideas and adopt practice change.
- **The early adopters** (13.5%) – The early adopters are an important category, because they have the greatest degree of opinion leadership in most social systems, as this is very important in the diffusion process as previously described.
- **Early majority** (34%) – the early majority will adopt a new idea just before the average member of the social system. These individuals do not hold leadership positions within the social system, but do interact with their peers.
- **Late majority** (34%) – the late majority will tend to accept a new innovation just after the average member of the social system. Any innovation – or change to practice – is viewed with scepticism, and this is the cardinal attribute of this adopter group.
- **The laggards** (16%) - These individuals do not have any opinion leadership role within the social system and are suspicious of the innovators and change agents within it.

When the adoption curve is converted to a cumulative percent curve a characteristic ‘S’ curve (as shown in Figure One) is produced that represents the rate of adoption of the innovation within a given population (Rogers, 1995). The rate of adoption of innovations is impacted by five factors: relative advantage, compatibility, trialability, observability, and complexity (Rogers, 1995). The first four factors are generally positively correlated with rate of adoption while the last factor, complexity, is generally negatively correlated with rate of adoption (Rogers, 1995). The actual rate of adoption is determined by both the rate at which an innovation ‘takes off’ and the rate of later growth.
When interpreting this hierarchy of adopters, the early majority, and the late majority each account for 34% of adopters (total of 68%). It is generally agreed in diffusion research that early adopters have more years of education, higher social status, greater empathy, greater ability to deal with abstractions and uncertainty, and more social and professional contact than the later adopters depicted in Rogers’ model. It could therefore be argued that when promoting a change in healthcare practice that innovations need to target these majority groups.

### 3.2 Summary

In summary, the multidisciplinary nature of diffusion research reaches across many scientific fields because it offers a useful means to gain understanding of practice change. The collective concepts that constitute the theory of the Diffusion of Innovations are of direct relevance to the investigation of palliative care practice in neonatal nursing. There is a need to examine the diffusion-innovation process from an organisational and social system perspective to effectively improve palliative care practice in neonatal nursing. It is postulated, therefore, that palliative care practice in neonatal nursing is dependent upon the social system within the NICU. Given this, a
better way of understanding the lack of adoption of palliative care practice is through the lens of this theoretical framework.

The adoption of practice change is complex, often culturally sensitive and needs to take into account the social system into which the innovation is to be diffused. Identifying the barriers and facilitators to palliative care in neonatal nursing is only one component to understanding why palliative care is not widely practiced in the NICU, and a translational research approach is necessary to generalise the findings of basic research into policy directives. This is why this research will combine both quantitative and qualitative methods in a mixed-method design which will be described in the following chapter. The theoretical framework discussed in this chapter will inform the structure of this research design.
CHAPTER 4 - Methodology

4.1 Introduction

As the previous chapters have described, caring for marginally viable and critically ill newborns is a complex and emotive field of nursing practice. Scant empirical evidence is available to describe this scope of practice. Furthermore, a search of the literature found that no psychometrically tested measures were available to assess the research questions raised by this study. The literature that is available is largely polemic, revealing a social discourse that informs and governs palliative care practice for this fragile patient population. Given these complexities, an innovative approach is warranted for this research design to describe the facilitators and barriers to palliative care practice in neonatal nursing. This chapter will provide a detailed discussion of the methods that were used to conduct this study.

The overall aims of this study were to develop a knowledge base about palliative care practice in neonatal nursing, thus identifying facilitators and barriers to practice, and; to draw upon these findings to develop policy recommendations to improve this field of nursing practice. These aims informed two research questions:

- What are the barriers and facilitators that influence palliative care practice in neonatal nursing?
- How can the identified issues be addressed to inform policy and clinical guidelines in the practice environment?

To answer these research questions, a two-phased approach was undertaken. Phase one was a survey. In this phase, a pilot-tested instrument developed for the purposes of this research was administered to a population sample of neonatal nurses in Australia to explore the barriers and facilitators to palliative care practice. Phase two used a translational research approach to translate the survey findings into policy recommendations that have clinical application in the practice area. This was achieved by conducting focus group interviews with neonatal nurses to discuss and contextualize the survey findings within the theoretical framework utilised by this
research. The interface of data analyses from these two phases aimed to develop research findings that have direct application to nursing policy in the NICU.

The mixed-method approach used for this research provides an opportunity to study a multitude of variables associated with palliative care practice, from both a population and applied perspective, that would otherwise be overlooked using a more traditional methodological approach (Creswell, 2003). Carcelli and Green (1993) describe a category of mixed methods research as conducting analyses separately, and then engaging in the integration of findings during the interpretation phase of the research: this study is an example of this methodological approach, in that the quantitative and qualitative data from this study were analyzed and reported separately, but the results from each were considered together in the discussion of the study findings.

The analytical framework presented in Figure Two illustrates the research steps undertaken in this study. This research approach was informed by the theoretical and empirical literature discussed in the previous chapters.
Figure Two: Analytical Framework

**Social Discourse**

**Literature review**

**INSTRUMENT DEVELOPMENT**
- Development of Items
- Expert Panel
- Face & Content validity
- Reliability - Pilot test

The Instrument (NiPCAS)

**Population Survey**
- Data analysis
- Data reduction

Identification of 3 Factors that indicate the barriers and facilitators to palliative care practice

**Phase Two Interpretive Study**

Focus Groups:
*Discuss and contextualize population study findings*

*Deductive analysis of interpretive data*

Development of research findings that have direct application to nursing policy in the NICU
4.2 Phase one

Survey methods were used in this phase of the study to identify the barriers and facilitators to palliative care practice. Survey research is the most dominant form of research in the social sciences, as it provides for efficient collection of data over broad populations (Dillman, 2000). The instrument developed for this research was an attitude scale, as this is one established method of asking participants about values, beliefs and opinions (Ajzen, 2002).

4.2.1 Instrument development

The development of the instrument used in this research was based upon Rogers (1995) Diffusion of innovation theory. As reported in the literature review, there were several themes identified that potentially present both facilitators and barriers to palliative care practice in neonatal nursing – thus, the literature informed the content, and the theoretical framework the structure of the instrument. Utilizing surveys to study diffusion theory has become increasingly popular, and this is because previously the individual was usually the unit of analysis, yet a number of studies have been conducted in which the individual’s perception of their organisation is the unit of analysis (Wildemuth, 1992; Zaltman, Duncan, & Holbek, 1973), in the case of this research, the social system of the NICU.

The first step in instrument development was to organise the themes identified in the literature to inform the content for the instrument. These preliminary items included 8 demographic questions and 24 attitude questions. A Likert scale was used as the psychometric response to provide a measure of extremity and direction (Dillman, 2000). The response scale was coded accordingly: Strongly Disagree = 1; Somewhat Disagree = 2; Unsure (neutral) = 3; Somewhat Agree = 4; and Strongly Agree = 5. This scale represented a continuum of variables, therefore, the ‘Unsure’ response was coded to the middle and assigned a score of ‘3’ (Pett, Lackey, & Sullivan, 2003 p 42). However, on the actual instrument, the ‘Unsure’ response was situated to the far right of the scale to discourage participants from routinely selecting ‘Unsure’ responses by making them less conspicuous in the instrument (De
Vaus, 2002). Once the preliminary items had been determined, a number of steps were necessary to develop the instrument for the population survey. These steps included determining face and content validity, and undertaking a pilot test. These steps will be discussed in the following sections.

4.2.1.1 *Face and content validity testing*

Face and content validity testing was undertaken to determine whether the items in the questionnaire would make sense to those being measured, and to experts in the clinical area (Beck & Gable, 2001; Dittmar & Greshman, 1997; Polit & Hungler, 1987). To achieve this, an international panel of experts was assembled. Five panel members were selected for the various expertise they could bring to the development of this instrument. These rationales included: expertise in the clinical area; expertise in the development of scales; experience in using Rogers’ (1995) model to inform the development and analysis of an instrument (the theoretical framework upon which this research is based) and; expertise in neonatal palliative care related research.

Members of the Expert Panel included:

- A nurse academic and ethicist (USA);
- Two neonatal nurse clinicians (Australia);
- A nurse academic with expertise in instrument development (USA), and;
- An expert in instrument design (Australia).

This process included the Expert Panel receiving a synopsis of the literature review to familiarise them with how the literature had informed the development of the items. The Panel received a validation scale to rate their agreement to each item using a ‘yes’ or ‘no’ scale, and were asked to comment on each item. De Vaus’ (2002 p 97) checklist for the wording of questions was included for the panel’s reference (see Appendix III). Following this, correspondence with the Expert Panel was conducted via email, telephone and in person, depending upon their location.
The first iteration of this instrument resulted in several changes to the wording of some items. In particular, concerns were raised that in the first iteration, the items were all worded negatively, and thus conveyed a negative picture of palliative care practice that may have subjected the items to response bias. This opinion correlated with expert opinion, whereby DeVaus (2002) suggests that using a series of positively and negatively worded items to form a scale assists in avoiding an acquiescent response set. Amendments were made, and a further round occurred, whereby the panel agreed with the changes that were made. Only items that reached 100% consensual validation were retained in the instrument, resulting in an instrument prior to pilot testing with 24 items and 7 demographic items.

This process of face and content validity resulted in the development of an instrument named the Neonatal Palliative Care Attitude Scale (NiPCAS) (see Appendix VI) that was ready for pilot testing to examine reliability prior to the population survey.

4.2.2 The pilot study

Pilot studies are useful for instrument testing and alerting researchers to the potential pitfalls in the research process (Gardner, Gardner, MacLellan, & Osborne, 2003). The pilot testing of this instrument employed test-retest repeatability procedures to determine temporal stability using intraclass correlation. Based upon the results of pilot testing, the items for the population survey instrument were established.

4.2.2.1 Pilot study sample and procedures

Following ethics clearance, a pilot test was conducted with a convenience sample of 93 neonatal nurses at a single NICU in South-east Queensland, Australia. This sample was thereafter excluded from the sample used for the population study. All full-time, part-time and casual nurses on the NICU roster were invited to participate (N=93). This sample was determined following consultation with the Nurse Unit Manager and consideration of the number of nursing staff on the NICU roster at the time the pilot test was to be conducted. The questionnaire package consisted of a personally addressed envelope; a cover letter explaining the purposes
of the pilot study and the processes involved; the questionnaire, and; a self-addressed return envelope. These packages were given to a nominated nurse in the NICU, who then took responsibility for distribution. To maintain confidentiality, participants were asked to nominate a four digit code, suggesting they use the two initials of their mother’s maiden name, and the last two numbers of their year of birth. Participants were asked to write this on the participant information statement so they would not forget this code. This allowed for repeatability testing of the instrument following a three-four week interval. Participants were asked to return completed questionnaires in the self-addressed envelope provided, with the option of returning it through either the internal mail system or the ‘return’ box in the clinical area. Return of completed questionnaires implied consent to participate, and all responses were anonymous.

As this was a pilot study, space was included in the questionnaire for the participant to comment on the study, the procedures and the items. The comments received were positive, with enthusiasm for the study expressed. Only one demographic question (What is the highest nursing/midwifery qualification you have obtained?) caused some confusion regarding the difference between a ‘Graduate Diploma/Certificate’ and ‘Post-graduate degree’. This question was altered in the population survey to state only the latter.

Twenty-eight (30%) of the sample responded to the first administration of the instrument. The instrument was then re-administered three – four weeks later. Despite intensive follow-up, 16 of the 28 participants from the first administration (57% - 17% of total sample) responded to the repeated administration (n = 16). The characteristics of the pilot study sample are described in Appendix I.

4.2.2.2 Testing of the pilot instrument

All data were entered using SPSS 13.0 for Windows statistical software (SPSS, Chicago, USA). Test-retest repeatability, over a three – four week period, was determined using data obtained from 16 cases. To begin with, there were no missing data, with all participants answering all 33 items. The lack of missing data further indicates the acceptability of items in the instrument by the sample (Altman, 1991).
The next step in preparing these data for reliability testing involved computing frequencies to compare the data collected in the first administration of the instrument (T1) and the second administration (T2). The T1 mean was 78.68, median 80.00 and T2 mean 80.06 and median 83.50, indicating that the data were normally distributed, and suitable for intraclass correlation coefficient testing between repeated measures. The difference between the T1 and T2 mean and median in the dataset was approximately 1.7% following a Shapiro-Wilk test.

Test-retest reliability was assessed by administering the questionnaire to the same subjects, under a similar condition, in two or more situations (LoBiondo-Wood & Haber, 1998; Polit & Hungler, 1987) – typically a few weeks to one month is considered a standard time frame for the repeated measure (Ashton, 2000). Reliability of the scale was calculated using a traditional psychometric statistic, the test-retest coefficient (Intraclass correlation coefficient - \( r \)). The intraclass coefficient \( (r) \) is a measure of reliability, and is considered an overall indication of the test quality. This statistic ranges between 0 (low reliability) and 1 (high reliability). Although there is no commonly agreed cut off score, usually a score of 0.7 and above is deemed to be acceptable (Crocker & Algina, 1986; Nunnally, 1978).

In the pilot testing of the NiPCAS, the level of agreement for each participant was within 95% confidence estimates, indicating that the instrument was stable over time. There was no significant difference between the two administrations of the instrument, the mean difference being \( M = 1.37, \text{SD} = 5.31 \). The mean-item intraclass coefficient correlation (two-tailed test) was calculated to determine the strength of the relationship between the responses to test the reliability of the NiPCAS over time. This calculation was \( r = 0.77 \) (min. \( r = .12 \), max \( r = 0.90 \)).

The level of agreement between T1 and T2 was plotted using a method described by Bland and Altman (1986) (see Figure Three). This approach was taken to test the level of agreement between the repeated measurements. A Bland-Altman plot compares the repeated measures by plotting the difference between the two measurements on the Y axis, and the average of the two measurements on the X axis. If the measurements are comparable, they can be observed on the plot as being
tightly scattered about the line, as demonstrated in the level of agreement plotted for the current study in Figure Three. This approach to measuring the level of agreement rather than Pearson’s correlation ($r$) was utilised because $r$ measures only the strength of a relationship between two variables, not the agreement between them (Altman & Bland, 1983). Altman and Bland (1983) argue that the use of Pearson’s correlation to test the agreement between repeated measures is often misleading, stating that their alternative approach, based on graphical techniques and simple calculations, together with the relation between the analysis and the assessment of repeatability is more appropriate (Altman & Bland, 1983).

**Figure Three: Bland-Altman plot**

![Bland-Altman plot for reproducibility](image)

The inter-item correlations of the pilot-NiPCAS indicated a wide range ($r = .07 - .83$). These correlations, using Pearson’s correlation ($r$), are described in Table one in descending order. However, rather than deleting items with low inter-item correlations, the instrument was returned to the Expert Panel following pilot testing for final consensus regarding the scale. Problematic items were either deleted from the instrument, or reworded. Also, three items were added to the NiPCAS following
consultation with the Expert Panel. These included items about the impact of technology, and the demands of parents. There was also an item added stating that: Curative care is more important than palliative care in the neonatal intensive care environment (q33). The final outcome of pilot testing, following re-examination with the Expert Panel after pilot-testing resulted in wording changes to 5 items, the deletion of 2 items, and the addition of 3 items. This process, including the final wording of the items, is described in Appendix II.

Table One: Inter-item correlations between T1 & T2 repeated measures (Pearson’s \(r\))

<table>
<thead>
<tr>
<th>Pilot tested item</th>
<th>Inter-item correlation between T1 &amp; T2 (r)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative care is necessary in neonatal nursing education</td>
<td>.85</td>
</tr>
<tr>
<td>My previous experiences of providing palliative care to dying babies have been rewarding</td>
<td>.83</td>
</tr>
<tr>
<td>When a baby dies in my Unit, I have sufficient time to spend with the family</td>
<td>.82</td>
</tr>
<tr>
<td>I have received in-service education that assists me to support and communicate with parents of dying babies</td>
<td>.79</td>
</tr>
<tr>
<td>Palliative care is as important as curative care in the neonatal environment</td>
<td>.79</td>
</tr>
<tr>
<td>When a baby dies in my Unit, counselling is available if I need it</td>
<td>.71</td>
</tr>
<tr>
<td>The medical staff support palliative care for dying babies in my Unit</td>
<td>.69</td>
</tr>
<tr>
<td>Palliative care is against the values of neonatal nursing</td>
<td>.69</td>
</tr>
<tr>
<td>Caring for dying babies is traumatic for me</td>
<td>.69</td>
</tr>
<tr>
<td>The physical environment of my Unit is \textit{not} conducive to providing palliative care to dying babies</td>
<td>.66</td>
</tr>
<tr>
<td>There are available resources in my Unit to support a palliative model of care</td>
<td>.61</td>
</tr>
<tr>
<td>In my Unit the team express their opinions, values and beliefs about providing care to dying babies</td>
<td>.55</td>
</tr>
<tr>
<td>I have had experience of providing palliative care to dying babies and their families</td>
<td>.53</td>
</tr>
<tr>
<td>There is support for neonatal palliative care in society</td>
<td>.52</td>
</tr>
<tr>
<td>I feel a sense of personal failure when a baby dies</td>
<td>.52</td>
</tr>
<tr>
<td>I am often exposed to death in the neonatal environment</td>
<td>.52</td>
</tr>
<tr>
<td>In my Unit, when a poor diagnosis is made, parents are informed of palliative care options</td>
<td>.43</td>
</tr>
<tr>
<td>Society’s values \textit{do not} support palliative care for dying babies</td>
<td>.42</td>
</tr>
<tr>
<td>There are policies/guidelines to assist in the delivery of palliative care in my Unit</td>
<td>.40</td>
</tr>
<tr>
<td>Babies requiring palliative care is a priority when organising staffing in my Unit</td>
<td>.35</td>
</tr>
<tr>
<td>In my Unit, parents are involved in decisions about their dying baby</td>
<td>.28</td>
</tr>
<tr>
<td>My attitudes to death affects my willingness to deliver palliative care</td>
<td>.25</td>
</tr>
<tr>
<td>When babies die in my Unit, providing pain relief is a priority for me</td>
<td>.22</td>
</tr>
<tr>
<td>There is conflict surrounding the decision to implement palliative care for a dying baby in my Unit</td>
<td>.07</td>
</tr>
</tbody>
</table>
Although the pilot study was limited due to a small sample size, much was learnt for the population study phase by engaging in this process. Firstly, increasing response rates to survey research is time consuming, potentially costly and still may not result in increased responses (De Vaus, 2002). Attempts to increase the response rate were unsuccessful, including reminder letters sent to the entire sample, the use of promotional posters and scheduling further information sessions. The sampling frame proved to be inaccurate because it included names of nurses who were no longer actively working or were on leave or deployed to other areas between administration and re-administration of the instrument. However, this explained only a small proportion of non-responders. One could also speculate that nurses who were interested, or had opinions about palliative care, were more inclined to respond. Other possible reasons for non-response include a lack of interest in the research, high workloads and associated lack of time to complete the questionnaire, or ‘survey overload’ as nursing staff had been involved in two other surveys within a few months of this research.

In summary, temporal stability, using an Intraclass correlation and a Bland-Altman Plot demonstrated a strong relationship between the responses at two different administration times, and a strong level of agreement between individual responses over time \( r = 0.773 \) albeit with a small sample size (Kain, 2007b).

### 4.3 Population study

#### 4.3.1 Setting & sample

The remaining 22 NICUs within Australia were eligible to participate in this research (the pilot study site was not included). These neonatal units are classified as tertiary referral centres (Level III), capable of providing extensive life support to the neonatal population they service. The size of these Units vary, and range from surgical units with less than 6 cots to medical units with 14+ cots. All 22 NICUs were approached to take part in this research, and all agreed to participate. However, following 100% HREC approval, 3 sites withdrew citing ‘survey overload’. These sites included two of the largest tertiary NICUs within Australia, and a smaller, surgical neonatal unit. The two large NICUs were in separate states, and given the involvement of other
large NICUs in these areas, these states were adequately represented in the overall population. This resulted in an overall 86% participation rate of Australian NICUs in this research.

The participants in this national study were neonatal nurses practising in level III NICUs within Australia, full-time, part-time and casual, regardless of experience in the area. There were no exclusion criteria provided that the inclusion criteria were met. As a nursing sub-specialty NICU nursing numbers are comparatively small, therefore a population (census) survey was necessary for this research to achieve a large sample size. The sample size for this research was based upon best estimates following discussion with each of the Nurse Unit Managers at each site. These estimations of sample size were based upon how many NICU staff were on the roster during the study period. This number was not static and was dependent upon unexpected staffing fluctuations such as annual leave, resignations and other staff absences.

Adequacy of sampling size was an important consideration in this research as factor analysis procedures were used to identify constructs measured by the research instrument. These statistical tests are dependent upon as large a sample as possible (Gorsuch, 1983; Kline, 2002; Swisher, Beckstead, & Bebeau, 2004), as a small number can result in an unstable factor solution due to chance (Nunnally & Bernstein, 1994). In terms of optimal sample size, the literature is divided, and explicit guidelines for sample size fluctuate significantly (Floyd & Widaman, 1995). However, as a general rule, an acceptable minimum is at least five times as many observations as there are variables to be analysed. However, more acceptable is a 10:1 ratio, with some sources purporting as many as 20:1 (Hair, Anderson, Tatham, & Black, 2005). The sample for the current study was N=1285. A response rate of 50% resulted (n=645) – a ratio of 26:1, which was considered more than adequate for conducting factor analysis procedures.

4.3.2 Recruitment and data collection

Following negotiation with Nurse Unit Managers, a liaison person was nominated at each site. This was necessary due to the geographical spread of the national study.
The liaison person’s role included receiving and distributing the questionnaire packages (as described in Appendix IV), as well as displaying the HREC approved promotion posters. Communication with the liaison person at each site was conducted via telephone and e-mail. The liaison person agreed to personally address each questionnaire package with names from the NICU roster and place the packages into the mailbox areas. The recruitment procedures were discussed with each of the liaison persons, including the importance of not coercing participants to participate, reassuring participants that confidentiality would be maintained, and that returned questionnaires could not identify the participant, the site, or the State from which they were received.

Reminder letters, with a duplicate copy of the questionnaire, were sent to each site 2 weeks after the first administration (De Vaus, 2002) to allow potential participants who had overlooked or mislaid their questionnaires another opportunity to participate. Where practicable, further information sessions were conducted in clinical areas to answer questions and remind staff to complete the questionnaires. The liaison person was asked to collect the questionnaires from the nominated pick up point and return in the reply-paid envelopes provided. Participants also had the option of returning the questionnaire via an Australia Post mailbox if they preferred.

4.3.3 Data Analysis

Initially, data were prepared by identifying cases with missing data and screening for errors and irregularities. This was undertaken in a three step process, including: examining the data for errors and identifying variables with scores that were out of range; when an error was detected, locating the data file in which the error had occurred and correcting the data file itself, and; following this process, repeating the frequencies to ensure that a second error had not occurred during the data cleaning process (Pallant, 2005).

Descriptive statistics were employed (frequencies, means, standard deviations and ranges) to describe the seven demographic characteristics of participants and to communicate an overall picture of palliative care practice in neonatal nursing (n=645). These items were not included in data reduction techniques.
Prior to data reduction techniques, the data were prepared in 3 ways. Firstly, cases with missing variables were deleted listwise from the dataset to avoid reducing the quality of the data prior to factor analysis procedures. This step resulted in the deletion of 40 (6.2%) cases (following this process n=605). Opinion in the literature suggests deleting missing variables prior to factor analysis procedures, providing it does not lead to a loss of more than 15% of the data (Hertel, 1976). DeVaus (2002) also suggests that excluding cases with missing data is a reasonable solution in large samples where there are only a few cases with missing values, and the missing values are randomly distributed across the cases. In the current research, the deletion of these cases made little difference to the adequacy of the sampling frame for factor analysis. Furthermore, upon analyzing the characteristics of the deleted cases, all belonged to the demographic with the least experience in the NICU area (<1 year duration), and thus the least experience of palliative care delivery.

Secondly, prior to factor analysis, items were reverse coded for items 10, 24, 27, 28, 29, 30, 32 and 33 so that high scores represented the highest or more positive end of the measure. It is common when constructing scales to disarrange the direction of the statements to which people respond with some being positive, and some negative. However, prior to data analysis, it is important to reverse code these items so that they are all coded in the same direction (De Vaus, 2002; Pallant, 2005).

Thirdly, correlational statistics between the 26 attitude items were undertaken as a crucial step prior to factor analysis procedures because, in general, if an item does not correlate at least moderately (e.g., $r = .20$ or greater) with other items for the same construct, then the item will perform poorly in a factor analysis (Floyd & Widaman, 1995). In the current research, all of the 26 attitude items were found to correlate above .20 with at least one other variable, with the exception of item 32. Item 32 was therefore not included in factor analysis procedures. Following data preparation and correlational statistical processes, exploratory factor analysis, using a principal components analysis, was undertaken to identify the constructs measured by the items.
4.3.3.1 Data reduction

Factor analysis (principal components analysis) was the data reduction technique used in this study as this is one of the most commonly used procedures in the development and evaluation of attitude measures (De Vaus, 2002; Floyd & Widaman, 1995). Principle components analysis is a method of reducing a number of variables to groupings to aid interpretation of the underlying relationships between the variables (Crichton, 2000) whilst capturing as much of the variance in the data as possible.

Suitability of the data for undertaking factor analysis was determined by testing for sampling adequacy and sphericity. This included determining that the Kaiser-Meyer-Olkin test (KMO) exceeded the value of 0.6 or above (Kaiser, 1974). In the current research, the KMO was .78, therefore the suitability for factor analysis was confirmed.

Examination of factor loadings was undertaken to determine which items belonged to which factor, and items were considered to have loaded if they had a factor loading of 0.40 or more. Following extraction of these factors, varimax was the rotational approach applied as it is the most commonly used, and is a variance maximizing procedure that simplifies and assists in the interpretation of factors (Tabachnick & Fidell, 2001). Item loadings were then reviewed to determine their conceptual fit. Cronbach’s alpha coefficients were calculated for items that resulted in theoretically valid scales as this is one of the most common determinants of internal consistency (Bland & Altman, 1997), and it indicates the extent to which a set of test variables can be treated as measuring a single latent variable (Cronbach, 1951). This statistic ranges from 0 – 1, with values of .60 - .70 deemed to be the lower limit of acceptability – the higher the value, the higher the reliability among indicators (Hair et al., 2005). It is possible for this statistic to decrease to .60 in exploratory research, and this is considered acceptable (Hair et al., 2005).

4.3.3.2 Analysis of variance to compare groups
One-way factorial analysis of variance (ANOVA) tests were performed using a
general linear model on each of the subscales identified. These statistical tests were
performed to test the hypothesis that demographic groups would answer the
questions in the same way, regardless of their age, experience or qualifications. The
explanatory (independent) variables used in these analyses were the demographic
variables of how many years the neonatal nurse had worked in a NICU ‘exp’ (q3),
whether the neonatal nurse had qualifications in the sub-specialty (‘neoqual’) (q3),
and the highest qualification the nurse had received (‘qual’) (6), and; the dependent
variables were the subscales identified.

Two of the demographic variables were not included in these tests for these reasons:
Question 1 (sex) was omitted due to the marked discrepancy in group sizes (625
females vs. 17 males). Question 2 (age) was not selected for analysis of variance due
to the confounding nature of including two questions about years of experience, and
years of age. To explain, a neonatal nurse in the 20-30 year old age group could not
possibly of had >15 years experience in the NICU. Including both a question about
age, and a question about years of experience would have resulted in the presence of
several structural zeroes for the interaction tests. After consideration, the
demographic variable of ‘exp’ was selected, as this demographic question would
provide more information about the exposure of the nurse to caring for marginally
viable and critically ill newborns than simply the age of the nurse. Other
demographic variables not included in this stage of analysis included employment
status (q4) and workplace designation (q7). These questions were asked to provide a
general overview of the employment characteristics of the population.

These ANOVA tests were conducted in the following way: each of the three
subscales that identified in this research were examined for their interactions with the
explanatory variables of ‘exp’, ‘qual’ and ‘neoqual’; this resulted in 3 x one-way
factorial analysis of variance tests.
4.4 Phase Two: Interpretive study

Phase one of this research utilised quantitative methods to identify the barriers and facilitators to palliative care practice. A translational research approach was then used to develop the findings from the population study for policy recommendations in the clinical environment. Phase two of this research utilised an interpretive interface to contextualize the population study findings using focus group interviews. Figure Four provides an overview of how this method was used as an interface to link the population study findings to practical interventions.

Figure Four: The interpretive design

TRANSLATIONAL RESEARCH APPROACH
- Translate population study findings into clinical practice by engaging in consensus discussion with neonatal nurses;
- Development of evidence based policy to inform and improve practice

Development of research findings that have direct application to nursing policy in the NICU
Ricoeur (1974) describes the interpretive approach as the hinge between language and the lived experience. Interpretive research can assist researchers to better understand their clinical environment, their place within that world, their colleagues and their interaction with those people (Astedt-Kurki & Heikkinen, 1994). Undertaking the interpretive phase of this research resulted in an insight into the phenomena, not by establishing causality, but by improving the overall comprehension of palliative care practice and translating the findings from the population study into practical applications.

Focus groups interviews were conducted in this phase of the study to contextualize the population study findings and translate them into policy recommendations. Merton and Kendall’s (1946) influential article on focus group interviewing set the parameters for this research approach, supporting that data collected from focus group interviews can be used to interpret survey responses when conducted in a mixed-method research project (Merton & Kendall, 1946; Schattner, Schmerling, & Murphy, 1993). This research is an example of such an approach.

4.4.1 Sample, recruitment and procedures

The focus group interviews were conducted in 3 tertiary centre NICUs along the Eastern border states of Australia, including South-east Queensland, Victoria and South Australia. Morgan (1998) recommends undertaking three to five focus groups, yet emphasizes that the number of groups is directly related to the nature of the inquiry. Funding allowed for a maximum of 3 focus groups to be conducted in this research.

Purposive sampling was used, which is the standard sampling technique in focus group research (Kuzel, 1992; Macleod Clark, 1996; Mays & Pope, 1995; Miles & Huberman, 1984). Following HREC consent from each Site, Nurse Unit Managers were contacted to recruit full-time and part-time neonatal nurses from the NICU roster, who had at least two years experience in the clinical area, to participate in a focus group interview. Recruiting only nurses with at least two years experience maximised the participants’ exposure to providing care to marginally viable and critically ill newborns. Nurse Unit Managers were asked to invite up to 8
participants to each focus group interview. There is little consensus in the literature about the optimal number of participants for a successful focus group. Many experts advocate a group ranging from 8-12 (Kitzinger & Barbour, 1999), 6-12 (Lindlof, 1995), 6-8 (Krueger, 1998), or 5-6 participants (Green & Hart, 1999).

To facilitate the collection of quality data, and given time restraints of one hour per focus group, potential participants were sent an information package two weeks prior to the interview outlining the purpose of the focus group (Kitzinger & Barbour, 1999). This information is included as Appendix V, and included a cover letter and a HREC approved consent form. At each of these interviews, the facilitators and barriers indicated in the population study findings were presented to the participants, and two questions were asked: how can policy be developed to improve upon the facilitators identified, and; how can policy be developed to address the barriers identified.

**4.4.2 Data management**

The focus group interviews were audio-taped following informed consent from participants. Although there are various techniques that can be used for attaining data generated during focus group discussions, audio taping and verbatim transcription is the most common method (Morgan, 1998). A deductive approach to data analysis was employed with the findings from the population survey providing a ‘scaffold’ of prior knowledge that was relatively known (Morse & Mitcham, 2002). Deductive analysis is indicated when the general findings from survey research need to generate more specific findings (Thorne, 2000). In this study, the survey findings constituted the *a priori* knowledge. This knowledge is conceptual and provides important insights into the barriers and facilitators to palliative care in the NICU. The additional step of using these findings to guide focus group interviews with experienced NICU nurses provided experiential data, providing added depth to translate these findings into policy recommendations.

The data collected from these interviews were aggregated in deductive analysis against the subscales – ‘organisation’, ‘resources’ and ‘clinician’ – identified by the population study findings. Meaningful textual patterns were identified (Sandelowski,
As these sub-themes were identified, analyses were discussed with an experienced nurse researcher with considerable expertise in qualitative analysis. Discussion of these findings occurred around the areas of congruence and incongruence, and based upon this discussion, further refinements to the coding schemes were made. Therefore, validity checking in this research adhered to one of the four criteria for methodological rigor proposed by Lincoln and Guba (1985), referred to as confirmability. In this criteria, the researcher uses self-critical reflexive analysis of the methodology used in the research to ensure quality. Validity checks such as member checking were not considered for this research, as informed by the concerns raised by Barbour (2001), which include the possibility of collusion when researchers disregard their own interpretations to accept those of respondents at face value. Related to these concerns, focus groups capitalise on a process for participants to build upon the responses of others in the group to create a synergistic environment that is conducive to eliciting quality information (Morgan & Krueger, 1993; Patton, 1990). Given this synergistic production of data, and the logistical barriers to re-convening each focus group for member checking this validation criteria was not considered appropriate.

4.5 Ethical considerations

The ethical considerations in this study were guided by the National Health and Medical Research Council’s publication for the ethical conduct of research (NHMRC., 2006). Each Phase of this research will be considered separately. In Phase One, negotiation of access to the target population was made initially by contacting and discussing the research with Nurse Unit Managers and/or Clinical Nurse Consultants in the 22 sites throughout Australia with neonatal intensive care facilities. All contacts expressed an interest in conducting this research at their organisations, and ethics approval was sought from each of the site’s Human Research Ethics Committees (HREC). Permission was granted from each site over a six month period and the questionnaire was administered at each site as permission
was granted. Each questionnaire was accompanied by a HREC approved participant information statement and cover letter which outlined the purpose and significance of the research. This information is included as Appendix IV. The return of the questionnaire was interpreted as an expression of consent (Dillman, 2000). Confidentiality was assured as the researcher did not have access to the names on the roster of NICU nurses at each site, and a liaison person was engaged at each site for this purpose. The cover letter stated that the questionnaire would take approximately ten – fifteen minutes to complete. While risk is present in all research, the risks to subjects in this research were minimal but due to the sensitive nature of the questionnaire nationwide counseling information contacts were provided.

In Phase two, three sites were selected to conduct focus group interviews. Ethics approval was sought from Ethics Committees for these three sites. Ethics proposals for Phase Two took into account the potentially sensitive nature of the discussion at the focus groups, and the potential for participants to experience emotional distress. Therefore, site specific counseling information was provided to each participant on the participant information statement and written and signed consent was sought from each participant prior to their involvement in this phase of the research. This information is included as Appendix V.

Ethical considerations for focus groups are the same as for most other methods of social research (Homan, 1991). This extends to when selecting and involving participants, researchers need to ensure that full information about the purpose and uses of participants’ contributions is transparent. A candid and honest approach ensures that participants are informed about the expectations of the group and discussion, and not pressurising participants to speak is also considered good practice. One particular ethical issue that was considered when conducting the focus groups was the handling of sensitive material and confidentiality, especially when one considers that there will always be more than one participant in the group. Therefore, at the outset, the researcher clarified that each participant’s contributions would be shared with the others in the group as well as with the researcher. Participants were encouraged to maintain confidentiality in terms of what they heard during the focus groups interview and the researcher had the responsibility of de-
identifying data from the group. These ethical considerations were observed during the conduct of the focus group interviews in this research.
CHAPTER 5 - Population Study Results

This chapter reports the results of the factor analysis of the items developed for the NiPCAS scale. This chapter will also report: (a) findings from the descriptive analysis of the scales and subscales; (b) statistical analyses undertaken to generate hypotheses regarding the relationships between the subscales and the characteristics of the study population.

5.1 Data preparation

Initially, the data were screened for errors using the steps outlined by Tabachnick and Fidell, including checking the data for errors by identifying variables with scores that were out of range (Tabachnick & Fidell, 2001 chap. 4). This process involved inspecting the frequencies for each of the variables, including all of the individual items that made up the scales. Any errors were corrected before the total scores for the scales were calculated. Following this, the frequencies were repeated to ensure that a second error hadn’t occurred during the data cleaning process (Tabachnick & Fidell, 2001 chap. 4).

5.2 Description of the sample

Of the 1285 neonatal nurses surveyed for this phase of the study, 645 returned the questionnaire resulting in a response rate of 50%. The demographic data from respondents was compared with labour force data obtained from the annual Nursing (and Midwifery) Labour Force Surveys administered by the Nurses and Midwives Registration Board in each State and Territory of Australia on behalf of the AIHW (2005).

Table Two describes the age, sex and years of NICU experience of the sample. As this table describes, there was a high female to male ratio, which was commensurate with AIHW findings. The comparison of the proportion of male nurses (8.6% in the Labour Force Survey), however, was lower at 3%. In 2005 the AIHW reported the
average age of a Registered Nurse in 2003 as 43 years: this was reflected in the demographic data collected for this research with 34% of participants aged 41-50 years, the largest demographic represented in the age category. The majority of the sample responding to the survey had considerable experience in the NICU of above 15 years duration, representing 37% of the sample.

**Table Two: Age, Sex & Experience (n=645):**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>96.9</td>
</tr>
<tr>
<td>Male</td>
<td>2.6</td>
</tr>
<tr>
<td>did not answer</td>
<td>0.5</td>
</tr>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
</tr>
<tr>
<td>20-30</td>
<td>21.1</td>
</tr>
<tr>
<td>31-40</td>
<td>20.0</td>
</tr>
<tr>
<td>41-50</td>
<td>33.3</td>
</tr>
<tr>
<td>51+</td>
<td>24.8</td>
</tr>
<tr>
<td>did not answer</td>
<td>0.8</td>
</tr>
<tr>
<td><strong>Experience in a NICU (years)</strong></td>
<td></td>
</tr>
<tr>
<td>&lt; 1 yr</td>
<td>7.3</td>
</tr>
<tr>
<td>1-5 yrs</td>
<td>26.8</td>
</tr>
<tr>
<td>6-10 yrs</td>
<td>16.9</td>
</tr>
<tr>
<td>11-15 yrs</td>
<td>13.0</td>
</tr>
<tr>
<td>15 yrs</td>
<td>35.7</td>
</tr>
<tr>
<td>did not answer</td>
<td>0.6</td>
</tr>
</tbody>
</table>

Table Three presents the education level of the sample, including whether the participant had education specific to the sub-specialty, such as a neonatal intensive/critical care qualification. The majority of the sample (41%) reported their highest nursing/midwifery qualification as a postgraduate degree. The majority had received formal education in neonatal nursing (68%), with 36% obtaining a hospital based qualification and 32% a post-graduate qualification in this sub-specialty.
Table Three: Qualifications (N=645):

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Formal education in neonatal nursing</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>23.4</td>
</tr>
<tr>
<td>Yes – hospital certificate</td>
<td>37.2</td>
</tr>
<tr>
<td>Yes – post-graduate qualification</td>
<td>32.6</td>
</tr>
<tr>
<td>Currently undertaking</td>
<td>6.7</td>
</tr>
<tr>
<td>did not answer</td>
<td>0.5</td>
</tr>
<tr>
<td>Highest nursing/midwifery qualification obtained</td>
<td></td>
</tr>
<tr>
<td>Hospital certificate</td>
<td>33.0</td>
</tr>
<tr>
<td>Undergraduate qualification</td>
<td>23.9</td>
</tr>
<tr>
<td>Postgraduate qualification/Masters</td>
<td>42.7</td>
</tr>
<tr>
<td>PhD/Doctoral qualification</td>
<td>0.0</td>
</tr>
<tr>
<td>did not answer</td>
<td>0.5</td>
</tr>
</tbody>
</table>

The final Table in this section represents the employment characteristics of respondents, including employment status and primary role in the workplace. Also commensurate with AIHW findings was the proportion of nurses employed part-time, representing 50% in this sample (AIHW 49%), with 86% of participants providing direct patient care (AIHW 86%).

Table Four: Employment characteristics (n=645):

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current employment status</td>
<td></td>
</tr>
<tr>
<td>Full-time</td>
<td>42.6</td>
</tr>
<tr>
<td>Part-time</td>
<td>48.2</td>
</tr>
<tr>
<td>Casual</td>
<td>3.6</td>
</tr>
<tr>
<td>did not answer</td>
<td>0.6</td>
</tr>
<tr>
<td>Primary role in the workplace</td>
<td></td>
</tr>
<tr>
<td>Direct patient care</td>
<td>87.2</td>
</tr>
<tr>
<td>Nursing Management</td>
<td>6.8</td>
</tr>
<tr>
<td>Nursing Education</td>
<td>4.2</td>
</tr>
<tr>
<td>Nursing Research</td>
<td>1.6</td>
</tr>
<tr>
<td>did not answer</td>
<td>0.2</td>
</tr>
</tbody>
</table>

5.3 Population study findings

Prior to data reduction techniques, descriptive statistics were employed to calculate the frequencies of the responses to the 26 attitude items in the NiPCAS. ‘Somewhat Agree’ and ‘Strongly Agree’ responses (likewise for ‘Disagree’) were combined to
provide an overall understanding of the direction of the responses: this is described in Table Five. Although not all items would factor analyse in data reduction procedures, and therefore may not have reliably captured the construct being measured in the NiPCAS, there were some salient findings that will be discussed briefly in this section.

Firstly, the majority of items were answered by participants, with ‘did not answer’ responses ranging from just 1-2%. There were small-moderate ‘unsure’ responses for 4 items, ranging from 11-19%. Two of these items (11 and 16) did not load highly on any factors following factor analysis procedures.

Items that loaded highly on factors were considered in the construction of the subscales of the NiPCAS and will be discussed in detail elsewhere in this thesis. Items that failed to load, however, include item 10, where the majority of the sample (74%) indicated that they did not feel a sense of personal failing when a baby in their care died. This was contrary to literature findings, suggesting that healthcare professionals may experience this perception of personal failure (Davies et al., 1996; Hartline, 2002; Lo et al., 1999; McIntosh & Eldridge, 1984; Papadatou, 1997; Pierucci et al., 2001). Commensurate with literature findings, however, was item 25, whereby respondents generally disagreed that they had received education to assist them in supporting the parents of dying babies (64%). In regard to education to meet this need, the literature generally concurs that whilst this is an important skill in end-of-life care, it is often neglected in curriculum (Contro et al., 2004; Engler et al., 2004; Ferrell & Borneman, 2002; Levy, 2001; McDonnell et al., 2002; Miya et al., 1991; Rogers et al., 2000; Vachon, 1995; Wilkinson et al., 1998; Wyatt, 1999).

Authors such as Hammer (1992), Papadatou (1997) and Davies (1996) suggest that the caregivers own personal attitudes towards, or experiences, of death may affect their ability or willingness to care for dying babies. This was explored in item 29. The findings of the population study, however, found that 73% of respondents disagreed with this.
Ninety-six of respondents agreed that palliative care was equally important in the NICU as curative care (item 1). Following pilot testing, this item was also worded in reverse (item 33). Although neither item factor analysed, it would be expected that if the question was well understood that responses would be the same, albeit on opposite sides of the response scale. In item 33, however, 25% of respondents agreed that curative care was more important than palliative care. This suggests that these items may have been misunderstood, or perhaps subject to a degree of response bias.

Table Five: Population Study Findings

<table>
<thead>
<tr>
<th>NiPCAS Item</th>
<th>Strongly/ somewhat Disagreed %</th>
<th>Strongly/ somewhat Agreed %</th>
<th>Unsure %</th>
<th>Did Not Answer %</th>
</tr>
</thead>
<tbody>
<tr>
<td>8 Palliative care is as important as curative care in the neonatal environment</td>
<td>3%</td>
<td>96%</td>
<td>1%</td>
<td>-</td>
</tr>
<tr>
<td>9 I have had experience of providing palliative care to dying babies and their families</td>
<td>11%</td>
<td>87%</td>
<td>0.5%</td>
<td>1.5%</td>
</tr>
<tr>
<td>10 I feel a sense of personal failure when a baby dies</td>
<td>74%</td>
<td>21%</td>
<td>4%</td>
<td>1%</td>
</tr>
<tr>
<td>11 There is support for neonatal palliative care in society</td>
<td>36%</td>
<td>44%</td>
<td>19%</td>
<td>1%</td>
</tr>
<tr>
<td>12 The medical staff support palliative care for dying babies in my Unit</td>
<td>17%</td>
<td>80%</td>
<td>3%</td>
<td>-</td>
</tr>
<tr>
<td>13 The physical environment of my Unit is ideal for providing palliative care to dying babies</td>
<td>70%</td>
<td>29%</td>
<td>1%</td>
<td>-</td>
</tr>
<tr>
<td>14 My Unit is adequately staffed for providing the needs of dying babies requiring palliative care and their families</td>
<td>42%</td>
<td>56%</td>
<td>2%</td>
<td>-</td>
</tr>
<tr>
<td>15 In my Unit, parents are involved in decisions about their dying baby</td>
<td>5%</td>
<td>92%</td>
<td>2%</td>
<td>1%</td>
</tr>
<tr>
<td>16 My previous experiences of providing palliative care to dying babies have been rewarding</td>
<td>19%</td>
<td>68%</td>
<td>11%</td>
<td>2%</td>
</tr>
<tr>
<td>17 When babies are dying in my Unit, providing pain relief is a priority for me</td>
<td>2%</td>
<td>97%</td>
<td>1%</td>
<td>-</td>
</tr>
<tr>
<td>18 I am often exposed to death in the neonatal environment</td>
<td>29%</td>
<td>69%</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>19 Palliative care is necessary in neonatal nursing education</td>
<td>1%</td>
<td>98%</td>
<td>1%</td>
<td>-</td>
</tr>
<tr>
<td>20 When a baby dies in my Unit, I have sufficient time to spend with the family</td>
<td>21%</td>
<td>69%</td>
<td>8%</td>
<td>2%</td>
</tr>
<tr>
<td>21 There are policies/guidelines to assist in the delivery of palliative care in my Unit</td>
<td>27%</td>
<td>61%</td>
<td>12%</td>
<td>-</td>
</tr>
<tr>
<td>22 In my Unit, when a diagnosis with a likely poor outcome is made, parents are informed of palliative care options</td>
<td>14%</td>
<td>77%</td>
<td>8%</td>
<td>1%</td>
</tr>
<tr>
<td>23 In my Unit the team expresses its opinions, values and beliefs about providing care to dying babies</td>
<td>24%</td>
<td>68%</td>
<td>7%</td>
<td>1%</td>
</tr>
<tr>
<td>24 Caring for dying babies is traumatic for me</td>
<td>37%</td>
<td>60%</td>
<td>2%</td>
<td>1%</td>
</tr>
</tbody>
</table>
25 I have received in-service education that assists me to support and communicate with parents of dying babies

<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>26 All members of the healthcare team in my Unit agree with and support palliative care when it is implemented for a dying baby</td>
<td>64%</td>
<td>34%</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>27 In my Unit, the staff go beyond what they feel comfortable with in using technological life support</td>
<td>19%</td>
<td>71%</td>
<td>9%</td>
<td>1%</td>
</tr>
<tr>
<td>28 In my Unit, staff are asked by parents to continue life-extending care beyond what they feel is right</td>
<td>21%</td>
<td>64%</td>
<td>14%</td>
<td>1%</td>
</tr>
<tr>
<td>29 My personal attitudes about death affects my willingness to deliver palliative care</td>
<td>73%</td>
<td>22%</td>
<td>4%</td>
<td>1%</td>
</tr>
<tr>
<td>30 Palliative care is against the values of neonatal nursing</td>
<td>93%</td>
<td>4%</td>
<td>2%</td>
<td>1%</td>
</tr>
<tr>
<td>31 When a baby dies in my Unit, counselling is available if I need it</td>
<td>22%</td>
<td>73%</td>
<td>4%</td>
<td>1%</td>
</tr>
<tr>
<td>32 There is a belief in society that babies should not die, under any circumstances</td>
<td>47%</td>
<td>47%</td>
<td>6%</td>
<td>-</td>
</tr>
<tr>
<td>33 Curative care is more important than palliative care in the neonatal intensive care environment</td>
<td>69%</td>
<td>25%</td>
<td>5%</td>
<td>1%</td>
</tr>
</tbody>
</table>

5.4 Data reduction

Prior to performing a principal components analysis (PCA) the suitability of data for performing factor analysis was assessed. The first stage of analyses involved exploration of the relationships between items using correlational (Pearsons Product-Moment Correlation = r) statistics. This was to identify items that did not correlate at least moderately (e.g., r = .20 or greater) with other items, as items with lower correlations would be likely to perform poorly in a factor analysis (Floyd & Widaman, 1995). Only one item (32 – ‘there is a belief in society that babies should not die, under any circumstances’) failed to correlate with any other variable at this level – consequently, this item was not included in the factor analysis.

The remaining 25 NiPCAS items were factor analysed, using the principal components method of factor extraction. The Kaiser-Meyer-Oklin statistic as a measure of sampling adequacy was .78, which exceeded the recommended value of 0.60 (Kaiser, 1970, 1974). Using a minimum eigenvalue of 1.0 as the criterion for factors, six factors that accounted for a total of 48.1% of the variance were extracted. The factors were orthogonally rotated using the varimax procedure, and the results are presented in Table Six. Factor loadings that were above .40 were considered to have loaded (Pohlmann, 2004). The rotated solution demonstrated the presence of simple structure with all components showing a number of strong loadings and a
tendency to load uniquely onto only one factor. The items in this Table are ordered and blocked by size of loading to facilitate interpretation of the factor matrix. An inspection of Catell's (1966) scree test (see Figure Five) indicated that the variance accounted for by the factors levelled off between the fourth and fifth factors.

Figure Five: Scree plot to indicate the variance accounted for
Table Six: Rotated factor matrix for PCA of the NiPCAS (N=605)

<table>
<thead>
<tr>
<th>Item</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>communality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents are informed of palliative care options</td>
<td>.671</td>
<td>.049</td>
<td>.030</td>
<td>.024</td>
<td>.039</td>
<td>.057</td>
<td>.45</td>
</tr>
<tr>
<td>Medical staff support palliative care</td>
<td>.664</td>
<td>-.001</td>
<td>-.007</td>
<td>.106</td>
<td>.121</td>
<td>.091</td>
<td>.47</td>
</tr>
<tr>
<td>Team can express opinions, values and beliefs</td>
<td>.654</td>
<td>.026</td>
<td>-.030</td>
<td>.002</td>
<td>.032</td>
<td>.023</td>
<td>.43</td>
</tr>
<tr>
<td>Parents are involved in decision making</td>
<td>.610</td>
<td>-.020</td>
<td>.050</td>
<td>-.003</td>
<td>.246</td>
<td>-.295</td>
<td>.52</td>
</tr>
<tr>
<td>Staffing is adequate for the needs of dying babies</td>
<td>.595</td>
<td>.186</td>
<td>-.051</td>
<td>.058</td>
<td>.126</td>
<td>-.073</td>
<td>.41</td>
</tr>
<tr>
<td>Healthcare team agrees with and supports palliative care</td>
<td>.595</td>
<td>-.037</td>
<td>.158</td>
<td>-.028</td>
<td>-.038</td>
<td>.199</td>
<td>.42</td>
</tr>
<tr>
<td>the physical environment is ideal for palliative care</td>
<td>.530</td>
<td>.242</td>
<td>-.121</td>
<td>.216</td>
<td>-.055</td>
<td>-.048</td>
<td>.40</td>
</tr>
<tr>
<td>There are policies/guidelines to support palliative care</td>
<td>.528</td>
<td>.118</td>
<td>.023</td>
<td>-.037</td>
<td>.056</td>
<td>.254</td>
<td>.36</td>
</tr>
<tr>
<td>When a baby dies counselling is available if needed</td>
<td>.512</td>
<td>-.061</td>
<td>-.034</td>
<td>.080</td>
<td>-.069</td>
<td>-.024</td>
<td>.27</td>
</tr>
<tr>
<td>When a baby dies, there is time to spend with families</td>
<td>.450</td>
<td>.369</td>
<td>.034</td>
<td>.062</td>
<td>.304</td>
<td>.083</td>
<td>.44</td>
</tr>
<tr>
<td>I have had experience of providing palliative care</td>
<td>-.045</td>
<td>.723</td>
<td>.066</td>
<td>-.053</td>
<td>.186</td>
<td>.152</td>
<td>.59</td>
</tr>
<tr>
<td>Experiences of providing palliative care were rewarding</td>
<td>.169</td>
<td>.678</td>
<td>.077</td>
<td>.036</td>
<td>.008</td>
<td>.074</td>
<td>.50</td>
</tr>
<tr>
<td>I am often exposed to death in the neonatal environment</td>
<td>-.045</td>
<td>.584</td>
<td>-.144</td>
<td>-.203</td>
<td>.120</td>
<td>-.163</td>
<td>.44</td>
</tr>
<tr>
<td>Received education to assist in communicating with parents</td>
<td>.364</td>
<td>.421</td>
<td>.081</td>
<td>-.053</td>
<td>-.147</td>
<td>.135</td>
<td>.35</td>
</tr>
<tr>
<td>Palliative care is against the values of neonatal nursing</td>
<td>.052</td>
<td>-.064</td>
<td>.750</td>
<td>-.247</td>
<td>.064</td>
<td>.160</td>
<td>.66</td>
</tr>
<tr>
<td>Personal attitudes about death affect willingness to deliver PC</td>
<td>-.045</td>
<td>-.030</td>
<td>.636</td>
<td>-.106</td>
<td>.011</td>
<td>-.195</td>
<td>.45</td>
</tr>
<tr>
<td>I feel a sense of personal failure when a baby dies</td>
<td>.037</td>
<td>.285</td>
<td>.626</td>
<td>.003</td>
<td>-.023</td>
<td>-.124</td>
<td>.49</td>
</tr>
<tr>
<td>Curative care is more important than palliative care</td>
<td>-.042</td>
<td>-.031</td>
<td>.572</td>
<td>.174</td>
<td>.172</td>
<td>.292</td>
<td>.47</td>
</tr>
<tr>
<td>staff go beyond comfort in using technological life support</td>
<td>.132</td>
<td>-.088</td>
<td>.030</td>
<td>.819</td>
<td>.008</td>
<td>-.095</td>
<td>.70</td>
</tr>
<tr>
<td>Asked by parents to continue care beyond what they feel is right</td>
<td>.099</td>
<td>-.056</td>
<td>-.214</td>
<td>.774</td>
<td>-.067</td>
<td>.057</td>
<td>.66</td>
</tr>
<tr>
<td>Palliative care is necessary in neonatal nursing education</td>
<td>.179</td>
<td>-.007</td>
<td>.076</td>
<td>-.136</td>
<td>.674</td>
<td>-.133</td>
<td>.52</td>
</tr>
<tr>
<td>When babies are dying providing pain relief is a priority</td>
<td>.030</td>
<td>.057</td>
<td>-.038</td>
<td>-.029</td>
<td>.641</td>
<td>-.042</td>
<td>.41</td>
</tr>
<tr>
<td>Palliative care is as important as curative care</td>
<td>.023</td>
<td>.171</td>
<td>.201</td>
<td>.154</td>
<td>.551</td>
<td>.283</td>
<td>.47</td>
</tr>
<tr>
<td>There is support for neonatal palliative care in society</td>
<td>.312</td>
<td>.181</td>
<td>.015</td>
<td>-.035</td>
<td>-.119</td>
<td>.578</td>
<td>.47</td>
</tr>
<tr>
<td>Caring for dying babies is traumatic for me</td>
<td>-.104</td>
<td>-.453</td>
<td>-.312</td>
<td>-.145</td>
<td>.178</td>
<td>.454</td>
<td>.57</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Eigenvalue</th>
<th>4.26</th>
<th>2.35</th>
<th>1.65</th>
<th>1.39</th>
<th>1.30</th>
<th>1.0</th>
</tr>
</thead>
<tbody>
<tr>
<td>% of variance explained</td>
<td>17.0</td>
<td>9.4</td>
<td>6.6</td>
<td>5.5</td>
<td>5.2</td>
<td>4.2</td>
</tr>
<tr>
<td>Cronbach’s alpha</td>
<td>.79</td>
<td>.55</td>
<td>.57</td>
<td>.63</td>
<td>.40</td>
<td>-.09</td>
</tr>
</tbody>
</table>
The first factor, accounting for 17.0% of the variance, had 10 items with loadings above the cutoff of score of .40. All of these items loaded substantially onto only one factor. This factor appears to capture constructs relating to the organisation in which the nurse practices, and the resources available to support palliative care practice within that organisation. However, to assist in theoretical interpretability, it was split to represent the organisation in which the neonatal nurse practices (items 12, 15, 22, 23 and 26 Cronbach’s alpha = .73) and the available resources to support a palliative model of care (items 13, 14, 20, 21 and 31 Cronbach’s alpha = .65). The first factor identified was labeled ‘organisation’, and the second factor, ‘resources’.

The second and third factors each contained four items. It could be argued that each of these factors contained items that had a degree of theoretical resonance. In particular, in factor three, the items relating to personal attitudes to death, and personal failure certainly appear to share a similar construct. However, a primary rationale for conducting factor analysis is to determine that the factors identified reliably measure a construct, and reliability testing of these items demonstrated a low Cronbach’s alpha of .55 (factor two) and .57 (factor three). Investigation of the Cronbach’s alpha for the scale items if an item was deleted was also undertaken. The removal of an item actually weakened the alpha further. Given this, neither of these factors were accepted.

The fourth factor was represented by just two items. Although there were only two items represented in this subscale, there was a degree of theoretical integrity regarding the clinician and how the inappropriate use of technology and the demands of parents resulted in feelings of discomfort. Given this theoretical integrity and acceptable alpha (.63), this factor was accepted as measuring a construct relating to the attitudes, in terms of moral and ethical concerns, of the clinician. This factor was labelled ‘clinician’.

Three items loaded onto factor five, and two items on factor six. Neither of these factors had any theoretically meaningful factorability. Subsequent low alpha scores substantiated this conclusion (.40 and -.09 respectively, the latter value due to a
negative average covariance among items, violating reliability model assumptions), and neither were accepted as reliable factors. A theoretically meaningful three factor solution is therefore proposed. Table Seven reports the internal reliability of the three subscales with inter-item correlations which ranged .15 to .60, this would suggest an adequate degree of discriminate validity.

Table Seven: Means, SD, Alphas, and Correlations for the Scales

<table>
<thead>
<tr>
<th>Factor</th>
<th>M</th>
<th>SD</th>
<th>Alpha</th>
<th>A.</th>
<th>B.</th>
<th>C.</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. ‘organisation’</td>
<td>3.3</td>
<td>.95</td>
<td>.73</td>
<td>1.0</td>
<td>.60**</td>
<td>.16**</td>
</tr>
<tr>
<td>B. ‘resources’</td>
<td>2.8</td>
<td>1.00</td>
<td>.65</td>
<td>.60**</td>
<td>1.0</td>
<td>.15**</td>
</tr>
<tr>
<td>C. ‘clinician’</td>
<td>3.2</td>
<td>.97</td>
<td>.63</td>
<td>.16**</td>
<td>.15**</td>
<td>1.0</td>
</tr>
</tbody>
</table>

Key:
# - Mean divided by number of items in the scale
** <.01 level

Possible mean score 1 – 5. Score of 5 indicates that participants responded ‘strongly agree’ to all items on the scale. A score of 1 indicates that participants responded ‘strongly disagree’ to all the items on the scale.

In terms of the description of the scales, the initial definition of the NiPCAS was based upon the input of an expert panel, and a review of the literature. Utilizing the criteria of eigenvalues being greater than 1, the items in the NiPCAS extracted 6 factors which accounted for 48.16 % of the variance amongst the items. By further examining the questions within each factor and the Alpha of each factor, factors were subsequently accepted or rejected upon the basis of this analysis. The constructs represented by these subscales indicated the barriers and facilitators to palliative care practice relating to: (1) the organisation, (2) the available resources and (3) the clinicians themselves. In the next section, the frequencies for each of the items within these subscales will be presented.

5.5 Exploration of the frequencies of the dependent variables

5.5.1 ‘Organisation’

The subscale ‘organisation’ measures the extent to which the institutional setting, or the social system, in which the neonatal nurse operates presents barriers and
facilitators to palliative care practice. The overall mean score for this subscale was 3.3, indicating a level of agreement for the items represented in this subscale. This means that mostly facilitators to palliative care practice are indicated by this subscale. The individual items in this subscale were about whether clinical staff support a palliative model of care; the involvement of parents in decision making; whether parents are made aware of palliative care treatment options; whether the team have the opportunity to express their morals and values, and; whether members of the healthcare team agree with treatment options for marginally viable and critically ill newborns. Table Eight illustrates that the majority of participants answered that they ‘somewhat agreed’ and ‘strongly agreed’ with most of these items relating to the organisation they practiced within.

Table Eight: Distribution of responses: ‘organisation’ subscale

<table>
<thead>
<tr>
<th>NiPCAS item</th>
<th>Strongly disagree</th>
<th>Somewhat disagree</th>
<th>Unsure</th>
<th>Somewhat agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical staff support palliative care in the Unit (M = 3.27 SD = .85)</td>
<td>2.9</td>
<td>14.1</td>
<td>3.6</td>
<td>39.9</td>
<td>39.4</td>
</tr>
<tr>
<td>Parents are involved in decisions about their baby (M = 3.64 SD = 62)</td>
<td>0.5</td>
<td>4.7</td>
<td>2.1</td>
<td>26.8</td>
<td>65.9</td>
</tr>
<tr>
<td>Parents are informed of palliative care options (M=3.4 SD = .91)</td>
<td>3.4</td>
<td>11.0</td>
<td>8.3</td>
<td>35.4</td>
<td>41.9</td>
</tr>
<tr>
<td>Team can express opinions, values &amp; beliefs (M=3.1 SD = .96)</td>
<td>4.9</td>
<td>18.7</td>
<td>7.1</td>
<td>42.0</td>
<td>27.3</td>
</tr>
<tr>
<td>Members of healthcare team agree with and support palliative care when implemented (M = 3.26 SD = .96)</td>
<td>2.9</td>
<td>18.2</td>
<td>9.4</td>
<td>38.3</td>
<td>31.2</td>
</tr>
</tbody>
</table>

5.5.2 ‘Resources’

The ‘resources’ scale had a lower overall mean score of 2.8, and included individual items about a range of resources related issues in the NICU. This lower mean score can be interpreted as a tendency towards a level of disagreement for the items represented by this subscale. This means that barriers to palliative care practice are indicated by this subscale. The resources identified in this subscale included the physical environment, staffing needs, accommodating the time needed to be spent
with families, policies and guidelines to support a palliative model of care and whether counselling was available to nurses when a baby died. Again, respondents mostly answered that they ‘somewhat agreed’ to ‘strongly agreed’ with these items. However, in item 13, respondents mostly indicated ‘strongly disagree’ (31.5%) and ‘somewhat disagree’ (37.7%) that the physical environment in their Unit was ideal for providing palliative care.

Table Nine: Distribution of responses: ‘resources’ subscale

<table>
<thead>
<tr>
<th>NiPCAS item</th>
<th>Strongly disagree</th>
<th>Somewhat disagree</th>
<th>Unsure</th>
<th>Somewhat agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical environment of my Unit is ideal for palliative care (M= 2.0 SD = .96)</td>
<td>31.5%</td>
<td>37.7%</td>
<td>1.6%</td>
<td>23.1%</td>
<td>6.2%</td>
</tr>
<tr>
<td>Unit is adequately staffed for providing needs of dying babies (M = 2.67 SD = 1.00)</td>
<td>14.8%</td>
<td>26.6%</td>
<td>1.9%</td>
<td>37.5%</td>
<td>19.2%</td>
</tr>
<tr>
<td>I have sufficient time to spend with family when a baby dies (M = 3.20 SD = .95)</td>
<td>4.1%</td>
<td>17.4%</td>
<td>8.1%</td>
<td>40.9%</td>
<td>29.5%</td>
</tr>
<tr>
<td>There are policies/guidelines to support palliative care (M = 3.10 SD = 1.13)</td>
<td>9.9%</td>
<td>17.7%</td>
<td>12.3%</td>
<td>37.7%</td>
<td>22.4%</td>
</tr>
<tr>
<td>There is counselling available if I need it when a baby dies (M = 3.2)</td>
<td>8.3%</td>
<td>13.5%</td>
<td>5.0%</td>
<td>33.4%</td>
<td>39.8%</td>
</tr>
</tbody>
</table>

5.5.3 ‘Clinician’

The ‘clinician’ scale had an overall mean score of 3.2, indicating a level of agreement with the items in the subscale. Given the nature of these items, this could be interpreted as implying barriers to palliative care practice. In this scale, participant’s responses reported that, mostly, staff were uncomfortable with the use of technology for marginally viable and critically ill newborns, and that they generally agreed that they were asked to continue life extending care by parents beyond what they felt was right.
Table Ten: Distribution of responses: ‘clinician’ subscale

<table>
<thead>
<tr>
<th>NiPCAS item</th>
<th>Strongly disagree</th>
<th>Somewhat disagree</th>
<th>Unsure</th>
<th>Somewhat agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>n=605 (alpha = .63)</strong></td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Staff go beyond what they feel comfortable with in using technological life support (M = 3.22 SD = 1.05)</td>
<td>4.5 n=27</td>
<td>18.5 n=112</td>
<td>14.8 n=89</td>
<td>42.2 n=255</td>
<td>20.0 n=122</td>
</tr>
<tr>
<td>Staff are asked by parents to continue life-extending care beyond what they feel is right (M = 3.24 SD = .93)</td>
<td>5.2 n=31</td>
<td>11.5 n=70</td>
<td>7.6 n=46</td>
<td>45.0 n=272</td>
<td>30.7 n=186</td>
</tr>
</tbody>
</table>

5.6 Variations in the facilitators and barriers based upon the demographic findings

Factorial analysis of variance tests (ANOVA) tests were conducted to investigate whether there would be variations in the way the population reported barriers and facilitators to palliative care practice. This process tested the hypothesis that the demographic groups would not answer the questions differently, and that their responses would be the same regardless of their age, experience and/or qualifications. Each dependent variable (the subscales) was examined separately to determine any interactions with the explanatory variables of ‘exp’, ‘qual’ and ‘neoqual’. This process resulted in 3 x one-way factorial analysis of variance tests.

Preliminary assumption testing was conducted to check for normality, linearity, univariate and multivariate outliers, homogeneity of variance-covariance matrices, and multicollinearity. No serious violations were observed in this process. In the three-way between groups ANOVAs, there was a mild statistically significant main effect noted only for ‘qual’ and the subscale ‘resources’ [F(2, 600)=2.22, p=.05]; however, the effect size was small (partial eta squared = .01). Post hoc comparisons using Tukey HSD test indicated that this interaction effect did not reach statistical significance (p=.24). This finding supports the hypothesis that the demographic groups would not answer the questions in the NiPCAS any differently.
5.7 Summary

The analysis of the population study results were conducted in two stages: describing the scales and subscales, and; conducting statistical analyses to generate hypotheses about the relationships between the subscales and the characteristics of the study population.

Data reduction techniques using a principal components analysis demonstrated three factors that indicated the barriers and facilitators to palliative care practice. These barriers and facilitators to practice were identified as being influenced by: the organisation in which the nurse practices (‘organisation’); the availability of resources to support the model of care (‘resources’) and; technological imperatives and parental demands (‘clinician’). Each of these subscales had acceptable Cronbach’s alpha scores to demonstrate the reliability of the measured construct: .73, .65 and .63 respectively. A series of one-way factorial analysis of variance tests revealed there no statistically significant interactions observed, supporting the hypothesis that demographic groups would not respond to the NiPCAS questions differently.

In summary, these findings support that there are three factors that indicate barriers and facilitators to practice. The identification of these barriers and facilitators form the basis of the content for the next phase of this study. The following chapter will discuss the findings of a series of focus group interviews conducted with groups of neonatal nurses to discuss and contextualise the findings presented in this chapter to inform evidence based policy.
6.1 Introduction

There is increasing recognition in nursing research that the findings from exploratory research can be translated to inform policy that will have practical, in addition to theoretical applications (Gardner, 2006). This principle informs the aim of the second phase of this research. Analysis of the NiPCAS data identified both barriers and facilitators to palliative care practice in neonatal nursing: the organisation in which the nurse practices (subscale identified as ‘organisation’); the available resources to support a palliative model of care (‘resources’) and; the effects of technological imperatives and parental demands upon neonatal nurses (this construct is simplified to the term ‘clinician’ to describe this subscale). These findings were contextualized by engaging the clinical intelligence of neonatal nurses to explore these barriers and facilitators. This analysis lead to the development of recommendations to inform policy for improving palliative care practice.

To achieve this, interpretive methods were utilised to conduct three focus group interviews in eastern border states of Australia. Participants included neonatal nurses with more than two years experience in the specialty. Prior to these interviews, a summary of the findings from the population study were made available to participants. At the interviews, two main questions were asked: how can we qualify the identified facilitators, and; how can we address the identified barriers. The data collected from the focus group interviews was merged and deductively analyzed. A minimal use of the literature will be used to assist with the interpretation of these narratives, and the steps in this process are described in Table Eleven.
Table Nine: Steps in the analytical process

Population study findings

Three Factors – ‘organisation’ ‘resources’ & ‘clinician’

<table>
<thead>
<tr>
<th>Indicated facilitators</th>
<th>Indicated barriers</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘Organisation’</td>
<td>‘Resources’</td>
</tr>
<tr>
<td>There is support for palliative care from the healthcare team (M=3.2), and medical staff (M=3.2); The healthcare team informs parents about palliative care options (M=3.4) and includes them in decision making (M=3.6); The healthcare team is able to express its values, opinions and beliefs about providing care to dying babies (M=3.1).</td>
<td>There is some level counselling of support for neonatal nurses (M=3.2), and nurses have time to spend with families (M=3.2); There are guidelines available to support PC (M=3.1);</td>
</tr>
<tr>
<td>‘Organisation’</td>
<td>‘Resources’</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Qualitative transitional phase:

Interface between population study findings and policy recommendations

Focus group interview – questions relate to the 3 Factors

Deductive analysis of qualitative data

<table>
<thead>
<tr>
<th>Qualifying the facilitators</th>
<th>Addressing the barriers</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘Organisation’</td>
<td>‘Resources’</td>
</tr>
<tr>
<td>Support for palliative care dependent upon team agreement; Parents require consistent information to make informed decisions; Opinions, values and beliefs unheard – nursing decision making role negligible.</td>
<td>Counselling support mostly collegial, not formal; Clinical guidelines in use not necessarily evidence based or take into account needs of babies, parents, caregivers.</td>
</tr>
</tbody>
</table>
6.2 Qualifying the facilitators to palliative care practice

The facilitators identified by the population study phase of this research were presented to the focus group participants to explore these findings. For each of the indicated facilitators, neonatal nurses reported that there were caveats. Primarily, this discussion identified the caveats to these facilitators and extended the survey study findings to describe five areas for improvement: facilitating the team approach to palliative care through consensus; expanding the nursing role in decision making; providing formal support counselling for clinical staff; introducing clinical guidelines that were evidence based, and; facilitating the parental role in the decision making process.

6.2.1 Facilitating the team approach through consensus

The NiPCAS identified that the healthcare team supported and agreed with palliative care when it was implemented (level of agreement 69% M=3.2) and that neonatal nurses believed medical staff were supportive of a neonatal palliative model of care (79% M=3.2). Neonatal nurses at the focus group interviews were asked to comment upon these findings, and suggest how these processes could be improved. The ensuing discussion demonstrated the importance of the individual members of the social system, as identified by Rogers’ (1995) Diffusion research principles. As Rogers argues, practice change is dependent upon system norms, the characteristics of the individuals within that system and the level of support for an innovation. If individuals within the social system of the NICU fail to accept palliative care as a treatment option for marginally viable and critically ill newborns, conflict may result. This principle was discussed with focus group participants, and there was agreement that although theoretically there was support for palliative care within the healthcare team, individual opposing points of view were often not considered, and this often resulted in conflict. Therefore, a number of neonatal nurses from these interviewed recommended that the team approach to palliative care could be fortified by developing consensus at a team level, prior to patient care conferences involving parents. As illustrated, some of the neonatal nurses interviewed described how conflict occurred due to disagreement about the direction of treatment options amongst the healthcare team:
“We should be able to make our comments known before we have parent meetings. I think often you just follow the doctor into a meeting and this is the first time you have had the opportunity to say how you feel, and the parents are present, and you can’t say it then, and this discussion has to happen beforehand. And often with what the doctors do offer parents you are thinking ‘that’s too much!’ and you think to yourself, you’ve offered an olive branch to the parents, and now they’re never going to give up. And nobody thinks in the long term! If we knew beforehand that this is the plan, we could contribute in a useful way. We could discuss how we are going to manage the death. Or to bring the death on earlier in the case of if we are going to pull the tube. We all need to be talking this way before the discussion with the parents even happens.”

“I think that these discussions need to happen before going before the parents, rather than in front of the parents – if we have issues, we cannot say these in front of the parents. It’s really too late, we can only sit there dumbly and look on.”

Here, participants advocate the consensus approach before engaging in discussion with parents. In the second narrative, the nurse speaks of ‘sitting there and dumbly looking on’ (sic) during patient care conferences; clearly, when parents are present is not the appropriate time to engage in ethical debate about treatment directions. In terms of expanding the level of team agreement for palliative care options, recommendations such as these may be crucial. In the literature, Catlin and Carter (2002) also support consensus meetings aimed at the multidisciplinary level, particularly if some team members are reluctant to support a palliative model of care. The results of the focus group discussion concerning this issue supports that consensus meetings prior to family meetings may address the concerns of neonatal nurses concerning their reticence in engaging in ethical debate regarding treatment decisions.

These findings are commensurate with Diffusion research imperatives. Rogers (1995) emphasises that the rate of adoption of practice change is always going to be affected by the old idea that it supersedes. To illustrate, if a new philosophy of caring for dying babies were completely congruent with the existing practice of favouring technological imperatives and curative care, there would be no innovation, at least in the mind of the potential adopters within that social system. Simply, the
more compatible an innovation is with existing opinions in that system, the less of a change in behaviour it represents. Furthermore, if the healthcare team have experienced conflict when engaging in palliative care for a dying baby previously, this negative experience can damn the adoption of palliative care for future babies. These points emphasise the importance of engaging in consensus to achieve team agreement for palliative care before this model of care is adopted for individual cases.

6.2.2 Expanding the nursing role in decision making

The NiPCAS asked a population sample of neonatal nurses whether they were able to express their opinions, values and beliefs when caring for babies who were dying. The level of agreement for this item was reasonably high, with two-thirds of the sample (M=3.1) reporting that they somewhat or strongly agreed that they were able to express these views. However, discussion at the focus groups contextualized this finding to suggest that although values, opinions and beliefs were expressed, this did not mean they were necessary acknowledged. This was demonstrated by the discussion that occurred regarding the neonatal nurses’ minimal role in ethical decision making. Focus group participants could see they had a role in decision making, yet the desire to participate did not always translate into clinical practice:

“I don’t think that even as a senior person that I could sit with and say to the director of the Unit – I think you are wrong. And there have been experiences here where I could tell you the names of the babies. And I did not agree with the treatment decisions that were made!”

Here, the nurse expresses reluctance and discomfort in engaging in discussion with medical staff about treatment decisions, despite seniority in the Unit. The nurse was able to refer to multiple instances where the desire to participate in decision making had not occurred and could recall the names of babies when decision making had been inconsistent. The literature supports that decision making needs to be interdisciplinary, with all potentially involved staff members (medicine, nursing, labour and delivery, social services, ethics and chaplaincy) having a role in the planning of palliative care (Catlin & Carter, 2002). Therefore, whilst the NiPCAS results indicate that neonatal nurses feel able to express their opinions, they may not
necessarily participate in the decision making process in a consistent manner. This has vast implications, as nurses are in a unique position as perhaps the patient’s greatest advocate in life, and death (Ross, 1992; Zeigler, 2003) and patient advocacy is considered a key role of the neonatal nurse (Monterosso et al., 2005). Despite this, nurses struggle to define their advocacy role in decision making processes (Sheeran Brophy, 2001). This is evident whereby the nurse defines the role of an advocate as ‘backing up’ what the doctor says:

“In a situation like that, when the parents are being counselled, part of your role would be to draw attention to episodes when their baby had been unstable. It helps them to focus on those things so they can match up their decisions with what the medical officer is trying to offer them. That’s what I feel our role is, to back up the medical staff – sadly, we don’t really have a voice, or a role in that, though.”

Here, the nurse describes feelings of impotence in the decision making role. Their ability to advocate for the baby is relegated to one of self-imposed ‘interpreter’ for the medical staff. This may also indicate a lack of understanding of the advocacy role. With such a fragile patient population, it is imperative that the neonatal nurse be a learned and effective advocate. Given this, the advocacy role of neonatal nurses requires further facilitation via educational and organisational support.

Although 79.3% (M=3.2) of respondents in the NiPCAS reported that palliative care received support in their setting, focus group participants discussed medical orders and care paths as changing from shift to shift:

“If only there was agreement about treatment. We’re just the meat in the sandwich, following orders that chop and change from shift to shift.”

“The nurses aren’t included in discussion about the direction of care, so if you have 6 consultants, you basically have 6 different ideas – and that changes shift to shift at times – this would be quite horrible for parents, I should think.”

This reinforces the difficult position neonatal nurses occupy when orders are not followed through due to a lack of documentation, or are poorly communicated to staff and families. When treatment decisions move from technological life support to palliative care, written documentation needs to continue to reflect a consistent
approach (Catlin & Carter, 2002). Participants described being ‘the meat in the sandwich’ when there is physician disagreement about treatment orders. Furthermore, when nurses are not included in discussion about the direction of care, it may place them in an untenable position with parents, resulting in conflict.

Given the dominant discussion at the focus groups regarding the nursing role in decision making, participants were asked how this role could be developed. However, this question resulted in tentative discussion regarding the components of bioethical principles such as autonomy, veracity, beneficence and non-malefiscense. These components were not referred or even alluded to, instead, some participants interpreted ethics as being about religion, life experience and one’s personal morals, beliefs and values:

“Ethics are about your life experiences, your morals, beliefs and values – that is what ethics is all about”

“Yes, I believe that ethics are about your religious beliefs …”

This represents just a sample of the discussion that was generated by this question, and is representative of the lack of understanding of bioethical principles revealed by this nursing cohort. Participants attributed life experience, religiosity and personal values to ethical principles, suggesting a lack of ethical competence that may further encumber the nurses decision making role. Cheetham and Chivers (1996) define ethical competence as the possession of appropriate personal and professional values and more importantly the capacity to apply them effectively in the clinical setting. In the current research, participants were asked if they had received ethics training that would foster ethical competence in the decision making process:

“I think got some in our nursing degree, or if you have had hospital training we talked about ethics. Not to any real degree though.”

“We received some ethics in our training, but it’s very little, and one can’t apply it. It was a while ago, I can’t remember what it was all about.”

The participants describe their rudimentary education in bioethics. That they ‘couldn’t apply it’ also suggests the nurses’ grasp of ethical principles may not be
applicable to the clinical area. Ethical competence and advocacy skills are both skills identified as facilitating nursing involvement in decision making processes.

In summary, a population sample of Australian neonatal nurses state that they can express their values, opinions and beliefs about caring for dying babies. However, in this interpretive phase, experienced neonatal nurses contextualise this finding to suggest that these opinions may not necessarily be heard due to their negligible role in ethical decision making. Therefore, in this phase of the research it is suggested that these processes could be facilitated by supporting and expanding the nurses’ role in decision making.

6.2.3 Counselling and support for clinical staff

Providing end-of-life care to newborns and their families can be very intense. It is, therefore, essential that clinical staff participating in this form of care have both ongoing support and debriefing after difficult cases from outside experts (Catlin & Carter, 2002) if required. The NiPCAS indicated that the majority of participants (73.2% M=3.2) agreed that counselling was available to them if they required it when a baby died. This finding was discussed with the focus group participants to determine the nature of this counselling support, and how these processes could be facilitated. Participants described that they were supportive of one another, and when debriefing occurred, it was informal and generally peer-to-peer:

“Well I think as nurses we debrief very well together, but not as a whole team. It usually occurs in the tea room, or in the car park after work. To be honest it can happen at the pub after work sometimes, too. I think that we do support each other. We have each other.”

“We do have a counseling service available if we want it but I think that more often than not its just a collegial thing. Colleague to colleague, and you might prefer to cry on another nurses’ shoulder than make a big issue over it, or to go public with it. That way you can have a debrief with your friends, and try to rationalize the death and go over it and try to make it a logical process.”

This suggest that nurses generally provide informal support to one another. Utilizing formal counselling services was interpreted as making ‘a big issue’ out of the death
of a baby. For the most part, peer-to-peer support was considered effective, a finding supported by the literature (Davies et al., 1996; Heuer, Bengiamin, Downey, & Imler, 1996), and referred to as ‘healing conversations’ (Davies et al., 1996). Although there were suggestions that formal counselling was available to them in the form of psychiatry/psychology support, the availability of such resources were not always made explicitly clear to nursing staff:

“Yes, we have a psychiatrist on staff, but there would be a stigma attached about going to see that person. I personally wouldn’t use that service and have management believe I wasn’t coping with my job.”

In this example, the nurse spoke of formal counselling as having a stigma attached to it and that by utilizing such a service, there would be reprisals of being perceived as not coping with their work. Debriefing following a critical incident or a difficult case were ad hoc at the sites where the focus group interviews were conducted:

“Okay, with debriefing, I do feel that a lot of the time the people that were involved in the situation aren’t even present in the meeting – people just come along. I don’t know if they’re there out of interest or what, some of the time they’re not actually involved in the situation and come anyway, and they talk the most, and the people who actually were involved go away and haven’t said a word. And that happens a lot”

“With debriefing, we have the session several days down the track when it fits into the schedule, and by then it just doesn’t mean anything anymore, and you have moved on, but not necessarily dealt with it.”

These narratives concur that although there is at least some counselling and debriefing support available as per the NiPCAS findings, the provision of formal debriefing was impromptu and inconsistent. This may have lead to the grief experienced by these nurses as unacknowledged. Some of the nurses interviewed explained how they were expected to attend staffing debriefs or patient funerals in their own time. The literature suggests that attending such events can assist in bringing closure, and assist healthcare professionals in dealing with grief (American Academy of Pediatrics, 2000; Serwint, 2006; Ufema, 2001). Furthermore, some of the literature suggests that staff should attend debrief sessions and/or funerals if they choose to do so either in working hours, or if attending in off-duty time, being paid
to attend (Catlin & Carter, 2002; Serwint, 2006). This was suggested to the focus group participants:

“Would the organisation pay for you to attend, or give time in lieu if a funeral or a debrief was scheduled during your off duty time? You are joking, aren’t you?”

“Budgets are very tight – there is no way you would be paid to attend a debrief even if you were bereaved and stressed out by the situation. As an example, they don’t even like paying over time when you stay back with a baby who is dying to provide continuity of care for the families. Not from my recent experience!”

The suggestion that management paid for the time (or the promise of time in lieu) to attend funerals or debrief sessions after difficult cases was met by bemusement at the focus groups interviews. However, Catlin and Carter (2002) state that policy needs to include the proviso that debriefing meetings or counselling sessions should be part of regular work hours and not held during voluntary or be deemed as unpaid time (Catlin & Carter, 2002). Given this lack of formal counselling services, the reluctance to attend when available, and a lack of debriefing following a difficult case, participants were asked what was needed in terms of counselling and formal support services.

“We don’t have coping skills, and you don’t want to make it an issue for everybody else or feel that you are seeking attention by demanding a debrief session or needing to see a shrink. But if we had coping skills in the first place, you would be able to deal with the grief afterwards – that sadness you hold in – we need help to develop skills in order to cope with this type of work and care for these types of baby.”

“With coping skills, forewarned if forearmed. Sometimes you need some counselling prior to withdrawal of treatment, and then having to watch a baby die. This would give us coping skills.”

The nurse states that requesting a debrief after a difficult case would be interpreted by the organisation as ‘seeking attention’. The nurse describes their lack of coping skills, which is elaborated upon in the second narrative with the nurse describing coping skills as highly necessary.
In summary, although the majority of NiPCAS respondents reported that there was counselling available, such counselling may be mostly peer-to-peer, and although some neonatal nurses are satisfied with this, for others, it is not enough. This cohort of nurses suggest a reluctance to avail themselves of formal counselling, yet there is a need for the development of coping skills to work with these types of babies. The lack of debriefing sessions for those involved in the care of a newborn who had died was a source of contention. Although debriefings after patient deaths and other critical incidents may be beneficial for some clinical staff, the literature also reports instances where group debriefing may encumber the individual’s emotional healing (Bisson, Jenkins, Alexander, & Bannister, 1997; Hobbs, Mayou, Harrison, & Worlock, 1996), with one study reporting that individuals attending group debriefs were actually no better in their emotional adaptation (Lee, Slade, & Lygo, 1996). This would suggest that group debriefs need to be conducted by specialised individuals. Given these arguments, the criteria for when group debriefing should occur needs to be delineated and made available first and foremost to those directly involved, if they wish to attend.

6.2.4 The use of evidence based clinical guidelines

As demonstrated in the literature review, there are established clinical guidelines available to support a neonatal palliative model of care. Therefore, one of the goals of the focus group interviews was to facilitate discussion around the availability of guidelines in the Australian clinical environment. The NiPCAS findings support that there was at least some level of agreement (60% M=3.1) that there are clinical guidelines in place to support a palliative model of care. However, discussion of this finding with focus group participants revealed that when guidelines were used, they were not necessarily evidence based, or adapted from resources that are already available:

“We did start to write a protocol which was a literal ABC of what to do if a baby is dying. It didn’t have any references though, it was just a general idea of how we do things here. It wasn’t based on any evidence, though.”

As this participant highlighted, an attempt at developing written guidelines to support palliative care practice was made. However, that there ‘were no references’ to
support this protocol, indicating that it was not evidence based. Given this, participants were asked whether they were aware of published palliative care guidelines, such as Catlin and Carter’s ‘Neonatal end-of-life Palliative Care Protocol’ or Gale & Brooks ‘Palliative Care Program’ (Catlin & Carter, 2002; Gale & Brooks, 2006), but there was no knowledge of these within this cohort. Given this, participants were asked what information should be included in such a document. Much of this discussion related to the needs of the parents and providing consistent care:

“We need some sort of consistency in terms of feeding regimes, and pain relief regimes. Staff get very upset by certain feeding regimes, such as no longer feeding babies, and do they suffer and things like that. Generally there is a lack of knowledge about how to do palliative care.”

“If I had to say one thing about putting together a policy it would be to identify the needs and wants of the family because this is their experience, and they need to take that experience away with them for the rest of their lives.”

This suggest that there is a need for evidence based policies to emphasise consistent treatment regimes and the needs of parents. The lack of knowledge about palliative care was also highlighted. This would indicate that guidelines cannot assume that clinical staff understand the precepts of palliative care. That evidence based clinical guidelines are not present is highlighted in the following narratives:

“You see, we do funny things sometimes. We had a baby recently who was receiving palliative care and we were still giving caffeine, and oxygen therapy – and in another case, we were supposed to be withdrawing care aimed at curing the baby but we’re still giving CPAP and the baby’s desatting and screaming every time we do tube changes or re-tapes, and everybody was saying, ‘why are we doing this?’”

This supports the problems that a lack of consistent information can present to clinical staff. The nurse describes that the baby receiving palliative care is still receiving xanthine derivatives, CPAP and oxygen therapy. This treatment regime caused caregivers to ask ‘why are were doing this’, because there was no consistent treatment plan. How much treatment is too much? Which treatments are contrary to providing palliative care? Clearly, clinical guidelines need to address this criteria to foster a consistent approach to palliative care.
When developing clinical guidelines to support palliative care, participants focussed on the cultural aspects of providing care to marginally viable and critically ill newborns.

“We need to address the cultural aspects of providing care to dying babies. I recently looked after a Chinese baby, and its mum wouldn’t hold the baby once it had died, and I couldn’t understand that. I have always believed that it is part of the grieving process to hold the dead baby. Of course, I have learnt since that in the Chinese culture you don’t deal with dead bodies. I felt that I had tried to force her to do something she didn’t want to do – made her feel guilty, but I didn’t know at the time.”

The nurse was not aware of the cultural aspects of providing care to this baby caused them to experience considerable guilt. The nurse described that from the westernised perspective, it was considered ‘part of the grieving process’ for parents to handle the dead infant. This nurse believed they had forced their cultural norms onto the mother, indicating the need to incorporate cultural and religious needs into palliative care clinical guidelines.

Utilizing evidence based guidelines to promote a consistent approach to palliative care in Australian NICUs is integral to its acceptance. When one considers that the available resources to support palliative care practice are identified as the source, or the channel, for innovations in healthcare, the under utilization of evidence based guidelines may play a pivotal role in the lack of engagement of palliative care practice.

6.2.5 Facilitating the parental role in decision making

The NiPCAS indicated a strong level of agreement that parents are informed of palliative care options (77.3% M=3.4) and are involved in decision making processes when their baby is dying (92.7% M=3.6). Given this, nurses were asked to contextualise these findings in terms of the parental role in decision making. Participants suggested that there was still much that could be done in terms of supporting parents in their decision-making role, recommending that written information for parents be available, as supported by Catlin and Carter (2002).
“Written information would be useful because then parents could read it again and again until the penny drops. When you just talk to parents, they may not take it all in, when they have written stuff, they can keep going over it and ask questions from it.”

“Written information needs to talk about what palliative care is, this helps them to absorb the facts, because if you offer them anything, they are going to grab that because it gives them hope. It would be good to have something in writing that explains all of that as well as talking to them.”

In these narratives, participants supported using written information as an adjunct to verbal discussion with parents about palliative care, and other aspects of caring for dying babies. They suggested that there was ‘a lot to take in’, and offering written information afforded parents the opportunity to digest and process information at a time of stress. However, participants also described instances where it was difficult to communicate with parents, and questioned the approach of providing candid information to parents to inform their decision making role:

“Parents don’t understand that word – dying. So we need to talk around it rather than use the word directly. We’ve had 15 year old parents, and until you actually ring them and tell them that their baby is dying, they just don’t understand it. The doctors may not use the right words, they will say ‘the baby’s not doing so well’, but they still don’t understand it. It was two hours later, and the parents had gone home, and the baby was dying as the doctor spoke to them, but candy coated the truth to be nice. So what’s the point, they don’t understand the concept of dying.”

The nurse describes that there is little point in pragmatic communication with parents, because parents fail to ‘understand the concept of dying’. Literature suggests this is one of the myths that needs to be debunked regarding parental competence in decision-making, including: Parents are unable to understand the facts; parents are too involved and therefore besieged by emotions; and parents are unable speak out of concern for the infant’s interests, but act in their own self-interest instead (Carter & Leuthner, 2003). In order to debunk these myths, the healthcare team may need to improve communication, psycho-social and practical support for parents to engage them in informed decision making.
In summary, the NiPCAS demonstrated that Australian neonatal nurses report a level of agreement that parents are informed of palliative care options, and are involved in treatment decisions in the NICU. In this second phase of the research, experienced neonatal nurses suggest that parents require more information to make informed choices, including written information as an adjunct to verbal communication. However, some failed to recognize the parental capacity for decision making on behalf of their baby.

6.3 Addressing the barriers to palliative care practice

The NiPCAS suggested that there are barriers to palliative care practice which include inadequate staffing to support the practice; a substandard physical environment, and; the impact of technological imperatives and parental demands upon neonatal nurses. These issues were discussed with the focus group participants to identify how these barriers could be addressed in the clinical environment.

6.3.1 Fostering an environment to support palliative care practice

In the NiPCAS, 69.2% (M=2.0) of participants stated that the physical environment in their Unit was not ideal for providing palliative care. Discussion of this finding with focus group participants suggested that the physical infrastructure to support was inadequate because it was interpreted as a ‘low priority’ by the organisation. Suggestions by participants for addressing this concern were supported by Catlin and Carter (2002). These authors suggest that a room be set aside for palliative care that is ‘homelike’ with soft lighting, and is large enough to accommodate the extended family. Such a room should have recliner chairs and double beds to allow parents to lie down with their baby. There should also be kitchen facilities, an outlet for a music device, and a conference or consultation room nearby. They also suggest a small library with resources on grieving and a journal for parents to write in (Catlin & Carter, 2002). Participants in the focus group supported these suggestions:

“I agree with this suggestion, we need the simple things, such as recliner chairs for that last cuddle. I think that a comfy chair to put your feet up – but there’s no space for that in our Unit, so parents balance the baby on their knee on an uncomfortable chair.”
The nurse expressed dissatisfaction at the lack of these simple comforts for parents in their setting. In this case, there was no room set aside for such a purpose in their organisation, and when such a room was available it often had dual purposes for storage and meetings rather than for the purpose it was intended.

“It depends what the grieving room is being used for – it’s a low priority to have a quiet place for a baby to die – it shouldn’t be, but it is. Often it just isn’t available for use when a baby is dying. There’s a high requirement for meeting rooms.”

“We have a grieving room for this purpose, but its tiny, space is such an issue. There’re no windows and it’s a room that you just don’t want to spend time in.”

Here, the nurses describe the problems with rooms that are set aside for ‘grieving’. In the first narrative, although such a room exists, it was often unavailable for the reason for which it was intended due to the high demand for meeting rooms. Furthermore, the inadequacy of the ‘grieving room’ was depicted. In terms of policy development, the Wall Street Journal (Peterson, 2005) reports that the Sinai Hospital in Baltimore have remodelled a private room, with subdued lighting and comfortable furniture, designed for parents to hold their newborns after invasive life support had been removed. Prior to this, as in many NICUs, grieving parents were separated only by screens pulled around the cot side. This ‘traditional’ setting was described by nurses in the current research:

“The other point is that life goes on in the NICU – people laughing etcetera, regardless of the fact that there’s a baby dying – staff chit-chat, not inappropriately laughing, and all we have are flimsy curtains around the bed-space – we call them the iron curtain, but of course they achieve nothing in terms of privacy.”

“Usually parents stay in the Unit with the curtains drawn around when their baby is dying, but that is hard on the other parents, too. They are aware of what is going on, that a baby is dying, and it is distressing for all.”

Neonatal nurses describe the NICU environment as somewhat indifferent to the needs of dying babies, with staff ‘chit-chat’, laughter and the general relentless activity that is inherent to this environment going on around the dying baby and their family. The lack of privacy is also suggested to be a significant issue, with nothing
but ‘flimsy curtains’ providing a barrier between the grieving family and the often chaotic and seemingly indifferent NICU environment.

When a newborn is near death, relocation to another room away from the Unit may be an option, and is supported by the literature (Catlin & Carter, 2002). Within this room, life support can be continued for a time, and parents and family can remain with the newborn in privacy. Extended family access is important, and spiritual support can continue within such an environment (Carter, 2004). This was discussed with the participants in the current research who identified some problems with this, including that parents may feel abandoned if they leave the relative familiarity of the NICU.

“I’m not so sure about having a room dedicated to palliative care. I worry that parents may feel abandoned, coming out of the Unit for their baby to die, the NICU is the only environment that they have ever known.”

In this narrative, the nurse expresses their concern that families may feel abandoned by leaving the relative security and familiarity of the NICU. Participants supported the notion that parents needed to know that they would not be abandoned and would be offered the choice of either leaving the NICU, or moving to a more private location:

“I think that sometimes parents want to stay in the NICU, even if we can offer them a private room for palliative care. We offer them a choice sometimes – but they might prefer to stay in the Unit, in a familiar environment.”

This suggests that offering a choice of location is preferable, because in some cases, parents may not wish to leave the NICU where they have bonded with staff and have adjusted to the noise and activity. Such families, suggest Catlin and Carter (2002) might feel isolated if moved to a private place. If a transition out of the NICU is an option, this should be approached sensitively. Some parents, it was indicated, strongly wished to leave the NICU environment when their newborn died:

“I think the biggest issue with a dying baby for the parents is that their baby never gets to leave the hospital, and we need to be flexible about this. And often it would be nice to have a little alcove or a verandah where parents
could go with their baby in privacy, where they could take their child, even when dying to show their baby that there is an outside world, so they can at least say: ‘I got to take my baby outside’.”

“We had one baby that died outside, in the sunshine. The parents wanted him to taste chocolate – we did all we could to make it happen.”

These narratives describe how the Unit needed to be flexible to accommodate the needs of all families. In the first narrative, the nurse emphasises the importance of some parents simply wanting to ensure that their baby had experienced the outside world before death. In the second narrative, the nurse expressed their satisfaction at fulfilling the parents wish for their dying baby, which involved allowing the baby to succumb outside, ‘in the sunshine’, and to taste chocolate, both of which were important to the family.

Clearly, the lack of a physical environment conducive to palliative care is an important issue, and one highlighted by both the population study and the interpretive study findings. However, Catlin & Carter (2002) argue that it is also the mindset of staff that is far more important than the physical space. The attitude of the healthcare team and their willingness to care for marginally viable and critically ill newborns and their families, skills in accurate observation and the ability to support the process are considered far more important than simply providing the optimal physical environment (Catlin & Carter, 2002). In conclusion, the site of care must not be overshadowed by a pivotal focus upon the newborn’s best interests (Carter, 2004).

6.3.2 Providing staffing to support a palliative model of care

When neonatal nurses were surveyed about the adequacy of staffing to support caring for marginally viable and critically ill newborns, there was a lower level of agreement that staffing was adequate to meet this need. This finding was discussed with the focus group participants to address the staffing needs of caring for these types of babies. Caring for marginally viable and critically ill newborns were described by the focus group participants as labour intensive and emotional:

“Caring for these babies is very labour intensive, of course this depends upon the family. You can get a family that is very emotional and wants to talk, so it
can be very busy. At other times, the family don’t really want to speak to you. So at times, you need to be there all of the time for them. It also depends upon who you work with, and the support you get from your other colleagues. If you have to spend a lot of time with a mother, you need the help of other nurses with your workload. You might have more than one baby to look after, and you can’t get near the other baby, so you totally depend upon the other nurses, ‘cos you can’t depend on getting extra staff. The whole place can be stretched to the limit sometimes.”

This illustrates the time consuming nature of caring for dying babies. The needs of the family dictates the level of emotional support necessary by the neonatal nurse, and this varies from family to family. The nurse describes how some families want to talk, and others don’t. They also describe their dependence upon colleagues to provide back-up support when the labour intensive aspect of caring for these types of babies is not accounted for in staffing allocation. In this narrative, the nurse describes the situation as stretching resources to the limit. This may suggest that although neonatal nurses report sufficient time to spend with families when a baby is dying, this support may come from nursing colleagues within the Unit, rather than from organisational support.

The need for consistent staffing was recommended by the focus group participants. Such a model supports teamwork and communication and has been demonstrated as having a positive impact on both family and the nurse’s job satisfaction (Goldschmidt & Gordin, 2006). However, although nurses in the current study may have wanted to allocate their permanent staff to consistently care for these types of newborns, patient acuity needs and an ongoing lack of staff were prohibitive issues to continuity of patient care assignments:

“Continuity of care is an issue for staffing and caring for these babies. The family get close to a staff member, but the next shift, you are using agency staff or casual, more junior staff. It’s as though only babies who are really sick, and we are using a lot of technology get the most knowledgeable staff. If a baby is dying, and we’ve sort of given up, anybody can care for them. It’s a bit like that.”

Here, the nurse expresses the desire to provide consistent staffing, but suggests that babies who can be ‘saved’ are more deserving of the most knowledgeable staff. When a baby is dying, this nurse suggests that ‘anybody can care for them’ because
‘we’ve sort of given up.’ This fails to recognise the labour intensive, and highly specialised nursing care that newborns receiving palliative care require. This could be achieved by the development of an accurate patient dependency tool that captures this acuity. Patient dependency tools were discussed with the nurses in the current research:

“Whether we have a patient dependency policy or not is anyone’s guess – I don’t think we do, and I wouldn’t use it anyway. It’s just that we have been here for so long that they will listen to us in determining a 1:1 – but if you haven’t got the staff, then you haven’t got the staff – policy or no policy!”

“These patient dependency things, they’re a waste of time, and they can work against you – they’re just a piece of paper – I don’t use them, I just tell management what we need, and that’s it!”

Nurses described the reality of their situation. Patient dependency tools were not considered useful, and failed to capture the labour intensive nature of caring for dying babies. Currently, reliable tools did not exist at the sites participating in this research, and so it was the responsibility of the shift coordinator to lobby their case on a shift by shift basis. It was suggested that having patient dependency tools could lobby management to supply staff, determine staffing levels, and indicate the acuity level of marginally viable and critically ill newborns:

“You need to see the value of some sort of system, a patient dependency tool for example. Because with policy and maintaining staffing needs, if you can’t provide adequate nursing care numbers then you’re actually going against hospital policy, aren’t you.”

This nurse described how having a patient dependency tool to support patient care assignments were useful in terms of holding organisations accountable. When staffing was considered inadequate for providing care to marginally viable and critically ill newborns, yet patient dependency tools supported clinical decisions for staffing, then the hospital was ‘going against policy’. Generally, current dependency tools were deemed to be ‘useless’ and inaccurate, and the literature concurs that contemporary tools are problematic in critical care areas, particularly in the NICU. Many ‘traditional’ patient dependency tools were not originally developed for the objectives of workforce planning. Therefore, their usefulness in determining the
nurse: patient ratio required in critical care settings highlights a number of concerns for the organisation (Adomat & Hewison, 2004).

Organisations may not recognise the labour intensive aspects of providing care to marginally viable and critically ill newborns. When one considers the busy caseload in the NICU, it allows little time for nurses to come to terms with what has happened when a newborn in their care dies. This frenetic environment doesn’t allow time for the nurse to process these emotions before they are expected to provide challenging and potentially life saving care to another infant (Farrell et al., 2000). The NiPCAS finding demonstrated that following the death of a baby, neonatal nurses reported that they had sufficient time to spend with the family (M=3.2). This finding was discussed with focus group participants:

“I think probably Unit management staff recognize how time consuming caring for these babies is, but hospital management overall? Probably not. When the baby actually dies, they think you should be free straight away to set up for the next patient, but in reality, it isn’t like that. Sometimes your work just begins when the baby actually dies.”

In this narrative, the nurse describes how hospital management may perceive the work of the nurse ending when the baby dies, but in reality this is not the case, and the family needs to stay with the infant as long as they wish after death occurs and to continue to be supported by nursing staff.

6.3.3 The judicious use of technology

The NiPCAS identified that 62.2% (M=3.2) of respondents believed they went beyond what they felt comfortable with in using technological life support. Clearly, the fundamental nature of the fast-paced and highly technical environment of the NICU is one that poses constant challenges to the neonatal nurse. These challenges are frequently ethically derived, challenging the individual’s values and moral position, particularly concerning delivery of care to newborns with a poor prognosis and for whom survival is unlikely. Often the foundation of care delivery revolves around the use of technology. Due to its widespread availability in the western world, there may be a temptation to use it even when it may prolong the life of baby who will not survive. Furthermore, when palliative care is introduced, there may be
a temptation to continue to use technological life support because there are no clinical guidelines to mandate its judicious use. In the focus group interviews, neonatal nurses described what they perceived to be the inappropriate use of technological life support:

“We had three newborns die last year, and their lives were shockingly unpleasant due to treatment, drugs, machines, and it’s hard to daily look after a baby who is very ill, knowing that this baby is not going to go home, and you wonder if the parents have false hope because of what the doctors have said to them, so they think all of this mechanical support is necessary.”

This nurse was able to recall very specific information about each newborn described in this narrative. Furthermore, there was the suggestion that the parents had ‘false hope’ because they were not informed about the possible prognosis for their child, and were lead to believe that ‘all of the mechanical support was necessary’. This nurse revealed their unresolved ethical dilemmas when providing care to these newborns, and these unresolved dilemmas may be linked to the experience of moral distress. One participant described engaging in futile procedures as an act of ‘torture’:

“Well the doctors come around a couple of times a shift, and you can see that the baby is deteriorating, so you say to them that you think its time for that baby to come out for a cuddle, although that may not be the baby’s last gasp, you just perform more torture by doing unnecessary procedures, and that sends the wrong message to parents”

The participant describes bringing the baby out ‘for the last cuddle’, indicating that curative treatment is being withdrawn, whilst performing needless acts and performing ‘more torture’. That this sends the ‘wrong message to parents’ further suggests that decision making has been entered into with parents, yet there is lack of a consistent approach, and that the use of technology may not be judicious.

Literature findings strongly suggest that the advent of improved technology in the NICU has had a profound affect on neonatal intensive care nursing practice, and also may contribute to moral distress when inappropriately used. Technology has fostered an attitude that even the smallest, sickest newborns can be saved (Raines, 1994b) and when a newborn dies in the curative social system of the NICU, it is
often seen as a failure of medical science (Lo et al., 1999). One of the participants interviewed suggested that technology was often used just because it was there:

“If another ventilator is sitting there, or the oscillator, or whatever, it’s just so tempting for the doctors to say well let’s just try another machine just because it is there, just in case ... it’s annoying, frustrating, but you need to follow orders, I guess.”

The nurse describes a sense of powerlessness that technology is not used judiciously, suggesting that a machine is used ‘simply because it is there’. However, the nurse engages in this inappropriate use of technology because they perceive themselves as ‘needing to follow orders’. This discussion indicates that the concept of moral distress may play a significant role in the complex issues of providing technological life support to marginally viable and critically ill newborns. In summary, it is not technology that is a barrier to palliative care, but the lack of policy to delineate its judicious use when aggressive, curative care becomes inappropriate.

6.3.4 The demands of parents

In the NiPCAS, 75.7% (M=3.2) of respondents reported that they were asked by parents to continue life-extending care beyond what they felt was right. This ethical dilemma was identified as a potential barriers to a palliative model of care. The literature suggests that there is often anger and turmoil associated with end-of-life decision-making as parents cannot blame their baby and their anger is often displaced onto staff (Jellinek et al., 1992). This NiPCAS finding was discussed with the focus group participants in terms of how this barrier might be addressed:

“We’ve had several cases where parents don’t want to withdraw curative care, and what do you do then? You could shake the parents sometimes, this may seem harsh, but it’s awful to care for these babies.”

The nurse describes frustration when caring for babies for whom continuing life support was considered futile, but parents did not wish to cease curative care. The nurse describes caring for these babies as ‘awful’ and that they wanted to ‘shake’ the parents. Clearly, policy needs to be developed that supports a plan for conflict mediation when nurses are engaged in caring for babies for whose treatment they are ethically opposed. However, the healthcare team in general have no rights or
authority to substitute their own decision for that of the parents (Cranley-Grass, 2002). This narrative from the current research emphasises this point:

“To illustrate doctors doing their own thing, we had a case and the grandparents came in the next day to say goodbye to the baby, because the consultant the previous day had decided that treatment should be withdrawn, but another consultant was on duty and had changed the plan, and didn’t withdraw treatment, because of his own beliefs. I just could not believe what he was saying, and the parents and grandparents were so confused and said ‘but you said that you were going to turn the machine off, and we’ve come to say goodbye’. In this instance the family knew what they wanted, but the medical decision went against these wishes.”

In this narrative, treatment consensus had been decided, but due to a lack of policy to support the process of changing to a palliative model of care, the plan of treatment was altered due to a change of medical staff. Parental expectations regarding the long term outcomes of marginally viable and critically ill newborns may be idealistically high, and so might be the expectations placed upon neonatologists and neonatal nurses. Adding to these expectations are the influences of the media reporting upon the successes of neonatal medicine whilst seldom publicizing its limits (Carter & Stahlman, 2001). There is a societal view that newborns are not supposed to die (Romesberg, 2004). A child’s death is an atypical event that is viewed by society in general as unnatural (Contro et al., 2004). How these beliefs influence parents was discussed with the focus group participants with reference to a television series, ‘Saving Babies’ (Quail, 2007), being aired on an Australian commercial network station:

“Have you seen that ‘Saving Babies’ show? Did you notice how nobody ever dies? I mean, they never die! What message does that send out to parents? There is a focus in the media about miracle babies that reinforces the notion that babies just don’t die. Maybe I’m getting a bit intense about it, but parents will say ‘I know my baby can be saved, because they saved that one on the TV!’”

Here, the nurse describes the untenable position clinical staff may face due to the influence of the media. The nurse expresses concern about the message sent to parents and society when the media reinforces the notion that ‘babies don’t die’. The impact of the media upon parental expectations is also apparent in popular women’s magazines. The participants in the current research discussed their concerns at how
the media cherry picked cases of so-called ‘miracle babies’, conveying the notion to parents that all newborns can be saved:

“I think parents are coming around to talking about death and dying. But as to whether they take the reality of their baby’s situation on board is another matter. Parents might be thinking: ‘well I read in ‘That’s Life’ that this same thing happened to these parents, and their baby survived’.”

“I think society tells us these days that everything baby can be healed. Parents don’t read in ‘Women’s Weekly’ about babies who die, only about the miracle babies that survive.”

Participants discussed the impact that the media have upon parents and families in the NICU. There is discussion that ‘although parents are coming around’ to talking about death and dying, their expectations can be swayed by media reports, such as those described here. Nurses describe instances where popular magazines sensationalise babies who have survived, often at very low gestations. There are also concerns expressed about the disturbing precedence this sets, and the expectation that every baby, regardless of their gestation or prognosis, will survive.

For these nurses, engaging in palliative care in a supportive environment would have addressed undue suffering of the newborn, and alleviated the moral distress implicit to caring for these babies. However, the relationships of providing care to marginally viable and critically ill newborns and the nurses’ experiences of moral distress are unclear and require further exploration. This discussion also begs the question: is a disservice done to parents and families of marginally viable and critically ill newborns due to the influence of the media.

6.3.5 Summary

The subscales identified by the analysis of the population survey data identified the barriers and facilitators to palliative care practice. A series of focus group interviews with experienced neonatal nurses provided a conduit of discussion and further analysis to deepen the understanding of these findings. By engaging in this discussion, the facilitators identified by the survey findings were explored, and it was found that caveats were implicit to each of these facilitators. For example, the healthcare team agree with and support a palliative model of care when it is
implemented, but often only if a level of agreement via consensus is reached in the first instance. These caveats challenge the neonatal nurses’ potential to engage in palliative care practice, yet suggest a way forward in terms of informing policy makers in assimilating this model of care into routine practice.

The barriers identified by the population survey findings were also further clarified by engaging in discussion with groups of neonatal nurses. These barriers present substantial obstacles to implementing a palliative model of care. In the following chapter, the sum of the findings from both phases of this research will combine to provide a discussion of the facilitators and barriers to palliative care practice, in context to the theoretical framework used to inform this research.
CHAPTER 7 - Discussion

7.1 Introduction

This research has surveyed 1285 neonatal nurses practising in Australian NICUs with a response rate of 50%. Most of this population were aged 40 years or more (60%) and had considerable experience in the NICU (66% with greater than 10 years experience). Not only were the neonatal nurses who responded to the NiPCAS mostly experienced, they were also mostly qualified in the subspeciality with 75% either having qualifications in neonatal intensive care nursing or working towards them, and 41% having a postgraduate qualification. Analysis of the data provided by this sample identified 3 subscales that indicated the facilitators and barriers to palliative care practice. The interpretive phase of this research contextualised these facilitators and barriers to palliative care practice, and the sum of these findings generate new knowledge about neonatal palliative care that can be translated into evidence based policy to enhance this model of care.

The purpose of conducting this study was to answer two research questions: what are the barriers and facilitators to palliative care practice, and; how can policy be developed to qualify the facilitators and address the barriers. There were no validated instruments available to measure these issues, and so the process of developing such an instrument was central to the goals of this study. Another primary goal was that the findings from the population study could be translated into policy that had clinical resonance and practical applications. This chapter, therefore, will be organised primarily around the integrated findings from this research and will centre around two key areas: a discussion of the facilitators and the barriers to palliative care practice, and locating these findings within the theoretical framework used to inform this research.

7.2 The facilitators to palliative care practice

The findings from this research highlight the facilitators to palliative care practice in neonatal nursing. However, for each of the facilitators identified, caveats were
implicit, and may prevent these facilitators translating into clinical practice. A facilitator, by definition, can assist in bringing about an outcome by providing indirect or unobtrusive assistance, guidance, or supervision. However, these facilitators could be essentially conceptual.

Therefore, the purpose of the second phase of this research was to gather the clinical intelligence of experienced neonatal nurses to add context and clarity to these findings. This was necessary to identify how policy development could qualify these facilitators. The findings from both phases of this research were considered equally when interpreting these facilitators, and therefore the sum of the findings from both phases of this research will be discussed in this section. Given this sum of the findings, there are five facilitators identified by this research, which can be described as:

- Support for a neonatal palliative model of care by the healthcare team;
- A healthcare team that can express values, opinions and beliefs;
- The availability of counselling support for caregivers;
- The presence of at least some clinical guidelines to support practice, and;
- The support of parents by the healthcare team.

These facilitators are indicated by the following findings from the population study, and were identified in the subscales ‘organisation’ and ‘resources’, but not in ‘clinician’. In the ‘organisation’ subscale, neonatal nurses indicate that members of the healthcare team agree with and support palliative care when it is implemented for a dying baby (M=3.2), and that they practice in a social system where the team can express values, opinions and beliefs when providing this type of care (M=3.1). There is also a strong level of agreement (M=3.6) that parents are involved in decision-making if their baby is dying, and are informed of palliative care options (M=3.4). The ‘resources’ facilitators identified by this research indicate that counselling is available if needed when a newborn dies in their Unit (M=3.2); that they have time to spend with families (M=3.2), and; that there are guidelines available to support palliative care practice (M=3.1). However, as discussed, the
interpretive phase of this research suggests that each of these facilitators are subject to caveats. This means that for each of the facilitators identified, a way forward needs to be identified in terms of further facilitating and supporting these processes. This argument will form the basis for the following discussion points.

7.2.1 Reaching team agreement for palliative care

The survey findings indicate that although there is a level of agreement that the healthcare team supports palliative care practice, the interpretive phase of this research suggested that this level of support could be better facilitated by introducing consensus meetings prior to patient care conferences. Reaching agreement about the direction of care within the healthcare team is advocated in Catlin & Carter’s (2002) palliative care protocol. Though not referring specifically to mediated consensus, this protocol supports that agreement on a plan of care is essential.

This research has found that failing to reach team agreement through consensus may result in conflict. These findings give empirical support to the conclusion of a discussion paper by Paris et al (2000). In this paper describing a case study of marginally viable twins, Paris argued that conflicting values and opinions within the healthcare team often impinge upon decision making processes, and are a primary source of interpersonal conflict. The findings from other research also support the consensus view, with McHaffie & Fowlie (1998) suggesting that practices such as attempting a consensus view may minimize tension and conflict amongst caregivers and family members.

The current research emphasized that consensus meetings may also assist in fostering team agreement regarding options, and clarifying the plan of care. Clearly, continuity of care is integral to the success of a palliative model of care once this plan of action is embarked upon. Treatment directions cannot be altered on a shift by shift basis. Catlin & Carter (2002) have stated that to ensure continuity of information, the healthcare team need to decide who should attend these consensus meetings, determining who best represents the needs of the family—neonatologists, surgeons, a neurologist, a cardiologist, and nursing staff.
Whilst arguing the case for withdrawing aggressive management when an infant is dying, Wyatt (1999) stated that the decision to withdraw treatment should only be taken with the consensus of experienced clinical staff caring for the baby and the informed agreement of parents. Furthermore, although the current research identifies the benefits of attempting to reach consensus to facilitate team agreement for palliative care, it is acknowledged that there will always be occasions when there is no time to reach consensus due to the rapidly deteriorating status of a newborn, an issue highlighted by McHaffie & Fowlie (1998). However, the consensus approach may be efficacious in some cases, facilitating the mitigation of conflict that can arise between the healthcare team and families, or within the healthcare team itself when palliative care is considered.

7.2.2 Neonatal nurses and ethical decision making

This research has identified support for palliative care within a social system where individuals can express values, opinions and beliefs (69.3% M=3.1). However, the lack of both a nursing role in ethical decision making and effective advocacy skills were highlighted as an inhibitory caveat to these facilitators. In other research, neonatal nurses have reported powerlessness in their decision making role and confusion about their role as patient and family advocates. This is a pertinent issue, as surrogate decision-making is more necessary in the neonatal context than in other contexts of nursing care. Primarily this is due to the rather obvious fact that newborns do not have a means of representing themselves or expressing an opinion (Sheeran Brophy, 2001; Spence, 2000). Furthermore, neonatal nurses add significant value to the ethical decision making process on behalf of dying babies. The significance of the nursing role in decision making was identified by Engler et al (2004), who conducted a quantitative study using an instrument (a 55-item instrument, the Bereavement/End-of-Life Attitudes About Care: Neonatal Nurses Scale (BEACONNS) based upon parental needs for compassionate care when their baby had died. Firstly, nurses were found to often identify more personally with babies and parents than do other NICU professionals, and their perspectives can be especially valuable to the decision making process. Secondly, neonatal nurses have an unparalleled opportunity to build a relationship based upon trust, and this relationship is essential to provide optimal care for patients’ families and staff alike.
Engler’s findings resonated with the current research, identifying that although neonatal nurses express the desire to participate in decision making, there were issues identified that did not facilitate this process. There were several reasons identified for this, including a lack of ethical competence and uncertainty over the nursing advocacy role.

When discussing the ethical competence of nurses, Clark & Taxis (2003) indicated that neonatologists often failed to acknowledge the role of nurses in ethical decision-making and have stated that nurses are not educated adequately in ethics and therefore lack the ethical competence to allow them to participate in decision-making. This finding was corroborated by Dogan & Sahinoglu (2005) when investigating ethical approaches to caring for fetuses with neural tube defects. The findings from the current research support this, in that neonatal nurses are not seen as integral to the decision making process: if they happen to be available when such a meeting is conducted, they might attend. Yet, this research has also identified that when they do attend, some have little idea why they are there.

This research supports the findings from Raines (1996; Raines, 1994a), who suggests that becoming ethically competent to participate in decision making in a meaningful way involves much more than being aware of one’s code of ethics. Ethical competence involves an appreciation of the personal factors that comprise one’s ethical decision-making capacity, including morals, biases, religious and cultural values. Therefore, to engage in decision making processes effectively, the neonatal nurse needs to be able to differentiate their own personal values and judgments. However, to have this objectivity requires a considerable degree of ethical competence, and to remain objective, they must be able to separate their personal values from the perceived moral issues. The requirement of ethical competence extends into the nurses’ ability to assess the ethics of the clinical care for any given case. Nurses need to be able to evaluate the provision of family-centered patient care from an ethical perspective.

The findings from the current research indicate that some neonatal nurses may be confused about the fundamentals of ethics, and cannot expect to be instrumental in
the decision-making process if all they bring to the decision-making table is their own values and beliefs. Though it is true that values identification is an important step towards developing ethical competence, in an opinion paper, Turner (2003) argues that understanding the differences within the organisation and recognizing the relationship between behaviours and values provides a more reliable basis for education in ethical principles and moral reasoning. Furthermore, unbiased, more reasoned and less emotional ethical decision-making requires facts about the attendant risks and benefits of a clinical intervention. The findings from this research suggest that the nursing role in decision-making may be mitigated by the nurses’ own biases and emotionally based judgment.

A broader concept of the nursing advocacy role is necessary, a finding from this research supported by Mayberry (1986). Mayberry depicts the NICU as representing a complex advocacy role for nurses, because it represents an environment where patients are unable to decide or speak for themselves. Research findings by Monterosso (2005) expands this view, stating that parents are often interpreted as the advocates for their babies but suggests that this may be an unrealistic expectation as parents are limited by their knowledge in the area of neonatology. The findings from the current research support this finding, in that neonatal nurses may need to adopt a greater advocacy role than in other nursing disciplines.

In summary, this research identifies that the neonatal nurse may have a negligible role in decision making on behalf of marginally viable and critically ill newborns. The lack of this component of the nursing role may have extensive ramifications leading to diminishment of the nurses’ ability to be an effective advocate, and contribute to the silencing of the nursing voice and moral distress. Nurses in this research have indicated that they see a role in the decision making process, yet they may not fully engage in this task. Thus, although this research indicates that there is support for palliative care in the clinical environment, and that clinical staff feel able to express values and opinions about treatment options, these facilitators to palliative care practice are conditional on the presence of processes to engage nurses in the decision making role. Therefore, although neonatal nurses feel they can express values and opinions,
subjugation of the nursing voice in decision making processes means these values and opinions are not necessarily heard.

### 7.2.3 Supporting parents

This research brings into focus the way the NICU informs and supports parents in decision making on behalf of their child. The NiPCAS demonstrated a strong level of agreement (92% M=3.6) that parents are involved in decision-making if their baby is dying, and are informed of palliative care options (77.3% M=3.4). However, despite the strength of these findings, it is suggested that parental involvement could be further facilitated by providing written information, improving communication and fostering a consistent approach to palliative care. The findings from both phases of this research combine to indicate that although parents are informed of palliative care options, they may not receive enough information to make an informed decision. This notion is well described in the literature (Carter & Leuthner, 2003) whereby some healthcare professionals perceive parents as unable to effectively participate in decision-making processes regarding their child. These misconceptions are made on the grounds that parents are incapacitated due to feelings of guilt, an inability to make decisions because of a deficient comprehension of medical information, and a tendency to make decisions that are not in the best interest of the child (Martinez et al., 2005). These findings were supported by the current research, whereby some neonatal nurses interviewed in the interpretive phase described parents as unable to understand death, and a pragmatic and honest approach was considered futile.

Authors such as Carter & Leuthner (2003) suggest that parents are too emotionally involved to act as surrogate decision makers are ill-founded. It is agreed that the parenting role is complicated in the NICU, and there are long-held myths concerning the capabilities of parents and these need to be rejected. In the absence of parents being mentally incapacitated, acting with obvious harmful intent toward the infant, or simply being absent or uninvolved, all parents should be able to participate in decision-making processes that are in the best interests of their infants. In this research, neonatal nurses emphasize the need for a consistent approach when consensus has been reached, and treatment decisions made. This research has
demonstrated the difficult position they occupy when orders are not followed through due to a lack of documentation, or are poorly communicated to staff and families. Once a collaborative decision is made between the healthcare team and parents, that no further resuscitation efforts will occur needs to be made implicit to parents. When a shift change occurs for nurses or attending physicians the plan should not be altered (Catlin & Carter, 2002). Policies such as those suggested by Catlin & Carter (2002) to support consistency in palliative care need to specify the precepts of what palliative care constitutes, and the binding nature of treatment plans once they are made in consultation with parents.

Although this research found parents are involved in decision making, consistency of information may require facilitation, and parents need to receive the same information from each member of the health care team. Neonatal nurses in the interpretive phase of this research identified that written information for parents, as an adjunct to oral communication, would be of value in terms of reinforcing the goals of palliative management and giving parents the information necessary to make informed decisions. Parents often experience difficulty deciding whether decisions to continue or discontinue treatment are made in the best interests of the infant or in the best interests of other members of the family. Due to their unfamiliarity with the implications of decisions, parents may require assistance determining how to apply their own value system to the decisions they are being asked to make. In addition, they may require some reprieve from the burden or liability of feeling they have the sole responsibility for decisions. It is for this reason that a team approach to decision-making is the process most likely to fulfil the requirements of informed consent for infants (National Association of Neonatal Nurses, 1999). Handley (2003) argues that ensuring parents are given enough information to make informed decisions is imperative, and provides guidelines about the concept of informed consent: When making decisions about treatment choices for their infant, parents need act through informed consent; when making informed consent, parents have to be given time to assimilate the information given and understand the ramifications of their decisions; when making decisions about treatment, shared decision-making is essential, and neonatologists and parents in collaboration are the primary decision makers (Handley, 2003; Miya et al., 1991). The current research identifies that
although parents are informed of palliative care options, and this is identified as a facilitator, this may be conditional on a consistent approach to palliative care when it is introduced by the healthcare team.

The current research can add to the literature in the area, and supports the need to support the parental role in decision making. Whilst 645 Australian neonatal nurses mostly agree that parents are involved in decision making, they may also question the parents’ ability to make ethically sound decisions on behalf of their newborn. It can be argued that any pretences that serve to detract from the parental role in decision making need to be both explicated and discredited. This is because, in most circumstances, parents are most likely to make decisions on their newborn’s behalf that have legal significance. Furthermore, no one more than parents are more familiar with the needs of their baby’s interests, or are as likely to cherish them. Support in this context could be achieved by the sharing of ideas that deal with the infant’s interests both in the current context, and in the future, as well as quality of life issues and adequate attention to infant pain and suffering.

In summary, this research indicates that the parents of marginally viable and critically ill newborns in Australian NICUs are involved in decision making and are aware of palliative care as a treatment option. These findings can be identified as facilitators to palliative care practice. However, the extent of the parental role, and education about palliative care is conditional upon the policies available to support it, and may differ widely from Unit to Unit.

7.2.4 Supporting caregivers

The work of providing palliative care for newborns and their families is emotionally intense (American Academy of Pediatrics, 2000; Catlin & Carter, 2002; Stutts & Schloemann, 2002a, 2002b), and 73.2% (M=3.2) of NiPCAS respondents reported that counselling was available if needed when a newborn died in their Unit. Although this is identified as a facilitator, such counselling support is likely to be peer-to-peer, or take the form of ad hoc debriefing sessions. The availability of expert counselling for staff may not be made explicitly clear to nursing staff by the organisation. Furthermore, neonatal nurses have expressed reluctance to utilise
professional counselling to avoid being seen as not coping with their work. Professional counselling appeared to be stigmatised, and uptake of these services was poor. However, given these findings, much can be done to in terms of supporting neonatal nurses in this area of emotional work. Emotional work can be defined as an ingredient in any kind of occupation where the ‘object’ being cared for, or worked upon, is alive, sentient or reacting (Strauss, Fagerhaugh, Suczek, & Weiner, 1982), or as any labour involved in dealing with another person’s emotions (James, 1989). Emotional work is a component of all nursing genres to a degree, because nursing involves emotional work impacting upon the nurses’ emotional wellbeing, and emotional wellbeing is integrally correlated to professional practice (Rose, 2006).

Although debriefing did occur at the sites where the focus group interviews were conducted, these sessions were often difficult to access by those staff members most affected. Clinical staff were expected to attend in their own time if the sessions were conducted during off-duty time. There were no policies in place to delineate when debriefing should occur, and under what circumstances, rendering the process impromptu and, at times, inefficacious. Formal debriefing following critical incidences and difficult cases may facilitate this aspect of providing care to dying babies, although the literature is divided on this topic, and there is little reliable empirical evidence to indicate its beneficial effect (Gist et al., 1997). Although there is literature to support the debriefing approach following a critical incident (Antai-Otong, 2001; Brackenreg, 2007; Everly, 1995; Mitchell & Everly, 1997), there is also literature that reports that this approach derives no greater benefit for participants than more traditional venues of discussion and social support (Alexander & Wells, 1991; Gist, Lubin, & Redburn, 1998; Hytten & Hasle, 1989). Furthermore, there is also a body of literature reporting that formal debriefing following a critical incident may actually have deleterious effects upon those attending (Bisson et al., 1997; Hobbs et al., 1996). These findings would support that when debriefing is offered following a critical incident, it is offered by individuals with training in these processes.

The findings from both phases of this research combine to suggest that emotional support for neonatal nurses is largely peer to peer, which may be appropriate and all
that is needed. However, caring for marginally viable and critically ill newborns constitutes emotional work, and the needs of caregivers may be largely unmet by the organisations employing them. The findings from this research suggest that opportunities for debrief sessions after difficult cases are ad hoc, and training to engender nurses with effective conflict management skills and coping mechanisms are under-utilised. Neonatal nurses in this research describe engaging in and learning coping skills as a fundamental skill, and one which only develops through experience or by simply not acknowledging their work related stress and grief. Regular and ongoing staff training could be facilitated by appropriately trained staff and/or corporations to allow nurses opportunities to enhance their conflict resolution skills and develop effective coping mechanisms. This would further facilitate this aspect of the neonatal nursing role in caring for marginally viable and critically ill newborns.

In summary, this research has found that although Australian neonatal nurses report they receive counselling support when caring for marginally viable and critically ill newborns, this support may be mostly collegial, ad hoc or fail to assist nurses in developing efficient coping skills. Clearly, this type of nursing practice needs to be recognised by organisations as emotional work. Emotional work may result in disenfranchised grief (Doka, 1989), and caregiver suffering. Neonatal nurses in this research suggest that experiencing grief and distress when caring for these types of babies may be interpreted as a weakness. Given this, neonatal nurses express reluctance in availing themselves of counselling opportunities when they are available. Nurses suggest that developing their own coping skills, whilst acknowledging their grief and sadness may assuage many of the dilemmas they experience in caring for these babies, including conflict with parents and colleagues when differing opinions manifest. In terms of formal debriefing sessions, although they do occur in the practice environment, are described by neonatal nurses as ad hoc, poorly facilitated and inadequate in meeting their needs.

7.2.5 Facilitating evidence based clinical guidelines

In the NiPCAS, 60.1% (M=3.1) of respondents reported at least some level of agreement that there were guidelines in place to support palliative care practice, the
quality and nature of which was explored with groups of neonatal nurses. In the interpretive phase of this research, there was the suggestion that guidelines in use in the clinical area may not be evidence based, may be out of date or fail to address the needs of families and caregivers. It is argued in the literature that the lack of evidence based guidelines is a prohibitive factor to this model of care (Ross, 1992), and it is reported that no national professional organisations have standards for neonatal palliative care (Stringer et al., 2004).

It is the criteria that guidelines are evidence based that is crucial to the support of palliative care practice, and the current research suggests that evidence based palliative care guidelines may be under-utilised in Australian NICUs. Furthermore, although evidence based protocols exist, there may be a general lack of awareness of their existence. Yet, these protocols have potential value for Australian NICUs and can be modified, if necessary, to cater to the needs of Australian Units. These protocols and guidelines include those of Catlin & Carter (2002), and Gales & Brooks (2006), as well as Australian standards for palliative care (Palliative Care Australia, 2005) which are widely referred to throughout this research. Thus, evidence based guidelines and standards already exist, and can be incorporated into clinical guidelines in Australian NICUs.

In summary, the guidelines in use to support palliative care practice in the current environment may not be evidence based, and may fail to meet the needs of caregivers and parents. Evidence based protocols are available for clinical use, and could be adapted for use within Australian Units to support this practice. Adapting existing guidelines is preferable to a situation whereby improvised and insufficient guidelines are available on a Unit by Unit basis. The absence of relevant, evidence based clinical guidelines may result in an inconsistent approach to palliative care, and produce a lack of understanding of what the palliative approach actually encompasses.
7.3 The barriers to palliative care practice

This research has identified three salient barriers to palliative care practice in Australian neonatal nursing. These barriers were identified primarily from the findings from the population survey on the ‘resources’ and ‘clinician’ subscale, however, barriers were not indicated by the ‘organisation’ subscale. The findings from the interpretive phase of this research were considered equally when interpreting these barriers, which can be identified as:

- Inadequate staffing to support palliative care practice;
- A physical environment that is not conducive to palliative care practice, and;
- Technological imperatives and parental demands.

7.3.1 Promoting optimal staffing

Only 56.7% (M=2.5) of the neonatal nurses surveyed for this research reported staffing as adequate to support a palliative model of care. However, it is also acknowledged that Unit management recognised the labour intensiveness of caring for dying babies, with 70.4% (M=3.2) of respondents indicating that they had enough time to spend with the families of dying babies. Given this finding, in the interpretive phase of this research, neonatal nurses were asked for their opinion on this, and suggested that to meet this need, staffing resources were often stretched to the limit when a baby was dying.

Neonatal nurses also discussed their desire to use the most experienced staff to care for dying babies and provide excellence in palliative care, yet a lack of staff meant that this continuity of patient care assignments were not possible. Intensive care services provision is labour intensive and nursing personnel costs are estimated to account for three-quarters of total expenditure. Not unexpectedly, therefore, health systems are probing new ways to contain this expense while ensuring quality and managing risk (Gerdtz & Nelson, 2007). This may explain why justifying the expense of senior staff to manage palliative care patients is such a challenge.
Although a lack of adequate staffing is a reality in many NICUs, this research suggested that standardised and effective patient dependency models generally do not exist in Australian neonatal nursing practice. In the interpretive phase of this research, neonatal nurses described how their requests for adequate staffing to meet the needs of dying babies were generally acknowledged by the organisation, but this only occurred if the senior nurse lobbied for it: there were no formal processes to support this request. The introduction of an effective patient-dependency model may be an option, but neonatal nurses in the current research either had little faith in such a system, or had been exposed to the ineffectiveness of such systems in the past. Most nursing staff deployment and patient-dependency models centre on single issues such as nurse/patient ratio and nursing hour calculations. Such measures primarily address economic requirements, and are thus intrinsically limited in their capacity to differentiate the nursing mix by using solely numeric endpoints. These dependency tools have a restricted range because they come with the inherent postulation that ‘a nurse is a nurse’ (Rischbieth, 2006). Despite the difficulties in creating a patient dependency tool, according to Vail (1989) the elements of such a tool could be developed. Therefore, although the literature demonstrates that developing a dependency tool in the NICU is problematic on several levels, attention needs to be given to developing such a tool in conjunction with neonatal nurses that accurately captures the labour intensive aspect of caring for marginally viable and critically ill newborns. This would support nurses in justifying staffing decisions based upon the acuity of these newborns.

In summary, this research demonstrates that Australian neonatal nurses generally report that they are not adequately staffed to provide a palliative model of care, and meeting this need is dependent upon the lobbying ability of senior staff. This finding supports an Australian study by Spence (2006), demonstrating that organizational factors in the neonatal unit may have a more powerful influence on nursing workload than the acuity of the patients themselves that are assigned to individual nurses. In the current research, neonatal nurses also report that there are a lack of patient dependency tools that reflect the acuity of babies with these special needs, and that such a tool is not available for clinical integration that is deemed reliable or efficient.
7.3.2 Creating the optimal physical environment

The lack of an optimal environment in which to provide a palliative model of care was a salient barrier identified by this research. Rogers (1995) Diffusion theory suggests that the adoption of practice change is largely dependent upon the existing infrastructure and resources that can support it (Cain & Mittman, 2002). To begin with, 56.7% (N=2.67) of NiPCAS respondents reported that the physical environment of their Unit was not conducive to providing palliative care to dying babies. This finding was proportionate to the literature (Conway & Moloney-Harmon, 2004; Wyatt, 1999; Yam et al., 2001). In the focus group interviews, experienced neonatal nurses further contextualized this NiPCAS finding to support the conclusion (Conway & Moloney-Harmon, 2004; Gale & Brooks, 2006) that the chaos of a busy, open, and un-private NICU is not the place for palliative care to take place. Catlin and Carter (2002) advocate that environmental support should provide for as much of a normal and nurturing environment as possible. This includes noise being kept to a minimum with telephones and pagers turned low and staff conversations kept to a minimum (Catlin & Carter, 2002). However, the optimum space should be decided by the parents, and this research supports that parents need to make this choice for themselves. Nurses in this research describe parents feeling abandoned when vacating the NICU for a quiet place for the baby to die. Often by the stage curative treatment is withdrawn, parents have formed relationships with staff, and the NICU has become an environment in which they feel comfortable and familiar with. Given this, this research supports that infrastructure within the NICU needs to be improved with the introduction of appropriate furnishings such as recliner chairs. The findings from this research also highlights the importance of clinical staff being sensitive to the needs of the family if curative care is withdrawn in the NICU environment. Neonatal nurses in this research have described the general noise, bright lights and human traffic that does not relent even when a baby is in its dying stages.

This research supports the findings of Yam’s (2001) research, whereby neonatal nurses also reported that whilst they embraced palliative care in their nursing practice, they were hindered in providing it due to the lack of resources in their
organisation (Yam et al., 2001). In Yam’s research it was reported that the bureaucratic rules of the organisation made the experience for the family of the dying newborn ‘dehumanising’. In part, this was due to the lack of an appropriate area – or even a ‘multipurpose room’ – so that palliative care could be administered. The current research has also identified this lack of a dedicated room for palliative care purposes as a barrier. Even when such a room was available, it was not deemed suitable for palliative care due to the lack of an inviting atmosphere and family-friendly space. Identifying the optimal environment needs to be discussed with the family along with the available services to support them (Gale & Brooks, 2006).

In summary, this research clearly indicates that the physical environment to support a palliative model of care is substandard. This finding extends to the lack of basic infrastructure within the NICU itself (such as lack of appropriate furnishings and overcrowded conditions) and the lack of a dedicated area from which palliative care can be provided in comfort and privacy. Furthermore, this research highlights the importance that it is parents who decide where palliative care is best provided, and once this decision is made, that infrastructure is available to support this.

7.3.3 Technological imperatives and the demands of parents

Technological imperatives and the demands of parents were identified in the third subscale defined by the NiPCAS. The recognition of the issues identified by this research may lead to moral distress, a phenomenon frequently discussed in nursing literature (Corley, 1995; Elpern, Covert, & Kleinpell, 2005; Erlen, 2001; Gutierrez, 2005; Hefferman & Heilig, 1999; Kain, 2007a; Raines, 1994a; Rodney, 1988; Sundin-Huard & Fahy, 1999; Tiedje, 2000; Wilkinson, 1988, 1989; Yam et al., 2001). However, the actual impact of technological imperatives, and whether this results in ethical and moral concerns for the neonatal nurse has not been studied before. This research has demonstrated that the technological imperatives used in contemporary neonatal care raise salient moral and ethical concerns for the neonatal nurse.

This subscale, representing the ethical concerns of neonatal nurses, was simplified to the construct ‘clinician’, and identified two prevalent issues that present considerable
barriers to successful palliative care for newborns. To begin with, this section will discuss the impact of technological imperatives and what this research has added to this context of neonatal nursing care delivery. Specifically, these issues relate to the impact of technological life support in the NICU, and its judicious use.

A common cause of moral distress for nurses is following orders that support newborns with often painful technological interventions at the end of their lives, when a palliative approach would be a more humane option. In the literature, nurses have reported the perception of harming babies or contributing to their suffering when they could be providing comfort care (Hefferman & Heilig, 1999). The findings of Hefferman & Helig’s (1999) survey research was strengthened by the findings in the current research that 62.2% (M=3.2) of the 645 Australian neonatal nurses interviewed agreed that they often went beyond what they felt comfortable with when providing technological life support to newborns who were dying.

With reference to the literature, neonatal nurses may struggle with the transition from curative to palliative care in a technically driven area such as the NICU (Prior & Poulton, 1996). Perhaps technology itself is to blame, because it is this technology that has been fundamentally responsible for the exponential growth in the NICU (Raines, 1994b). The findings of the current research supports the suggestion that healthcare has used it’s impressive arsenal of life-saving equipment to preserve life, but minimal attention is given to whether it should. There is strong evidence provided by the NiPCAS findings that supports literature the suggests healthcare professionals effectively feel ‘held hostage’ by technological imperatives in the NICU (Hefferman & Heilig, 1999), resulting in the potential to prolong suffering of the newborn that may be considerable (Sklansky, 2001). This finding fosters the growing debate that continuing aggressive, futile treatment may be inappropriate, or even inhumane (Pierucci et al., 2001).

This research has described how neonatal nurses report a sense of powerlessness when technology is not used judiciously. In the interpretive phase of this research some neonatal nurses have described how they engage in this practice because they perceive themselves as ‘needing to follow orders’, and using technology just because
it was there. This extended to babies supposedly receiving palliative care, yet still reliant on invasive technology. This sense of powerlessness, and of providing nursing care for which they are morally opposed is a hallmark of moral distress in contemporary nursing. This suggests that neonatal nurses may feel powerless to speak out against futile technological intervention whilst expressing the need to practice in a social system that allows them to maintain their fidelity to the newborns in their care. Neonatal nurses need to be able to follow their conscience, yet practice in a collaborative environment that allows them to follow orders from their medical colleagues with integrity and a degree of moral comfort. This also stems back to the need for neonatal nurses to be able to reach consensus with medical staff, and families, to provide the most appropriate care to the small population of newborns who will not survive, despite these technological interventions.

The subscale ‘clinician’ also identified that 75.7% (M=3.2) of the 645 neonatal nurses surveyed reported that they were asked by parents to continue life extending care beyond what they felt was right. There are two issues highlighted by this finding: firstly, why are parents making these demands in the first instance, and; secondly, how can the ethical concerns of clinical staff be acknowledged in the current healthcare setting. In this research, neonatal nurses have suggested that the demands of parents presents them with one of the most difficult areas of providing care to these babies. The media, they argue, have unmitigated access to the community in perpetuating the notion that babies don’t die, and that all babies can be saved. Changing these prevalent points of view will take considerable time, and in the interim, parents require candid and pragmatic information from a team that is unified through a process of mediated consensus. Such an approach would provide consistent, evidence based information for parents to assist them in making decisions on behalf of their children, that take into account pain and suffering, and the likely prognosis and morbidity of the newborn. Even with this approach, it is unlikely that consensus between a unified healthcare team and parents will occur one hundred percent of the time, and during these times, organisational infrastructure needs to support it’s clinical staff to remain united, and to work alongside, rather than in opposition, to parents regardless of their treatment choices.
There may be many reasons that parents resist discussing palliative care options. However, it is suggested that this resistance may occur as the palliative approach may be interpreted as abandoning hope. Previous research has suggested that conflict between clinical staff and parents may arise when staff believe it is time to stop treatment for an unviable infant, but parents are not ready to make that decision (Catlin & Leuthner, 2000; Miya et al., 1991). Although treatments to relieve pain are often welcomed, it can take some parents days or even weeks to accept a terminal diagnosis and agree to cease aggressive treatment. Some parents will never accept a terminal diagnosis, and will wish to continue to provide everything for their child until the end becomes inevitable (Peterson, 2005).

This conflict also stems from the parents’ role as decision makers for their children, and that doing the ‘right thing’ for a baby doesn’t always translate into ‘doing what parents want’ (Marzuk, 1985). Controversy and debate continue to surround the parental role as the decision-makers for their newborns. Paris et al (2000) argued that a more nuanced ethical analysis needed to be made when involving parents in the decision-making process. Paris suggested that the first question to ask parents when involving them in this process should be ‘what is going on?’ rather than ‘what do you want?’ It is suggested (Paris et al., 2000) that the focal point for the neonatologist and the healthcare team should be concerned with the best interests of the infant, and that there may be a fundamental problem in giving parents the ‘cruel decision’ to continue treatment or to allow their child die. When parents act as proxy decision makers for their infant, and these decisions contravene with the decisions and opinions of the healthcare team, the best interests of the child may be given greater weight. However, this concept relies on the child being considered a person in their own right. The concept of ‘personhood’ or moral status by a developing human being is widely debated. Personhood may be believed to be fully acquired at conception, and by others to be acquired gradually or stepwise through pregnancy and childhood (Boyle, Salter, & Arnander, 2004).

The findings of the current research demonstrate concerns about how the healthcare team should continue with care when families make seemingly ‘inappropriate demands’ to continue life support, which may result in the needless suffering of the
newborn and result in a waste of scarce and costly medical resources. Kopelman (2006) suggested that these conflicts between parents and the healthcare team could be prevented in many or most situations if neonatologists improved their communication with families about end of-life issues. I would add to this with the evidence gathered from this research that team agreement also needs to occur prior to negotiations and communication with parents about the direction of care. Furthermore, as Catlin and Carter (2002) stated, conflict may exist between parents and the healthcare team when they do not believe palliative care is appropriate for their baby. Therefore, a plan for facilitated mediation should be in place, and always available, when a palliative care program is considered and/or initiated (Catlin & Carter, 2002).

Literature findings (Craig & Goldman, 2003), coupled with the findings of this research suggest that the demands of parents upon the healthcare team may stem from the lack of information offered to them, which would enable them to make informed decisions. Neonatal nurses in the current research identify the lack of written information available for parents as an adjunct to verbal communication, and a lack of consistency in treatment plans when palliative care treatment is introduced. Some of the neonatal nurses interviewed for this research have described treatment plans as changing often on a shift to shift basis back and forth from curative to palliative. The demands placed upon caregivers impact negatively upon the nurse as they juggle these demands with their own morals and values. Often, parental demands lead to goals of care oscillating from one of saving a life to one of providing the most comfortable death, a concept also identified in the literature (Cranley-Grass, 2002). Catlin and Leuthner (2000) reported that nursing staff often struggle with the family when caring for marginally viable and critically ill newborns in the NICU. Conflict between nurses and parents occur most often when nurses believe it is time to cease aggressive treatment for the unviable newborn, but parents are not ready to make that decision (Catlin & Leuthner, 2000; Miya et al., 1991). This will often lead to conflict in the clinical setting.

The findings of the current research demonstrate that the ethical concerns of neonatal nurses manifest as two constructs. Both of these concepts feature heavily in
the literature, and have become part of the lexicon of concerns expressed by neonatal nurses. These include legitimate and poignant concerns about the indiscriminate use of technological life support for marginally viable and critically ill newborns, and the demands placed upon healthcare providers by parents. The origins of these concerns have been difficult to contextualise, and the findings from this research generate hypotheses that require further testing to extend upon these findings.

In terms of technological life support, the majority of this population sample of neonatal nurses believe that technology is misused in terms of marginally viable and critically ill newborns. This perception of misuse may be in part due to the lack of guidelines to support palliative care practice, and an inconsistent approach to palliative care. Currently, there appears to be confusion about what constitutes the palliative approach, as identified by this research: should cardio-monitoring continue? Should ventilatory support continue? How much intervention is too much? Furthermore, this research highlights the issue that medical staff may fail to recognise what constitutes this approach also with other, more aggressive forms of ventilation being introduced when palliation is being considered. Neonatal nurses in this research have asked: what message does this send to parents, suggesting that medical technology was used ‘just because it is there’.

The majority of the Australian sample of neonatal nurses surveyed for this research identified that staff were asked by parents to continue life-extending care beyond what they felt was right. Neonatal nurses in the interpretive phase of this research further contextualized this finding to suggest that the media certainly played a role in this. Although healthcare needs to acknowledge the role that the media plays in perpetuating the myths that a) all babies can be saved, and b) there is a technological ‘fix’ for everything, manipulating the media to portray the occasionally harsh reality of the NICU is beyond the scope of this research. This research indicates that parents require time to make decisions. For some, having factual information may assist them in these decisions; for others, religious and personal beliefs will never allow them to endorse a palliative approach.
In summary, in this research neonatal nurses have described their moral distress at the impact of technological advances, and it’s inappropriate use. The literature has described a sense of being ‘held hostage’ by these technological imperatives in both neonatal nurses and physicians alike, and this research strongly corroborates these findings. That neonatal nurses so strongly concur that technology is not used judiciously is both pejorative and counterproductive to the palliative approach in the NICU. Added to this barrage of moral distress for the neonatal nurse are the demands of parents to do all that can possibly be done for their baby, even when care is considered futile and potentially painful for the newborn. This is partly due to the impact of the media and that parents may perceive that all babies born beyond the 22 week gestational milestone will survive, and the lack of information given to them about treatment options and morbidity may both be held responsible for this. However, this also begs the question as to how clinical staff can be ethically supported to work alongside parents and families, whilst upholding their own morals and beliefs. Clearly, this intersection of clinical staff and parental values has the potential to cause considerable conflict in the NICU environment.

7.4 The diffusion of innovations and palliative care practice

The purpose of utilizing Rogers Diffusion of innovations as the theoretical framework for this research was to investigate the theory/practice gap between support for a neonatal palliative model of care, and it’s lack of adoption in the clinical area. This research has drawn upon several of the central themes fundamental to Rogers’ Diffusion theory (1995), the theoretical framework that underpins this research. In particular, the origin of the barriers and facilitators to palliative care practice identified by this research correlates strongly with what Rogers refers to as ‘the social system’ and it’s members. To clarify, the social system is defined as a set of interrelated units such as individuals, groups, organisations, subsystems, that are engaged in joint problem-solving to accomplish a common goal (Rogers, 1995). By identifying the barriers and facilitators to palliative care practice, this research has in essence identified aspects of the social system of the NICU by determining the norms and attitudes of clinical staff in the NICU. This has allowed aspects of the NICU’s social system to be better
understood, and neonatal nurses indicate that whilst they are keen to improve neonatal palliative care practice individually, they recognise that collectively as a team, they were not. This finding of individual support vs lack of organisational support for practice change has also been identified in the literature (Ohlinger, Brown, Lauder, Swanson, & Fofah, 2003).

The social system of the NICU is often simply described as ‘the way we do our work here’, which includes the beliefs, norms and attitudes of its members (Ohlinger et al., 2003). Therefore, the fabric of this social system will determine the degree to which the NICU environment will adapt to changes in models of care (Ohlinger et al., 2003). When addressing the facilitators and barriers identified by this research, according to Kramer et al (2004) the nurse is in a relative position of strength to influence the social system. It is essential that nurses are aware of the cultural norms of their Unit, and recognise their responsibility to initiate practice change. Nurses in positions of leadership are primarily responsible for establishing, maintaining, and even altering their social system. Changes such as incorporating policy to improve palliative care practice means that clinical leaders need to anticipate and recognise when changes are commensurate with cultural values, and if they are not, to develop cultural transformation plans correspondingly (Kramer et al., 2004). Misiorski (2003) suggests that nursing leaders are essential in addressing the critical elements for cultural change. To adopt any practice change, it is necessary for the NICU to review and revise their mission, values and visions. As an example, if a palliative model of care espouses supports care as a priority for newborns who are dying, this would need to be commensurate with the value statement of the Unit.

The social system identified by this research represents a complex set of issues: consistent support for palliative care; inclusiveness of all levels of clinical staff; freedom of information for parents and freedom of expression by neonatal nurses. All are powerful themes in the cultural dynamics of any organisation. Social systems within organisations have been described as ‘a series of rules and methods that a society has evolved to deal with the recurring problems it faces. These have become so basic that, like breathing, we no longer think about how we approach or resolve them’ (Crainer, 1997). Such is the power of the social system, and it’s potential to
influence practice change, and this can be better understood by exploring the individuals within the social system.

The individuals represented within the NICUs social system are identified by Rogers as the potential adopters of a palliative model of care. It is in this context that providing evidence-based policies to facilitate adoption of palliative care practice is most imperative. This is because, on average, healthcare is risk-adverse, and this adverseness will often result in a postponement of a clinical decision until further evidence has been gathered. However, providing an evidence base to promote a palliative model of care is not the only factor involved in the adoption of palliative care practice. Each individual’s innovation-decision is largely framed by personal characteristics, and this diversity is what makes diffusion of changes in clinical practice possible. For the successful adoption of palliative care practice, the potential adopter distributions follow a bell-shaped curve according to Rogers (1995 p 257). This bell-shaped curve can be divided to characterize five categories of system member innovativeness, where innovativeness is defined as the degree to which an individual is relatively earlier in adopting new ideas than other members of a system. These categories were identified in Chapter 3, and the characteristics of which have already been described, but include the: 1) innovators, 2) early adopters, 3) early majority, 4) late majority, and 5) laggards. The characteristics and interaction of these groups illuminates a domino effect, which means that the potential adopters’ uncertainty about adopting palliative care practices may be assuaged through a stepwise social process related strongly to the opinion leaders within the social system. Given this, following this study, how are these individuals represented within the NICU, and how does this affect palliative care practice? Firstly, this research has identified that opinion leaders need to be well-informed in order to communicate their approval of this model of care to the rest of the social system. This information stems from change agents, and the undertaking of research to generate evidence based policy is an example of a change agent. Rogers’ diffusion theory hypotheses that the majority may respond to the influence of opinion leaders by rapidly adopting practice change. This suggests that the spread of
palliative care practice hinges on a surprisingly small point: namely, whether or not opinion leaders vouch for it.

Rogers explains that the types of opinion leaders that research findings should target depend upon the nature of the social system. The nature of each NICU social system within which this research was conducted could not be measured, however in theory, social systems can be characterized as heterophilous or homophilous. Heterophilous social systems tend to encourage change from system norms, and there is more interaction between people from different backgrounds, indicating a greater interest in being exposed to new ideas. These systems have opinion leadership that is more innovative because these systems are desirous of innovation (Rogers, 1995 p 289). Alternatively, homophilous social systems tend toward system norms. Most interaction within them is between people from similar backgrounds. People and ideas that differ from the norm are seen as ‘strange’ and undesirable. These systems have opinion leadership that is not very innovative because these systems are averse to innovation (Rogers, 1995 p 288). Although it is beyond the scope of this research to generalize about these system norms, it would be in the interests of future research to investigate these system norms further in terms of palliative care practice. For example, in the heterophilous systems identified, the findings from this research can inform further research to concentrate on targeting the most innovative opinion leaders and then allowing the innovation to diffuse to other members. If an opinion leader is convinced to promote palliative care practice, Rogers’ theorizes that other individuals will exhibit excitement and a readiness to adopt it. The domino effect will commence with enthusiasm rather than resistance.

However, in homophilous systems, encouraging the diffusion of an innovation is far more difficult. In this context, research findings such as these need to target a wider group of opinion leaders, because practice change is less likely to diffuse. Opinion leaders who adopt practice change in homophilous systems are more likely to be regarded as suspicious and/or dismissed from their opinion leadership. Often, opinion leaders in homophilous systems avoid adopting innovations to protect their opinion leadership (Rogers, 1995 p 295).
In summary, taking into account the social system defined by Rogers, the findings from this research need to be communicated to opinion leaders. Opinion leaders can be engaged to utilise the findings from clinical research to support their own adoption decision. To accommodate this, the barriers and facilitators to palliative care practice, as identified by this research, have been translated into recommendations to inform nursing policy. These recommendations, as well as the main conclusions that can be drawn from this research, will be presented in the following chapter.
7.5 **Strengths and limitations of the study**

This research has developed an instrument to measure the barriers and facilitators to palliative care practice in neonatal nursing. This instrument has undergone face and content validity testing with an Expert Panel, and has been pilot-tested to establish temporal stability. It was then administered to a population sample of 1285 neonatal nurses, with a moderate response rate of 50%, resulting in a sample of 645. Experienced neonatal nurses were then interviewed in a series of focus groups to develop policy to translate these findings into policy recommendations. However, as with all research, there are limitations to the interpretation of these results that need to be considered when attempting to generalize these analyses to broader issues of interest. The following is a discussion of these issues.

The first limitation identified within this research concerns the sample, and sample size. When considering the interpretation of these findings, administration of the survey instrument resulted in a response rate of approximately 50%, despite considerable efforts to increase this rate. Although there are no standards for acceptable response rates, published opinion (De Vaus, 2002) suggests that an average response rate for a postal survey – of which this survey is an example – is approximately 61%. Therefore, the response rate of the NiPCAS may subject the results to a degree of bias (De Vaus, 2002), and this is acknowledged as a potential limitation of this research. Given the nature of this research, it could be postulated that neonatal nurses with opinions about palliative care, or were more supportive of it, were more likely to respond to the instrument.

A further limitation of this study refers to the interpretive phase. The focus group interviews were conducted in 3 out of 8 Australian states. Therefore, the findings from the second phase of the research are not representative of the entire Australian population of neonatal nurses, or representative of neonatal nurses in every state. Conducting further focus groups to include every Australian state would have strengthened the findings from this phase of the research. However, whilst this is acknowledged, the nature of this phase of the research also needs to be considered, the purpose of which was to contextualise the population study findings to inform
nursing policy, and thus used *a priori* knowledge and a deductive approach to data analysis. Had this phase of the research necessitated an inductive approach to generate hypotheses, this limitation may have had greater implications. Although not a limitation of the research design, it is acknowledged that the findings from this research are limited only to the Australian context.

Secondly, only preliminary reliability of the NiPCAS has been established using exploratory factor analysis (EFA) procedures. Exploratory factor analysis was used in this study because of the limited conceptualization of what factors might be present in the data. This lack of conceptualization is commensurate with EFA imperatives, as EFA generally does not consider a strong *a priori* theory (Daniel, 1989). Therefore, a confirmatory factor analysis (CFA) approach is necessary to further evaluate the reliability of the NiPCAS in measuring the barriers and facilitators to palliative care practice. Confirmatory factor analysis is typically driven by theoretical expectations regarding the structure of the data (Kline, 2002), and following this research and the generation of new theory about palliative care practice, hypotheses have been generated in terms of what the barriers and facilitators are. Given this, CFA will be considered in the future development of this instrument using an international cohort of neonatal nurses.

### 7.6 Summary

The purpose of this study was to identify the barriers and facilitators to palliative care practice, and this purpose has been achieved. Furthermore, the population study findings from this research can be translated into policy that have both clinical significance and practical applications. Prior to this research, the reasons why implementing a neonatal palliative model of care had been problematic, despite the availability of evidence based guidelines, were unknown. By surveying neonatal nurses about palliative care, and then translating these findings into policy directives with the clinical intelligence of experienced neonatal nurses, a comprehensive understanding of the facilitators and barriers to palliative care in Australian neonatal nursing can be understood.
However, although this research has identified that there are facilitators to palliative care practice in Australian neonatal nursing, these issues are conceptual rather than tangible constructs that can be interpreted as absolutely supporting this practice. For example, although this research indicates that there is widespread support for palliative care from the healthcare team; support for families and support for caregivers, this supportive framework is pivotal on the presence of robust policy and a social system to uphold it. Insofar, the facilitators identified by this research were all subject to caveats that had to be considered. Specifically, the notion of support for palliative care is reliant on addressing the potential barriers that may encumber this support. To illustrate this point, the findings from this research suggest that palliative care as a treatment option receives support and agreement when it is introduced for a dying baby, however, I would suggest that there are also caveats to this support: is there agreement within the team in every instance? Has consensus been reached to address any potential conflict, in that, are opinions, values and belief both expressed and heard? Are parents supported in their decision making role with consistent, accurate information from a unified team? Each of these facilitators need to translate from idealised and conceptual constructs into evidence based, tangible policy.

This research conveys an argument in favor of palliative care. However, this argument needs to accentuate the compatibility of palliative care practice with system norms, as identified by Rogers’ Diffusion theory. The barriers, and the facilitators, identified by this research represent issues that are amenable to policy directives. However, recommendations made to qualify facilitators and address barriers need to take the system norms of the clinical environment into consideration. The recommendations that can be made on the basis of these findings will be discussed in the following chapter.
CHAPTER 8 - Conclusions and Recommendations

8.1 Introduction

This research was conducted to provide an understanding of the barriers and facilitators to palliative care practice in Australian neonatal nursing. It was necessary to identify these issues to determine why palliative care practice is ad hoc in the clinical environment, despite the existence of evidence based protocols to support it. This objective has been achieved by providing both empirical findings and theoretical reflections upon these findings. The sum of these findings from the quantitative and qualitative phases of this study combine to produce new knowledge about palliative care practice, and most importantly, a way forward in terms of policy directives that are germane to the clinical environment. The chapter will clarify the main conclusions that can be drawn from this research, and the recommendations that can be made based upon these conclusions.

8.2 Conclusions

The overall findings from this research have lead to three primary conclusions that can be made about palliative care practice in Australian neonatal nursing. The first conclusion from this research relates to the organisation in which the neonatal nurse practices. Although facilitators have been identified at the organisational level to support practice, there are caveats implicit to each of these facilitators that impinge upon adoption of a palliative model of care. Specifically, these caveats can be contributed to the minimal role that the neonatal nurse has in decision making on behalf of dying babies, and their minimal advocacy role. I therefore conclude that the role of the neonatal nurse within the organisation is minimal in terms of their decision making and advocacy role. Neonatal nurses report a sense of powerlessness in facilitating a model of palliative care in the current clinical environment. Although there is support for palliative care, the nursing voice requires fortification in order to advocate effectively on behalf of marginally viable and critically ill newborns, and to be effective in the decision making process. This research has identified that although neonatal nurses report that values, beliefs and
opinions are expressed regarding treatment options for dying babies, these sentiments are not necessarily acknowledged. Neonatal nurses are acquiescent to a role in ethical decision making, and can see the value of being involved, yet the lack of organisational and curriculum support in this area requires attention. These issues, as well as the neonatal nurse’s lack of understanding of the advocacy role negate their ability to advocate on behalf of parents and babies.

The second conclusion relates to the resources available to support a palliative mode of care. I conclude that available resources such as physical infrastructure and available staffing are inadequate to meet the needs of dying babies and their families. Furthermore, the lack of engagement in clinical guidelines to support a palliative model of care means that neonatal nurses cannot necessarily accommodate the needs of dying babies and their families. When collaborative decisions are made in favor of a palliative model of care, parents need to be presented with options that can facilitate needs such as remaining within the NICU, or relocating to a purpose designed room when babies are dying. This research has found that adequate staffing to support palliative care is only met if senior nursing staff can effectively lobby management to provide sufficient staffing. Organisations may not consistently recognise the labour intensiveness of providing nursing care to marginally viable and critically ill newborns. Furthermore, this aspect of nursing care may not be recognised as emotional work. Although babies receiving palliative care no longer require high-tech life support, the palliative approach should not be misinterpreted as passive in contrast to a cure-oriented approach. Such an assumption fails to recognise the specialized skills, maturity and competence required to provide palliative care.

Finally, the third conclusion relates to the moral and ethical concerns raised by the neonatal nurse. This research has raised substantial ethical concerns relating to the technological imperatives used to support life, and the demands made by parents. These issues may be contrary to the values of a palliative model of care, and contribute markedly to the moral distress of caregivers and conflict in the clinical area. I therefore conclude that the lack of policy to guide the judicious use of technological life support is inhibitory to a palliative model of care.
Furthermore, although this research has found that parents are informed of palliative care options, and are involved in decision making on behalf of their baby, current organisational processes do not necessarily facilitate the involvement of parents in a consistent and structured manner. **I further conclude that the demands of parents may result from a lack of information to guide them in their treatment choices.**

### 8.3 Recommendations

The findings from this research, and the conclusions that can be made from these findings, strongly support the following recommendations. These recommendations are made with a view to influence nursing policy makers in terms of curriculum development, protocol development and the integration of a palliative model of care into routine neonatal clinical practice.

The first recommendations relate to the organisation in which the nurse practices. This research clearly identifies that although there is theoretical support for palliative care within the organisation, the minimal role that neonatal nurses have in context to decision making markedly detracts from this. Given this finding, two recommendations are made. Firstly, **I recommend that the neonatal nurses’ involvement in ethical decision making requires strengthening.** The neonatal nurses’ advocacy role on behalf of marginally viable and critically ill newborns and their parents requires greater understanding by neonatal nurses, and further support by organisations. Curriculum and training in bioethics and advocacy skills that are directly applicable to the clinical area need to be implemented to engage neonatal nurses in the decision making process, and expand the advocacy role. Developing curricula in these areas will characterize the neonatal nurse’s ability to communicate professionally within the healthcare team, and within interdisciplinary groups regarding palliative care for the marginally viable and critically ill infant. Secondly, **I recommend that team agreement for palliative care would be better facilitated through mediated consensus.** Such dialogue should occur for each individual case when palliative care is considered a treatment option. This initiative would assuage much of the conflict that arises due to a lack of consensus at the caregiver level. Furthermore, engaging
in consensus discussion in a collegial and supportive environment would afford a more consistent approach to palliative care by the healthcare team.

The second series of recommendations are based upon the resources available to support a palliative model of care. The findings from this research strongly indicate that issues such as inadequate staffing and poor physical infrastructure are inhibitory to a palliative model of care. Furthermore, there is inadequate, formalized support for caregivers and a lack of evidence based guidelines to support this practice. Therefore, on the basis of these findings, the following recommendations are made.

Firstly, I recommend that a physical infrastructure is provided to support parents whose baby is receiving palliative care. Such infrastructure will depend upon where parents decide palliative care should take place. In the NICU, this may mean relocating to a larger cot space set-aside for such purposes that affords comfort and privacy. When parents request to move from the NICU environment, a room for palliative care purposes should be available. The use of multiple purposes for such a room should be limited, to assure its immediate availability for palliative care purposes. The room should be close enough to the NICU to cater to staffing assignments and lessen the perception of abandonment by parents. Policy development should take into account the needs of siblings and incorporate a family friendly philosophy. Parents require the option to take their baby outside to die. This may extend to the availability of a private balcony, or a private garden for such a purpose. The provision of this infrastructure would demonstrate that the organisation is committed towards facilitating a palliative model of care, and could feasibly be incorporated into existing NICUs, and catered for when designing new Units.

This research has found that staffing levels may be inadequate to recognize the labour intensive aspects and highly specialized needs of providing a palliative model of care. Patient dependency levels are determined by senior staff, and are dependent upon their ability to lobby to secure this level of staffing. I therefore recommend that patient dependency tools are available to accurately reflect the acuity of babies who are dying, taking into account the psychosocial needs of their parents and family members. These tools need to recognise the labour intensive
aspects and specialised needs of providing care to these babies, as well as the
emotional support required by parents and families.

This research has found that guidelines that are in use to support the care of dying
babies are not necessary evidence based. Furthermore, established palliative care
guidelines and protocols (see footnote 1) are not widely used in Australia for neonatal
palliative care, or adapted for use. **Therefore, I recommend that palliative care
guidelines for clinical use within Australian neonatal units are based upon
evidence, and reflect best practice standards.** This is a burgeoning model of care,
and an opportunity exists for neonatal clinical leaders and their professional bodies to
collaborate and develop nationally endorsed palliative care guidelines for the
Australian neonatal population. Such guidelines should be based upon the evidence
based guidelines already available, taking into account the cultural and social needs
of the population they serve. The development of such guidelines could also
encompass many of the other policy directives recommended by this research to
support a palliative model of care within Australia.

The last recommendation relating to the resources to support a palliative model of
care is based upon the finding from this research regarding support for neonatal
nurses. Neonatal nurses report that counselling is peer-to-peer, debrief sessions are
ad hoc, and coping mechanisms under-developed. Given this, **I recommend that
formal counselling support is made available to caregivers, provided discreetly
and without prejudice.** Furthermore, **I recommend that neonatal nurses should
receive organisational support to develop coping skills in providing care to
dying babies, thus acknowledging caregiver grief and suffering.** Debrief sessions
are often ad hoc, and do not necessarily cater for those directly affected by neonatal
death. Therefore, **I recommend that mediated debrief sessions, conducted by
trained personnel, are delineated to determine when such sessions should occur,**

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1 These guidelines, standards and protocols are referred to throughout this thesis, and include:
Gale, G., & Brooks, A. (2006). Implementing a Palliative Care Program in a Newborn Intensive Care
Unit. *Advances in Neonatal Care, 6*(1), 37.e31-37.e21.
Palliative Care Australia. (2005). Standards for Providing Quality Palliative Care for all Australians.
and these regulations be written into policy to support this initiative. Neonatal nurses who are directly involved in such cases should be fully encouraged to attend. This encouragement extends to ensuring that staff are paid for the time involved in attending, and providing flexible patient assignments and team support that facilitates attendance.

Finally, the third set of recommendations that are made relate to the moral and ethical concerns raised by the clinician. This research has found that neonatal nurses have concerns regarding the use of technological imperatives to prolong life and possibly suffering, and; the demands made by parents to do all that is possible to maintain life. The injudicious use of technological, and pharmacological, support is inhibitory to a palliative model of care, particularly when its use is not clearly delineated. Therefore, I recommend that policy be developed that clearly outlines the judicious use of medical technology when caring for marginally viable and critically ill newborns. Incorporating the parameters of judicious use into the evidence based clinical guidelines recommended by this research will clearly delineate what interventions constitute a palliative approach, and when such interventions become inappropriate.

In terms of the concerns raised by neonatal nurses regarding the demands of parents, the findings from this research suggest that parents may not receive adequate information about palliative care to assist them in their decision making process. Given this, I recommend that parents require additional support to assist them in their decision making role. Evidence based clinical guidelines need to include information about communicating with the parents of marginally viable and critically ill newborns. Written information for parents, as an adjunct to consistent verbal information, provides a useful platform from which healthcare professionals can initiate and discuss palliative care options, particularly for individuals who may find the instigation of such dialogue with parents uncomfortable. Such verbal and written communication should be culturally sensitive and anticipate the questions that parents will have. The unique insight and wisdom of parents who have experienced neonatal death should be involved in the development of this information, as they can provide a unique perspective that would increase the veracity and credibility of
such information. Furthermore, providing parents with candid and consistent information allows informed decision making that may mitigate the demands of parents made upon healthcare staff that everything possible be done to maintain the life of baby who may not survive. However, clinical staff also require organisational support when they are ethically opposed to treatment directions for dying babies, and should not feel obliged to care for babies for who’s treatment they are ethically opposed.

8.4 Recommendations for further research

Exploratory research is conducted when there are few studies to which references can be made for information. The aim of undertaking such research, therefore, is to develop new knowledge rather than test or confirm a hypothesis. In exploratory research the focus is on gaining insights and familiarity with the subject area and develop further testing. Given this, on the basis of the results of this research, and considering the strengths and limitations of the study, a number of recommendations can be made for further research.

• The findings from this research are limited only to the Australian context. Thus, it would be valuable to replicate this work to survey neonatal nurses internationally using the subscales already identified in the NiPCAS. This will allow for comparison of these findings with an international cohort and generalization of these findings to occur.

• This research has identified the barriers and facilitators to palliative care as perceived by neonatal nurses only. It was beyond the scope of the research design to account for the identification of barriers and facilitators to palliative care practice by physicians. Furthermore, parents who are consumers by proxy of a neonatal palliative model of care, were not studied for this research. Therefore, results from this study cannot be generalised in any way to these populations of other significant stakeholders of a neonatal palliative model of care. Further research is necessary to survey physicians to identify the barriers and facilitators to medical palliative care practice. Potentially, the NiPCAS could be adapted to
achieve this. Only then would a comprehensive understanding of neonatal palliative care practice across both medical and nursing disciplines be available to inform practice.

- As discussed in the Limitations section of this thesis, only preliminary reliability of the NiPCAS has been demonstrated using exploratory factor analysis techniques. Further testing of this instrument is therefore necessary. It is suggested that a confirmatory factor analysis (CFA) approach be undertaken to further evaluate the reliability of the NiPCAS in measuring the barriers and facilitators to palliative care practice. Confirmatory factor analysis is typically driven by theoretical expectations regarding the structure of the data (Kline, 2002), and following this research and the generation of new theory about palliative care practice, hypotheses have been generated in terms of what the barriers and facilitators are. Given this, CFA is being considered in future development of this instrument using an international cohort.

- The findings from this research have generated recommendations that will need to be translated into policy, curriculum development and training in the clinical environment. Research imperatives in this respect need to be directed at engaging clinical leaders in the development of neonatal palliative care guidelines that take into account the needs of all key stakeholders. The impact of these findings upon neonatal nursing curricula include enhancing the ethical competence and advocacy skills of neonatal nurses to accommodate their role in ethical decision making. In Rogers (1995) Diffusion theory it is argued that since clinical leaders will directly affect the adoption of a practice change, a powerful way for research to affect this adoption is to affect these leader attitudes. This can occur by using research findings to persuade clinical leaders, and this is the most obvious way to stimulate positive attitudes towards palliative care practice. This reinforces the importance of the current research utilizing a translational research approach to give these research findings clinical application that are tacit to the NICU environment.
This research has suggested a link between the education of the neonatal nurse and the reporting of barriers and facilitators to palliative care, thus generating hypotheses about a plausible link between these two variables. Further research is necessary in this area to investigate whether this link is significant.

8.5 Closing comments

The purpose of this study has been to gain a composite understanding of palliative care practice in neonatal nursing. This has been achieved by identifying the barriers and facilitators to this area of practice. However, once these issues were identified, this study was concerned with translating the findings from this phase of the research into recommendations for policy. This goal was considered integral to not only identifying the issues that affect palliative care practice, but to addressing and enhancing these processes.

This research has identified that the facilitators that do exist for palliative care practice are subject to caveats that impinge markedly upon these processes. Furthermore, the barriers that were identified pose threats to the integration of a palliative model of care into Australian neonatal nursing practice. The results of this research have important implications for nursing policy makers, but most importantly for neonatal nurses themselves. The findings that have been presented in this research represent issues that are endemic not only to palliative care practice, but to the effectiveness of the nursing role in caring for babies who are born at the margins of viability, or who are critically ill. This study has argued that neonatal nurses have the potential to play an empowered and pivotal role in supporting the needs of this fragile patient population, their parents, and their families. The approach to addressing the issues identified in this work would be best addressed by engaging the clinical intelligence of neonatal nurses with representatives from all Australian states to participate in a collaborative working party to move neonatal palliative care from a theoretical construct to a recognised and supported model of care.
Thus, the results from this Australian research presents an opportunity for Australian neonatal nurses to unite and lead the way in developing, supporting and promoting a palliative model of care for the neonatal population.
Reference List


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Lo, B., Quill, T., & Tulsky, J. (1999). Discussing palliative care with patients. *Annals of Internal Medicine, 130*, 744-749.


Rogers, A., Karlsen, S., & Addington-Hall, J. (2000). 'All the services were excellent. It is when the human element comes in that things go wrong': dissatisfaction with hospital care in the last year of life. *Journal of Advanced Nursing, 31*(4), 768-774.


Simpson, T. (1999b). Response to "Neonatal viability in the 1990s: Held hostage by technology: by Jonathan Muraskas et al. and "Giving moral distress a voice: Ethical concerns among neonatal intensive care unit personnel" by Pam Hefferman and


### APPENDIX I: Characteristics of the Pilot Study sample

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Total sample (n = 28)</th>
<th>Retest sample (n = 16)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>F (%)</td>
<td>F (%)</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>27 (96.4)</td>
<td>15 (93.8)</td>
</tr>
<tr>
<td>Male</td>
<td>1 (3.6)</td>
<td>1 (6.3)</td>
</tr>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20-30</td>
<td>4 (14.3)</td>
<td>1 (6.3)</td>
</tr>
<tr>
<td>31-40</td>
<td>8 (28.6)</td>
<td>5 (31.3)</td>
</tr>
<tr>
<td>41-50</td>
<td>5 (17.9)</td>
<td>2 (12.5)</td>
</tr>
<tr>
<td>50+</td>
<td>11 (39.3)</td>
<td>8 (50.0)</td>
</tr>
<tr>
<td><strong>Experience in a NICU (yrs)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 1 yr</td>
<td>3 (10.7)</td>
<td>1 (6.3)</td>
</tr>
<tr>
<td>1-5 yrs</td>
<td>5 (17.9)</td>
<td>2 (12.5)</td>
</tr>
<tr>
<td>6-10 yrs</td>
<td>3 (10.7)</td>
<td>3 (18.8)</td>
</tr>
<tr>
<td>11-15 yrs</td>
<td>7 (25.0)</td>
<td>3 (18.8)</td>
</tr>
<tr>
<td>&gt; 15 yrs</td>
<td>10 (35.7)</td>
<td>7 (43.8)</td>
</tr>
<tr>
<td><strong>Current employment status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full-time</td>
<td>9 (32.1)</td>
<td>4 (25.0)</td>
</tr>
<tr>
<td>Part-time</td>
<td>19 (67.9)</td>
<td>12 (75.0)</td>
</tr>
<tr>
<td><strong>Formal education in neonatal nursing</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>7 (25.0)</td>
<td>5 (31.3)</td>
</tr>
<tr>
<td>Yes – hospital certificate</td>
<td>12 (42.9)</td>
<td>5 (31.3)</td>
</tr>
<tr>
<td>Yes – post-graduate level</td>
<td>2 (7.1)</td>
<td>2 (12.5)</td>
</tr>
<tr>
<td>Yes - Currently undertaking</td>
<td>7 (25.0)</td>
<td>4 (25.0)</td>
</tr>
<tr>
<td><strong>Highest nursing/midwifery qualification obtained</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital certificate</td>
<td>11 (39.3)</td>
<td>6 (37.5)</td>
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<td>Undergraduate degree</td>
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</tr>
<tr>
<td>Masters/honours</td>
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<tr>
<td><strong>Designation</strong></td>
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<td></td>
</tr>
<tr>
<td>Direct patient care</td>
<td>27 (96.4)</td>
<td>15 (93.8)</td>
</tr>
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<td>Research</td>
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<td>1 (6.3)</td>
</tr>
</tbody>
</table>
## APPENDIX II: Pilot-study - Results of reliability testing

*Intraclass coefficient between T1 and T2 r = .773*

<table>
<thead>
<tr>
<th>Pilot-tested question</th>
<th>inter-item correlation ((r))</th>
<th>Final question following pilot-testing and re-examination with Expert Panel</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative care is as important as curative care in the neonatal environment</td>
<td>.792</td>
<td>unchanged</td>
</tr>
<tr>
<td>I have had experience of providing palliative care to dying babies and their families</td>
<td>.537</td>
<td>unchanged</td>
</tr>
<tr>
<td>I feel a sense of personal failure when a baby dies</td>
<td>.522</td>
<td>unchanged</td>
</tr>
<tr>
<td>There is support for neonatal palliative care in society</td>
<td>.522</td>
<td>unchanged</td>
</tr>
<tr>
<td>The medical staff support palliative care for dying babies in my Unit</td>
<td>.695</td>
<td>unchanged</td>
</tr>
<tr>
<td>The physical environment of my Unit is not conducive to providing palliative care to dying babies</td>
<td>.662</td>
<td>The physical environment of my Unit is ideal for providing palliative care to dying babies</td>
</tr>
<tr>
<td>Babies requiring palliative care is a priority when organising staffing in my Unit</td>
<td>.352</td>
<td>My Unit is adequately staffed for providing the needs of dying babies requiring palliative care and their families</td>
</tr>
<tr>
<td>In my Unit, parents are involved in decisions about their dying baby</td>
<td>.288</td>
<td>unchanged</td>
</tr>
<tr>
<td>My previous experiences of providing palliative care to dying babies have been rewarding</td>
<td>.836</td>
<td>unchanged</td>
</tr>
<tr>
<td>When babies die in my Unit, providing pain relief is a priority for me</td>
<td>.222</td>
<td>unchanged</td>
</tr>
<tr>
<td>I am often exposed to death in the neonatal environment</td>
<td>.522</td>
<td>unchanged</td>
</tr>
<tr>
<td>Palliative care is necessary in neonatal nursing education</td>
<td>.851</td>
<td>unchanged</td>
</tr>
<tr>
<td>When a baby dies in my Unit, I have sufficient time to spend with the family</td>
<td>.825</td>
<td>unchanged</td>
</tr>
<tr>
<td>There are policies/guidelines to assist in the delivery of palliative care in my Unit</td>
<td>.407</td>
<td>unchanged</td>
</tr>
<tr>
<td>In my Unit, when a poor diagnosis is made, parents are informed of palliative care options</td>
<td>.439</td>
<td>In my Unit, when a diagnosis with a likely poor outcome is made, parents are informed of palliative care options</td>
</tr>
<tr>
<td>In my Unit the team express their opinions, values and beliefs about providing care to dying babies</td>
<td>.550</td>
<td>unchanged</td>
</tr>
<tr>
<td>Caring for dying babies is traumatic for me</td>
<td>.690</td>
<td>Unchanged</td>
</tr>
<tr>
<td>There are available resources in my Unit to support a palliative model of care</td>
<td>.611</td>
<td>Removed –ambiguous</td>
</tr>
</tbody>
</table>
I have received in-service education that assists me to support and communicate with parents of dying babies | .796 | unchanged
---|---|---
There is conflict surrounding the decision to implement palliative care for a dying baby in my Unit | .072 | Removed –low correlation
My attitudes to death affects my willingness to deliver palliative care | .253 | My personal attitudes about death affects my willingness to deliver palliative care
Palliative care is against the values of neonatal nursing | .690 | unchanged
When a baby dies in my Unit, counselling is available if I need it | .718 | unchanged
Society’s values do not support palliative care for dying babies | .423 | There is a belief in society that babies should not die, under any circumstances

These questions were added following pilot testing following further discussion with the Expert Panel.

- In my Unit, the staff go beyond what they feel comfortable with in using technological life support
- In my Unit, staff are asked by parents to continue life-extending care beyond what they feel is right
- Curative care is more important than palliative care in the neonatal intensive care environment
APPENDIX III: Wording of Questions Checklist
(De Vaus, 2002) p97-99

1. Is the language simple? Avoid jargon and technical terms;
2. Can the question be shortened? The shorter the question the less confusing and ambiguous it is;
3. Is the question double-barrelled? Avoid questions that ask more than one question;
4. Is the question leading? A leading question is one where either the question structure or wording pushes people to provide a response that they would not have given had the question been asked another way;
5. Is the question negative? Questions which use ‘not’ can be difficult to understand and can cause confusion;
6. Is the respondent likely to have the necessary knowledge? When asking about certain issues it is important that respondents have knowledge about the issue;
7. Will the words have the same meaning for everyone? The meaning of some words may vary – it is important to make their meaning clear;
8. Is there a prestige bias? This point is not relevant to this instrument;
9. Is the question ambiguous? The best way to avoid ambiguity is to use short, crisp, simple questions;
10. Is the question too precise? Avoid asking precise questions as this may result in inaccurate answers;
11. Is the frame of reference for the question sufficiently clear?
12. Does the question artificially create opinions? Always offer an ‘unsure’ response for those who have no opinion;
13. Is personal or impersonal wording preferable? Decide whether the question is asking how the participant feels, or if the question is asking them to comment upon how other people feel;
14. Is the question wording unnecessarily detailed or objectionable? Avoid questions that precisely ask about age, or income. Give a range instead, such as 40 – 50 years of age;
15. Does the question have dangling alternatives? Beware of constructing questions with alternative answers;
16. Does the question contain gratuitous qualifiers? Avoid italicised qualifiers which may affect the way people answer questions;
17. Is the question a ‘dead giveaway’? Absolute, all-inclusive or exclusive words are best avoided.
APPENDIX IV: SAMPLE OF INFORMATION FOR SURVEY PARTICIPANTS

Participant Information Sheet

Project title: DEVELOPING PALLIATIVE CARE MODELS IN NEONATAL INTENSIVE CARE: AN INVESTIGATION OF BARRIERS AND PARAMETERS FOR PRACTICE

Investigator: Victoria Kain
MN RN NICC (PhD candidate)
0419 771 208
v.kain@qut.edu.au
c/o School of Nursing, Queensland University of Technology
Victoria Park Rd., Kelvin Grove 4059.

Your Consent:

You are invited to take part in this research project which involves completing a survey that will investigate the attitudes to palliative care practice in neonatal nursing.
The outcome of this research will lead to the development of new knowledge that will inform policy development and neonatal nursing curricula.
This Participant Information sheet contains detailed information about the research project. It’s purpose is to explain to you as openly and clearly as possible all the procedures involved in this project before you decide whether or not to take part in it.
Please read this Participant Information sheet carefully. Feel free to ask questions about any information in this document. You may also wish to discuss the project with a relative or friend or colleague.
Once you understand what the project is about and if you agree to take part in it, you will be asked to complete a brief survey. By completing and returning this survey, you indicate that you understand the information and that you give your consent to participate in the research project.
You will be given a copy of the Participant Information sheet to keep as a record.
**Procedures:**

Your participation in this study will involve completing a questionnaire which will ask you about your attitudes to palliative care practice in neonatal nursing. It is anticipated that the total of your time commitment to this research project will be approximately ½ an hour. Please complete the questionnaire at a time that is convenient for you.

You can return your questionnaire in the box provided in the staff tea room, or to any Australia Post mailbox in the reply-paid envelope provided.

**Background:**

Despite technological advances, increases in the margins of viability and highly skilled healthcare delivery, some babies will still die in the NICU. A palliative model of care may be appropriate for some of these babies who are marginally viable, and critically ill. Despite support for a neonatal palliative model of care, little is known about palliative care practice in neonatal nursing. You are invited to participate in this research project which involves a questionnaire to investigate attitudes to palliative care practice in neonatal nursing. This will assist us in identifying the facilitators and barriers to palliative care practice. This questionnaire is being administered to a population sample of neonatal intensive care nurses throughout Australia.

**Possible risks:**

There is a possibility that the questions asked in this survey may cause you emotional distress. If this occurs, you should contact Australia wide counselling services on XX who will direct you to your nearest local contact.

**Potential benefits:**

The overall outcome of this research will lead to the development of recommendations for improving palliative care practice which will provide new knowledge, and policy directives, in neonatal nursing. This will be of direct benefit to practising neonatal nurses, dying babies and their families.

**Confidentiality:**

All comments and responses are anonymous and will be treated confidentially. The names of individual persons are not required in any of the responses. In any publication, information will be provided in such a way that you cannot be identified.
All data from this study will be kept in a locked filing cabinet at Queensland University of Technology, and a password protected computer accessible only by the researcher.

**Participation is Voluntary:**

Participation in any research project is voluntary. If you do not wish to take part, you are not obliged to. Your decision whether to take part or not to take part will not affect your relationship with your employer. Before you make your decision, you can contact the investigator to answer any questions you have about the research project. You can ask for any information you want. Complete and return the survey only after you have had a chance to ask your questions and have received satisfactory answers.

**Further Information or Any Problems:**

If you require further information or if you have any problems concerning this project, you can contact the principal researcher (Victoria Kain) on XX.

**Ethics concerns:**

This study has been approved by the XX Human Research Ethics Committee. If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact the XX Research Secretariat on XX.

**Feedback:**

Upon the conclusion of this research, the investigator will provide feedback to the participants involved in the study which will include a summary of the overall outcomes of this work. This will be made available to you via your Nurse Unit Manager.

*Thank You*
APPENDIX V: SAMPLE OF INFORMATION FOR FOCUS GROUP PARTICIPANTS

*Hospital Logo here (de-identified)*

Study title: 'Developing palliative care models in neonatal nursing: Phase two: Focus groups'

(Human Research Ethics Committee approval no: XX.)

Dear colleague,

You are invited to attend a focus group interview along with a few of your nursing colleagues in the NICU area, on XX at XX. I understand that you are rostered to work on this date, and as the focus group will be conducted during the afternoon staff overlap period, you will not be asked to attend during your own time. I am asking you to participate because of your experience in the NICU, and I would greatly value your opinions and recommendations at this focus group. Refreshments will be provided at the focus group.

In the first phase of this research, I distributed a survey to ask neonatal nurses about their attitudes to palliative care practice. The most important findings from this national, Australian study revealed both facilitators and barriers to palliative care delivery in the NICU setting.

This focus group is being conducted to ask neonatal nurses to discuss the findings of this national survey. At this focus group interview, I will be asking you and your colleagues about how we can develop policies to: improve the facilitators, and address the barriers identified by this research.
This will be an opportunity for you to influence nursing policy and clinical guideline development in this field as the findings from this study will be published internationally.

Please take the time to carefully read the important information in the Participant Information Statement. It would be appreciated if you could have your Participant Consent Form signed and brought with you on the day for collection.

I look forward very much to meeting with you.

Sincerely,

Victoria Kain - PhD candidate, Queensland University of Technology.
Study title: Developing Palliative Care Models in Neonatal Nursing: Phase Two: Focus Groups

INFORMATION FOR PARTICIPANTS

Introduction

Due to your experience and expertise in the Neonatal Intensive Care Nursery, you are being asked to take part in Phase Two of a research study to investigate neonatal palliative care practice by neonatal intensive care nurses.

Overall, this study is being undertaken so that we can learn more about neonatal nurse’s attitudes about palliative care provision to marginally viable and critically ill babies, and develop recommendations to improve palliative care practice in neonatal intensive care nursing.

A national, population survey has been conducted to ask neonatal nurses about their attitudes to palliative care. The results of this survey have identified the facilitators and the barriers to palliative care practice in neonatal nursing. We would like to discuss these results with groups of neonatal intensive care nurses in a series of focus group interviews. At these interviews, we will be discussing the survey findings to develop recommendations that will inform nursing policy to improve palliative care practice in neonatal nursing. This is one of three focus groups that will be conducted in different Australian states.

This study is being conducted within this institution by Victoria Kain (RN NICC MN & PhD candidate) and Professor Glenn Gardner (RN PhD) from Queensland University of Technology in Brisbane, Australia.

Study Procedures

If you agree to participate in this study, you will be asked to read this Participant Information Form. Once you are satisfied that all of your questions have been answered, you will be asked to sign the consent form, and advise your Nurse Unit Manager that you would like to attend the focus group interview. If you have any further questions, you should feel free to contact the Principal Investigator, Victoria Kain on XX or at v.kain@qut.edu.au

There will be approximately seven participants in the focus group, which will include your nursing colleagues. The focus group will take approximately an hour. You will not be expected to participate in this focus group outside of your normal working hours. The focus group will be conducted during the one hour over-lap between the morning and
afternoon shift. You will find the information regarding the time, data and venue of the focus group interview on the cover letter with this information package.

**Risks**

There is a possibility that participating in the focus group interview may cause you distress. If you experience any emotional distress by participating in this focus group, you are encouraged to contact your organisation’s staff counsellors for support and guidance. Alternatively, if you wish to seek counselling externally, you should contact the Principal Investigator who will provide you with this information.

**Benefits**

The overall outcome of both phases of this research will lead to the development of recommendations for adoption of palliative care which will provide new knowledge in neonatal nursing and inform policy direction and neonatal nursing curricula. This will be of benefit to practising neonatal nurses, dying babies and their families.

**Costs**

Participation in this study will not cost you anything, nor will you be paid.

**Voluntary Participation**

Participation in this study is entirely voluntary. You do not have to take part in it. If you do take part, you can withdraw at any time prior to the focus group without having to give a reason. Whatever your decision, please be assured that it will not affect your relationship with your employer.

**Confidentiality**

The focus group interview will be taped. Following the focus group interview, this tape will be transcribed verbatim by the researcher. If names are used in the focus group, these will be changed to pseudonyms so that you cannot be identified. If the organisation, or your State are alluded to, this information will be censored so that individuals, sites and states cannot be identified. Only group data from the three focus groups will be reported.

Your information will remain confidential except in the case of a legal requirement to pass on personal information to authorised third parties. This requirement is standard and applies to information collected both in research and non-research situations. Such breaches of confidentiality are rare; however we have an obligation to inform you of this possibility.
Further Information

When you have read this information, the Chief Investigator – Victoria Kain – is happy to discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact her on XX or at v.kain@qut.edu.au

This information sheet is for you to keep.

Ethics Approval

This study has been approved by the XX Research Ethics Committee. Any person with concerns or complaints about the conduct of this study should contact the Secretary of the Committee, XX on XX and quote protocol number XX.

Version No. : 2
Date December 2006.
CONSENT FORM

Project title: Developing Palliative Care Models in Neonatal Nursing – Phase Two Focus groups

I hereby consent to my involvement in the research project entitled:

Developing Palliative Care Models in Neonatal Nursing – Phase Two Focus groups

1. The nature and purpose of the research project described on the attached Information Sheet has been explained to me.

2. I understand that I may not directly benefit by taking part in this study.

3. I acknowledge that the possible risks and/or side effects, discomforts and inconveniences, as outlined in the Information Sheet, have been explained to me in this document.

4. I understand that while information gained in the study may be published, I will not be identified and information will be kept confidential.

5. I understand that there will be no payment to me for taking part in this study.

6. I have had the opportunity to discuss taking part in this research project with a family member or friend.

7. I am aware that I should retain a copy of the Consent Form, when completed, and the Information Sheet.

8. I understand that information will be kept confidential except where there is a requirement by law for it to be divulged.

Signed: ..........................................................

Full name of participant: ..............................................................

Dated:.........................
## APPENDIX VI: THE NiPCAS

### The Neonatal Palliative Care Attitude Scale (NiPCAS)

**Principal Researcher:**
Victoria J. Kain  
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Kelvin Grove, Brisbane 4059  
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v.kain@qut.edu.au

**Associate Researcher:**
Professor Glenn Gardner  
RN PhD  
Director – Centre for Clinical Nursing  
Royal Brisbane & Women’s Hospital  
& Queensland University of Technology  
[glenn_gardner@health.qld.gov.au](mailto:glenn_gardner@health.qld.gov.au)

### Information about this Questionnaire:

**Thank you** for taking the time to complete this questionnaire.

The NiPCAS has been designed to ask neonatal nurses about palliative care practice for babies who are not expected to survive due to a poor prognosis. Palliative care is defined as: “an approach which improves the quality of life of patients and their families facing life-threatening illness, through the prevention, assessment and treatment of pain and other physical, psychosocial and spiritual problems”\(^1\).

We ask that you read the statements in this questionnaire, and indicate whether you strongly disagree, somewhat disagree, somewhat agree or strongly agree with that statement.

When you have completed this questionnaire, please seal it in the reply-paid envelope provided. You can either return the sealed envelope to the labelled box in the staff tea-room to be posted on your behalf, or you can return via an Australia Post mailbox.

---

# The Neonatal Palliative Care Attitude Scale (NiPCAS)

## Section One:
*Firstly, we would like to ask some questions about you. Please circle your answer.*

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td><strong>Sex</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>20 – 30</td>
<td></td>
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<tr>
<td></td>
<td>31 – 40</td>
<td></td>
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<tr>
<td></td>
<td>41 – 50</td>
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<tr>
<td></td>
<td>51 +</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td><strong>How long have you worked in a neonatal intensive care unit?</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Less than 1 yr</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1 – 5 yrs</td>
<td></td>
</tr>
<tr>
<td></td>
<td>6 – 10 yrs</td>
<td></td>
</tr>
<tr>
<td></td>
<td>11 – 15 yrs</td>
<td></td>
</tr>
<tr>
<td></td>
<td>&gt; 15 yrs</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td><strong>Which statement best describes your current employment status?</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Full-time</td>
<td></td>
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<tr>
<td></td>
<td>Part-time</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Casual</td>
<td></td>
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<tr>
<td>5</td>
<td><strong>Have you received formal education in neonatal intensive care?</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>No</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes – as a hospital certificate</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes – as a postgraduate qualification</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes – currently undertaking</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td><strong>What is the highest nursing/midwifery qualification you have obtained?</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Hospital certificate</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Undergraduate degree</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Postgraduate degree</td>
<td></td>
</tr>
<tr>
<td></td>
<td>PhD/Doctoral degree</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td><strong>Which statement best describes how you spend the majority of your time in your current workplace:</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Direct patient care</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Nursing management</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Nursing education</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Nursing research</td>
<td></td>
</tr>
</tbody>
</table>
# The Neonatal Palliative Care Attitude Scale (NiPCAS)

**Section Two:**

*In the following statements, we will ask you about your attitudes to palliative care practice in neonatal nursing. To what extent do you disagree or agree with these statements?*

*(Please circle your answer)*

<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td><strong>8</strong></td>
<td>Palliative care is as important as curative care in the neonatal environment</td>
<td>Strongly Disagree</td>
<td>Somewhat Disagree</td>
<td>Somewhat Agree</td>
</tr>
<tr>
<td><strong>9</strong></td>
<td>I have had experience of providing palliative care to dying babies and their families</td>
<td>Strongly Disagree</td>
<td>Somewhat Disagree</td>
<td>Somewhat Agree</td>
</tr>
<tr>
<td><strong>10</strong></td>
<td>I feel a sense of personal failure when a baby dies</td>
<td>Strongly Disagree</td>
<td>Somewhat Disagree</td>
<td>Somewhat Agree</td>
</tr>
<tr>
<td><strong>11</strong></td>
<td>There is support for neonatal palliative care in society</td>
<td>Strongly Disagree</td>
<td>Somewhat Disagree</td>
<td>Somewhat Agree</td>
</tr>
<tr>
<td><strong>12</strong></td>
<td>The medical staff support palliative care for dying babies in my Unit</td>
<td>Strongly Disagree</td>
<td>Somewhat Disagree</td>
<td>Somewhat Agree</td>
</tr>
<tr>
<td><strong>13</strong></td>
<td>The physical environment of my Unit is ideal for providing palliative care to dying babies</td>
<td>Strongly Disagree</td>
<td>Somewhat Disagree</td>
<td>Somewhat Agree</td>
</tr>
<tr>
<td><strong>14</strong></td>
<td>My Unit is adequately staffed for providing the needs of dying babies requiring palliative care and their families</td>
<td>Strongly Disagree</td>
<td>Somewhat Disagree</td>
<td>Somewhat Agree</td>
</tr>
<tr>
<td><strong>15</strong></td>
<td>In my Unit, parents are involved in decisions about their dying baby</td>
<td>Strongly Disagree</td>
<td>Somewhat Disagree</td>
<td>Somewhat Agree</td>
</tr>
<tr>
<td><strong>16</strong></td>
<td>My previous experiences of providing palliative care to dying babies have been rewarding</td>
<td>Strongly Disagree</td>
<td>Somewhat Disagree</td>
<td>Somewhat Agree</td>
</tr>
<tr>
<td><strong>17</strong></td>
<td>When babies are dying in my Unit, providing pain relief is a priority for me</td>
<td>Strongly Disagree</td>
<td>Somewhat Disagree</td>
<td>Somewhat Agree</td>
</tr>
<tr>
<td><strong>18</strong></td>
<td>I am often exposed to death in the neonatal environment</td>
<td>Strongly Disagree</td>
<td>Somewhat Disagree</td>
<td>Somewhat Agree</td>
</tr>
<tr>
<td><strong>19</strong></td>
<td>Palliative care is necessary in neonatal nursing education</td>
<td>Strongly Disagree</td>
<td>Somewhat Disagree</td>
<td>Somewhat Agree</td>
</tr>
<tr>
<td></td>
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</tr>
<tr>
<td>---</td>
<td>---</td>
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<td>---</td>
<td>---</td>
</tr>
<tr>
<td>20</td>
<td>When a baby dies in my Unit, I have sufficient time to spend with the family</td>
<td>Strongly Disagree</td>
<td>Somewhat Disagree</td>
<td>Somewhat Agree</td>
</tr>
<tr>
<td>21</td>
<td>There are policies/guidelines to assist in the delivery of palliative care in my Unit</td>
<td>Strongly Disagree</td>
<td>Somewhat Disagree</td>
<td>Somewhat Agree</td>
</tr>
<tr>
<td>22</td>
<td>In my Unit, when a diagnosis with a likely poor outcome is made, parents are informed of palliative care options</td>
<td>Strongly Disagree</td>
<td>Somewhat Disagree</td>
<td>Somewhat Agree</td>
</tr>
<tr>
<td>23</td>
<td>In my Unit the team expresses its opinions, values and beliefs about providing care to dying babies</td>
<td>Strongly Disagree</td>
<td>Somewhat Disagree</td>
<td>Somewhat Agree</td>
</tr>
<tr>
<td>24</td>
<td>Caring for dying babies is traumatic for me</td>
<td>Strongly Disagree</td>
<td>Somewhat Disagree</td>
<td>Somewhat Agree</td>
</tr>
<tr>
<td>25</td>
<td>I have received in-service education that assists me to support and communicate with parents of dying babies</td>
<td>Strongly Disagree</td>
<td>Somewhat Disagree</td>
<td>Somewhat Agree</td>
</tr>
<tr>
<td>26</td>
<td>All members of the healthcare team in my Unit agree with and support palliative care when it is implemented for a dying baby</td>
<td>Strongly Disagree</td>
<td>Somewhat Disagree</td>
<td>Somewhat Agree</td>
</tr>
<tr>
<td>27</td>
<td>In my Unit, the staff go beyond what they feel comfortable with in using technological life support</td>
<td>Strongly Disagree</td>
<td>Somewhat Disagree</td>
<td>Somewhat Agree</td>
</tr>
<tr>
<td>28</td>
<td>In my Unit, staff are asked by parents to continue life-extending care beyond what they feel is right</td>
<td>Strongly Disagree</td>
<td>Somewhat Disagree</td>
<td>Somewhat Agree</td>
</tr>
<tr>
<td>29</td>
<td>My personal attitudes about death affects my willingness to deliver palliative care</td>
<td>Strongly Disagree</td>
<td>Somewhat Disagree</td>
<td>Somewhat Agree</td>
</tr>
<tr>
<td>30</td>
<td>Palliative care is against the values of neonatal nursing</td>
<td>Strongly Disagree</td>
<td>Somewhat Disagree</td>
<td>Somewhat Agree</td>
</tr>
<tr>
<td>31</td>
<td>When a baby dies in my Unit, counselling is available if I need it</td>
<td>Strongly Disagree</td>
<td>Somewhat Disagree</td>
<td>Somewhat Agree</td>
</tr>
<tr>
<td>32</td>
<td>There is a belief in society that babies should not die, under any circumstances</td>
<td>Strongly Disagree</td>
<td>Somewhat Disagree</td>
<td>Somewhat Agree</td>
</tr>
<tr>
<td>33</td>
<td>Curative care is more important than palliative care in the neonatal intensive care environment</td>
<td>Strongly Disagree</td>
<td>Somewhat Disagree</td>
<td>Somewhat Agree</td>
</tr>
</tbody>
</table>

Thank-you!