

<p style="text-align: center;">CHAPTER 3 THE ETHICAL COMPLEXITIES OF SAVING EXTREMELY PREMATURE BABIES</p>

3.0 Introduction

Caregiving dilemmas are experienced by all nurses in the course of their careers (Redman & Fry 2000, p. 36), as they deal with situations that cause them to question. For the neonatal nurse dilemmas may arise in relation to a neonate's right to life and parents' rights to make decisions on behalf of their children. Dilemmas may have arisen from care decisions that involve situations that are deemed to be futile. Disagreements related to care may cause conflict between staff and parents. Health care resources are finite, and the allocation of resources can present dilemmas for nurses. Providing care to extremely premature infants could be seen by the neonatal staff as an unwise use of valuable resources; resources that could be directed to more viable infants.

Nurses, at some time, will be likely to experience moral and ethical dilemmas (Edwards 1996, p. 8; Johnstone 1999, p. 6). Such dilemmas are confronting for nurses. When these dilemmas occur nurses may react by voicing their concerns, or retreat and become a passive deliverer of health care. Nurses are the largest number of professionals, they provide front line care, and they have intimate knowledge of patients and their families (Elizondo 1991, p. 55). They, however, are rarely involved in decision-making and the active resolution of ethical dilemmas (Monterosso et al. 2005, p. 116). This chapter will examine the ethical and complex issues that surround the care of infants 24 weeks gestation and less. Neonatal nurses are concerned about outcomes for infants who require the services of the NICU (Raines 1993, p. 44). This concern encompasses all infants requiring care, however, it is likely that they experience more ethical dilemmas surrounding the care, management and outcome of infants less than 24 weeks gestation.

Neonatal nurses, as primary caregivers to the infant and the family, have legitimate moral and ethical concerns, though it is not clear whether nurses make moral or ethical

decisions. The majority of nurses do not have knowledge of ethics (Norrie 1997, p. 167). Nurses have attained academic preparation relatively recently (Norrie 1997, p. 167). It is possible that this could be why they are underrepresented on institutional ethics committees. Such committees decide what is in the best interest of the patient population they serve. Without nursing input they could be seen to represent the views of the medical profession. For example, in Australia the National Health and Medical Research Committee Health Ethics Council (AHEC) has the brief to advise the NH&MRC on the ethical issues relating to health. Of the 15 members on the current AHEC there is only one nurse representative to six medical representatives (NH&MRC 2007).

3.1 The stressors facing neonatal nurses

Much has been written about the stress facing neonatal nurses (Luckner 1977; Duxbury & Thiessen 1979; Boxall & Garcia 1983; Walker 1982; Tyson, Lasky, Weiner, Caldwell & Sumner 1984; Consolvo, Brownell & Distefano 1986; Dopson 1988; Rosenthal, Schmid & Black 1989; Oates & Oates 1995). Most of the work on stress for neonatal nurses has centred around the often frenetic and chaotic environment (Marshall & Kasman 1980; Thornton 1984; Antonelli 1985; Blake 1987; Cohen 1990), the unrelenting nature of the work (Wilson 1989), exposure to dying babies and their families (Vachon & Pakes 1984; Hutchinson 1984; Green 1995; Downey, Benjamin, Heuer & Juhl 1995), dealing with distraught families (Gribbens & Marshall 1982a; Gribbens & Marshall 1982b), resource and staffing issues (Sande 1983; Duxbury, Armstrong, Drew & Henly 1984), conflict (Jacobson 1983), advocacy (Raines 1993), not being able to provide palliative care (Gale & Brooks 2006, p. 37; Kain 2006, p.387), responsibility for tiny lives (Schmidt 1977; Simone 1984), not being able to see the results of their work (Price 1979), anger from the family (Jellinek, Catlin, Todres & Cassem 1992, p. 120), the frustration and despair of prolonged caring (Chiswick, 1990, p. 1096; Catlin, Volat, Hadley, Bassir, Amigo, Valle, Gong & Anderson 2008, p. 102), and ethical and moral dilemmas (Jacobson 1978; Martin 1989; Miya, Boardman, Harr & Keene 1991; Oehler, Gage Davidson, Starr & Lee 1991; Chally 1992; Hefferman & Heilig 1999; Catlin et al. 2008, p.102). There is acknowledgement that ethical dilemmas are likely to cause stress

to neonatal nurses. Much of the literature about ethical issues encountered by neonatal nurses involves a theoretical exploration of the topic (Fost 1981; Scholz 1983; Strong 1983; McGovern 1984; Smith-Blair 1985; Sims-Jones, 1986; Vaux 1986; Yu 1986; Avery 1987; Berseth 1987; Reedy, Minogue & Sterk 1987; Marchwinski 1988; Cerase 1988; Mahon 1988; Townshend 1990; Stewart 1990; Mellien 1992; Schlomann 1992a; Schlomann 1992b; Wocial 1993; Mousdale & Johnston-Canjar 1993; Gill 1994; Binder 1994; Erlen 1994; Campbell & McHaffie 1995; Tyson 1995; Dimond 1995; Southgate & Annibale 1995; Jones 1997; Raeside 1997; Spence 1998; Anonymous 1998; Kraybill 1998; Wick 1998; Walkman & Schenk 1999; Wilder 2000; Becker & Grunwald 2000; Challinor Mifflin 2003), while little research addresses nurses' ethical concerns. Research that addresses ethical issues falls into categories of ethical dilemmas in general (Miya, Boardman, Harr & Keene 1991; Miya, Boardman, Keene, Spielman & Harr 1995; Guyer 2006; Miller 2007), participation in decision making (Martin 1989; Miya, 1989; Elizondo, 1991; McHaffie & Fowlie 1997; Hinson Penticuff & Walden 2000), advocacy (Raines 1993; Spence 1997), the way that neonatal nurses make moral decisions (Chally 1992), the choices neonatal nurses would make in clinically ambiguous situations (Raines 1996), and caring for extremely premature infants (Armentrout 1986; Armentrout-Richey 1988; Townshend 1990; Beausoleil, Zalnateraitis, Gregorio & Healey 1994; Heffernan & Heilig 1999).

Issues reported (Townshend 1990, p. 39 & 40) as causing stress to neonatal nurses are an awareness that they inflict pain and suffering, the continuation of treatment when they believe the prognosis was hopeless, and the allocation of extremely premature infants to inexperienced staff. Neonatal nurses have cited caring for infants less than 500 grams as something they preferred not to do, but do so because "it was their job" (Townshend 1990, p. 39). Nurses in Townshend's (1990, p. 39) study had a primary motivation for caring for extremely premature infants out of compassion for the parents, while many nurses struggled with the fear that resources might be denied to larger infants. Caring for an infant who could suddenly deteriorate and die was stressful, as was the fetal appearance of the infant (Townshend 1990, p.40). The following is a quote from Raines

(1993, p. 45), that articulates some of the tensions and dilemmas that NICU nurses experience as conflict.

The really immature kids, the fetuses, shouldn't even be here.
I mean they are not babies, so they don't belong in a nursery.
It's not right to bring them here where we are required to poke
and prod them to meet the standards of the unit, and it's not right
that valuable time is taken away from other children while we
watch a fetus die.

The technology that treats extremely premature infants has become a double-edged sword. While the physiologic existence of tiny infants can be maintained, the technology is unable to promote and enhance the neurologic, psychological, cognitive and spiritual development of such fragile humans (Anonymous 1998, p. 64). Ethical dilemmas are created for those who care for these infants. Nurses can experience a combination of guilt and relief. When an infant is too small to survive, neonatal nurses may feel comfort and relief knowing that a peaceful death is the best option (Moulsdale & Johnston-Canjar 1993, p. 14). Guilt may be experienced by neonatal nurses as they think of a different future, one in which a baby may have permanent, profound disabilities (Moulsdale & Johnstone-Canjar 1993, p. 14).

Conflict can occur between nursing and medical staff. Neonatal nurses have been shown to support less aggressive care of infants of marginal viability (Lee, Penner & Cox 1999, p. 110; Streiner, Saigal, Burrows, Stoskopf & Rosenbaum 2001; p. 152). This approach is thought to be the result of seeing unsatisfactory outcomes in infants. In a study by Streiner et al (2001, p. 152) physicians tended to be more optimistic than nurses regarding probability of survival and freedom from serious disabilities, and would recommend life saving interventions to parents. The same study showed that the attitude of parents can differ from the attitudes of health professionals. A significant number of parents believed that there should be an attempt to save all infants irrespective of condition or weight at birth, compared with only six percent of health professionals (Streiner et al. 2001, p. 152). Medical staff in a study by Catlin (1999) believed that they

were in the delivery room to do 'battle' (Catlin 1999, p. 272). One neonatologist suggested. "...in the heat of the battle you can't think about withholding treatment, you blink too much in resuscitation, you lose the chance to have a great outcome...I don't go into battles in this unit expecting to lose...because we go in to win" (Catlin 1999, p. 272). Saving babies with little thought of the consequences could be source of conflict for neonatal nurses. Medical staff in Catlin's (1999) study thought deeply about the issues involved. One neonatologist stated, "You see so many people suffer. You see the children suffer, you see the families, you see the nurses and everybody that works there go through this over and over again. You get so tired of death. You get so tired of disability and chronic handicaps" (Catlin 1999, p. 273).

There seems to be a difference between how nurses and doctors approach end of life dilemmas. Nurses and doctors have different objectives for dying patients. Nurses are concerned with dignity, comfort and wishes while doctors are more concerned with patients' rights and quality of life (Viney 1996). There seems to be a clear distinction between the roles of nurses and doctors. Doctors are primarily decision makers, while nurses are the patient's source of information. Doctors suffer moral dissonance, and nurses experience moral distress (Viney 1996, p. 182).

Caring for critically ill and dying babies is difficult for neonatal nurses (Green 1995). Much has been written about making life and death decisions in the NICU (Marshall, Casman & Cape 1982; Weir, 1984; Manney & Blattner 1984; Kuhse & Singer 1985; Lyon 1985; Gullemin & Holmstrom 1986; Harrison 1986; Gustaitis & Young 1986; Frohock 1986; Shelp 1986; Sparks 1988; Cohen 1990; Anspach 1993; Singer 1994; McHaffie & Fowlie 1996; Hume 2000). Much research has been carried out by those who do not have the day to day caregiving responsibilities for the babies, or who are not confronted by the ethical dilemmas associated with caregiving. These authors have varied backgrounds including medicine (Guillemin & Holmstrom 1986), political science (Frohock 1986), theology (Sparks 1988), sociology (Anspach 1993), philosophy and ethics (Weir 1984, Singer & Kuhse 1983, Shelp 1986), education (Cohen 1990), parents (Stinson & Stinson 1983), right to life advocates (Manney & Blattner 1984; Taylor &

Hoekstra 2000), disability advocates (Cohen 1990), journalism and ethics (Gustiatis & Young 1986) and journalism (Lyon 1985; Hume 2000). In comparison with other professionals, nurse representation is small (Marshall, Kasman & Cape 1982, McHaffie & Fowlie 1996). Nursing research would contribute another dimension.

Although neonatal nurses experience ethical dilemmas, they are not educationally prepared for these ethical dilemmas (Mouldsdales & Johnstone-Canjar 1993, p. 14). An informant in McHaffie and Fowlie (1997, p. 273) observed,

I suppose in basic nursing training you were faced with a fact of having to care for people in their last hours. But we were never given any instruction about the moral or ethical side of it. It was assumed that whatever decision was made would be right and we would support it.

For clinicians, there is conflict between theoretical ethics and real life ethics (McHaffie & Fowlie 1997, p. 275 & 276). In Martin's (1989) study the ethical dilemmas associated with caregiving could bring nurses to consider ending a baby's life. Although the neonatal nurses in this study realised that taking matters into their own hands and helping a baby die was an option, none would make a unilateral decision to end an infant's life. One participant explained,

We may think out loud about wishing that a baby's suffering would end – that he would go to meet the angels – but we would never actively end his life (Martin 1989, p. 470).

In thinking about taking a baby's life the extent of the nurses' dilemmas are shown.

Neonatal nurses have the right to ask questions of an ethically sensitive nature. It is not clear who is better placed to make ethical decisions on behalf of medically fragile infants. The medical staff might not have undertaken any more ethics education than nurses. Neonatologists may be experts in neonatal medicine, they are not expected to be expert in neonatal ethics. Battle (1987, p. 418) questions the motives of physicians and whether the

drive to save infants of marginal viability is part of the professional challenge of reaffirming their omnipotence. Neonatal nurses have an obligation to ask challenging questions, and to make rational well informed decisions (Power 2002, p. 17). The ethical conflict for nurses could be what they think should be done is in direct conflict with what is expected of them (Elizondo 1991, p. 58).

Nurses face moral and ethical dilemmas in the course of their work, however, repeated exposure to ethical dilemmas can predispose nurses to burnout. Nurses who experience higher levels of moral and ethical distress are more likely to become burned out and might even abandon their profession (Severinsson 2003, p. 59) if they are unable to resolve their distress. Burnout involves depersonalisation, emotional exhaustion and low personal satisfaction with work that leads to decreased work productivity and effectiveness. Coupled with anger and physical exhaustion the nurse loses interest in, and concern for, patients (Sherman 2004, p. 48). Job satisfaction is a significant predictor of burnout in nurses (Kalliath & Morris 2002, p. 648). Neonatal nurses have been found to identify satisfying situations in their work that compels them to continue working in the NICU (Archibald 2006, p. 176).

Skovholt (2001, p. 111) speaks of two types of burnout, those being, “meaning burnout and caring burnout”. When health professionals lose the meaning involved in their work an existential crisis can develop, resulting in ‘meaning burnout’. ‘Caring burnout’ is defined by Skovholt (2001, p. 113) as “disengagement of the self from the caring cycle of empathic attachment”. According to Kalliath and Morris (2002, p. 654) one of the first signs of burnout is that nurses may engage in ‘cognitive withdrawal’ from their job. This cognitive withdrawal leads to caring for without caring about, or going through the motions of patient care (McQueen 2004, p. 106). Wright (2003, p. 25) has suggested that burnout has a purpose and signals a crisis of meaning and purpose in life. Nurses are no longer able to tolerate aspects of their working life. One way for a nurse to avoid burnout is to recognise the limits to what can be endured. Burnout can be a factor in nurses leaving the profession.

3.2 The involvement of neonatal nurses in ethical decision making

Those who care for extremely premature infants deal with life and death simultaneously. This care involves the care of infants at the extreme edge of viability where science and technology are unable to make up for the lack of fetal maturity. Staff working in the neonatal unit are confronted with beginning of life and end of life decisions at the same time. It is not so much the life and death issues that seem to provoke the ethical dilemmas in neonatal nurses, it is the birth and death of the baby that can occur together within minutes, hours, days or even weeks. As a result Power (2002, p. 4) has suggested that neonatal nurses will deal with moral dilemmas more frequently than other nurses.

Neonatal nurses get to know the babies they care for, and because they spend a large amount of time with the babies, they learn their habits and idiosyncrasies. They form attachments to the baby. It would be easy to assume that extremely premature babies were devoid of anything but biological life. This, however, is not the case. Morris (1999, p. 23) states "...personalities develop from very early on, ensuring that the work of the NICU is never boring. Some babies are quiet and laid back yet quite alert, as if knowing their needs will be attended to in due time".

Neonatal nurses are frequently confronted with ethical dilemmas. The choices that nurses make when confronted with an ethical dilemma involve a maturational process. As nurses develop increased technical competence, they move their focus from the technology to the patient and their family (Erlen & Frost 1991, p. 398). One nurse in Martin's (1989, p. 469) study described how her feelings about saving babies had changed:

My feelings have really changed over time. When I first started in this unit, I believed that you had to provide maximum treatment for every baby; now I identify more with the baby's suffering and I find myself questioning very aggressive, painful treatment for babies who really cannot be helped. Are we doing this for our benefit or for the baby's?

Neonatal nurses are more likely to be involved in ethical dilemma resolution when they

perceive themselves to have high levels of influence in the clinical practice environment (Hinson Penticuff 1995, p. 406). Conversely, neonatal nurses have been found to perceive themselves as having limited ability to influence patient care. They do not have a sense of being valued by the institutions they worked in, and therefore their willingness to take action to resolve ethical dilemmas has often been limited (Hinson Penticuff & Walden 2000, p. 64). There are times when nurses feel powerless in the face of their ethical dilemmas. Erlen and Frost (1991, p. 403) have suggested that powerlessness occurs with physician dominance and a lack of knowledge of the alternative options to solve the problem. Nurses who were powerless described themselves as ineffective. This finding could have implications for staffing, as nurses who hold themselves morally accountable for their nursing practice are unlikely to remain in institutions where their contributions are not recognised (Hinson Penticuff 1995, p. 407), or they are unable to influence what happens to the patients in their care.

Knowing what to do in hypothetical situations is difficult. It is even more difficult to know what neonatal nurses would do if they were in premature labour. Gaining an accurate picture of what nurses believe they would do in a hypothetical situation is difficult. Unless faced with the situation, it is still very much a nurse believing he/she would know what to do in a given situation. McHaffie and Fowlie (1997, p. 277) found neonatal nurses would want fewer interventions for their own extremely premature babies, than that currently offered to patients in their NICU of employment. Perhaps their experience has led them to believe that not all babies can survive, and should it happen to them they would prefer not to be held “hostage to circumstance” (Harrison 1986, p. 172). Harrison (1986, p. 172) spoke of a midwife who had contingency plans in case of premature delivery, and “...she would drive to a remote area, as far from a tertiary unit as possible, and let nature take its course”. The following is a quote from McHaffie and Fowlie (1997, p. 275) where a neonatal nurse explains her beliefs.

I always try to think, if it was my baby, what would I want, and then weigh that up against what I know as a professional.....if I delivered a 23-week gestation baby, my heart would want me to do

as much as they can to save that baby. But my head says, no, it's not meant to be. And I wouldn't like that child to suffer. And the outcome is quite poor. So I wouldn't want them to pursue any active treatment...

3.3 The use of ethical principles

Ethical theories and principles provide a general approach to ethical analysis. Ethical principles are easy to articulate, but implementation has proven difficult (Kraybill 1998, p. 209). Much philosophical controversy surrounds the use of ethical principles (Johnstone 1999, p. 87). Principles and rules can provide a framework for identifying and reflecting on ethical problems (Beauchamp & Childress 2001, p. 15) Rules and principles have a place in the initial learning about bioethics. They are also a good place to start when confronting the issues related to extremely premature infants. Ethical dilemmas require an analysis of relevant rights, principles and values in order to make an educated decision. When considering extreme prematurity there needs to be a wider consideration beyond that built on ethical theories and principles.

3.3.1 Rights

In Australia the legal status of the fetus is unclear (Seymour 2000, p. 135). What will become of the fetus after birth is much more important, because the extremely premature infant who is born during the third trimester is now afforded the legal rights of the newly born (Seymour 2000, p. 135). Infants, even extremely premature ones, are seen as children, and are therefore recognised as having the rights and status accorded to all human beings. Moral rights entail claims about entitlement, which ought to be protected (Johnstone 1999, p. 96). A claim for 'rights' are entitlements that deserve respect. There is a distinction between legal and moral rights. The extremely premature infant is in no way able to exercise his/her rights and thus relies on surrogates. Feinberg (1987, p. 1507) suggests that having rights means having interests. In order for a rights claim to be honoured the individual must have interests, and to have interests means that the person must be able to be benefited or harmed. Benefit or harm is linked to the ability of the

human being to feel pleasurable states, feel pain and to suffer. It is doubtful that the extremely premature infant feels pleasurable states, because nothing in the early days of NIC for these tiny babies can be thought of as pleasurable (intubation, cannulation, heel sticks, and head ultrasounds to name a few). There is little doubt that babies of 24 weeks gestation can feel pain as the cortical connections with the thalamus are complete (Franck 1993, p. 789; Bildner 1999, p. 511). Previous thinking was that human newborns were considered incapable of doing, learning or knowing anything until at least six months of age (Kragnegor & Lacanuet 1995, p. 3). Feinberg (1987, p. 1508) sees the ultimate claim of interests resting on the individual having the capacity to suffer. It is difficult to know if the extremely premature baby has the capacity to suffer, and if so, whether it knows that it is suffering. Neonatal nurses are concerned about the suffering of extremely premature babies (Hinson Penticuff 1987, p. 9; Martin 1989, p. 470; Townshend 1990, p. 39; Miya et al. 1991, p. 254; Mouldsdales & Johnston-Canjar 1993, p. 14). It can be claimed, therefore, that extremely premature babies have been given rights by virtue of others, who believe them to be able to suffer.

3.3.2 Beneficence

Beneficence requires the provision of benefits (Mahowald 1986, p. 72), or above all, do good and avoid evil, or to act for the benefit of others (Johnstone 1999, p. 90). Positive beneficence requires the provision of benefits, while utility requires the balancing of benefits and burdens to achieve the most desirable results (Beauchamp & Childress 2001, p. 165). For the baby of 24 weeks gestation and less it is difficult to know whether living or dying would be of benefit to the baby. If the extremely premature baby is born and is vigorous, then by resuscitating the baby the medical staff will be acting beneficently towards him/her. If, however, the extremely premature baby is moribund at birth and requires active resuscitation, knowing that the baby will die or have a poor outcome (Lantos et al. 1988, p. 91), can be seen as an act of paternalism rather than beneficence. Johnstone (1999, p. 90) makes the point that health professionals are not obliged to act beneficently towards others when doing the act could result in their own moral harm.

This would suggest that neonatologists were not obliged to save infants who were deemed to be fetal, if doing so would cause them to experience ethical distress.

3.3.3 Non-maleficence

Non-maleficence requires that harm not be inflicted intentionally. It is closely linked to the maxim *primum non nocere* or ‘above all do no harm’ (Beauchamp & Childress, 2001 p. 113). Non-maleficence requires that the actions of health care professionals result in good rather than harm, and involves weighing the potential harm and benefits of life sustaining treatment. It could be argued that saving the life of an infant of marginal viability is a harm, especially if such treatment causes pain and suffering, and the infant is severely impaired. Conversely, depriving the infant of life is a harm from which it will never recover. It would be reasonable to resuscitate the infant and institute life support if the infant shows a willingness to live, and make decisions based on each new piece of clinical evidence. Evidence which points to the baby being harmed such as a head ultrasound showing grade IV P-IVH, or PVL, is likely to be the point at which decisions to withdraw life support are commenced. Non-maleficence also requires that the medical staff allocate resources equitably, and there will be some extremely premature infants for whom aggressive neonatal care is not beneficial (Young & Stevenson 1990, p. 549).

3.3.4 Autonomy

The respect for autonomy is at the heart of collective morality. Autonomous individuals are entitled to make their own decisions and life choices. Adults are entitled to make autonomous choices, however, infants and children require others to make decisions on their behalf. Extremely premature infants are unable to make decisions about treatment preferences and they rely on others to make decisions. It will never be known if the extremely premature infant would prefer to live or die, although erring on the side of caution and opting for life is common. A physician in a study by Catlin (1999, p. 272) practised indiscriminate resuscitation when he stated “...to me resuscitation is a procedure or a technique and I know I’m very good at it and I know I can make almost anything live

for a while. It doesn't really have any meaning to me in terms of what's important later on". Walden and Sala (1993, p. 574), however, suggest that the infant would choose intact survival, rather than face death or life with major handicaps. Kluge (2001) makes the point, although highly speculative, that when extremely premature babies grow up, and with increasing awareness, their disabilities could have such an impact on them in terms of psychological suffering that they might wish they had never been born.

In order for the parents to participate they need the available information about their child to help them make decisions. Informed consent becomes an issue here, because if parents are not told the truth about the full extent of the baby's condition, they might be giving consent willingly, but that consent is not informed. For consent to be valid, medical staff are required to disclose information about the baby's condition, and then assess the parents' understanding of the situation, before consent can be thought of as voluntary. Situations which could be problematic are those where the medical staff are not seen as telling the whole truth, not being honest or intentionally withholding information from parents. This intentional non-disclosure could be viewed by the medical staff as being justified because the success of treatment could be threatened, or the decision making process could become impaired (Beauchamp & Childress 2001, p. 84). While this might be well intentioned, it is paternalistic, and usurps individual responsibility. In today's society it is not acceptable to attempt to spare parents from decision-making, even if the motives are pure.

Consent implies competence. Situations can also occur when the parent's level of competence needs to be assessed for their ability to be actively involved in the decision making process. Extremely premature labour and delivery is a difficult and distressing time for the parents and they may be physically and emotionally unable to participate in decision-making, even though they are deemed competent. Situations can arise where the parents are adolescents or developmentally disabled, and lack the requisite decision making capacity. Competence assumes that the person has the necessary understanding and information processing skills. In these situations grandparents or significant others might be asked to contribute to the decision making process.

3.3.5 Justice

Justice is about fairness and equity and implies getting what a person deserves. For the infant of 24 weeks gestation and less, justice is seen to be done if the infant gets the opportunity to live at birth. If the extremely premature infant is vigorous and active then the principle of justice dictates that steps should be taken to save its life. If however, a infant is moribund at birth, justice could be served by allowing the infant to die peacefully. Distributive justice refers to the fair and equitable division of resources. Therefore, when resources are scarce in the NICU it might not be wise to spend a disproportionate amount of the resources on one extremely premature infant, if it means that there will be less resources available for other babies, babies who might have the potential for intact survival (Way 1996, p. 391). Decisions about treatment of extremely premature infants using a justice perspective would be based on their condition at birth, and not on the perceived cost to the community of these infants, and their possible long-term health care needs.

3.3.6 Benefits versus burdens

There comes a stage in the extremely premature infant's survival trajectory when it is time to consider the benefits of treatment versus the harms to the baby from the treatment. Infants in the NICU are subjected to many painful procedures, often on a daily basis. With the initial proliferation of technology, the pain imposed on these babies was not considered, however, it is now recognised that infants are more sensitive to painful stimuli than adults (Hinson Penticuff 1995, p. 413). Some benefits to the baby, such as survival, may not outweigh the pain and suffering, especially if life support cannot cure the baby. The benefit of survival will then be outweighed by the burdens presented by treatment, especially if the baby will be dependent on medical technology and left with severe disabilities.

There is a distinction between ordinary and extraordinary treatment when it comes to infants. Ordinary treatments are those currently offered to infants. These treatment

interventions include intubation, ventilation, intravenous fluids, inotropes, pain relief and antibiotics. Extraordinary treatments are those considered high risk, experimental and have a relatively small chance of benefit for the baby, and which can be ethically withheld or withdrawn (Glover & Caniano 2000, p. 59). When the outcomes are so poor, treating these infants could be considered to be extraordinary, remembering that what is today considered extraordinary treatment may be quite ordinary in the future (Way 1996, p. 392).

3.3.7 Best interests

It is difficult to know what is in the best interest of the extremely premature infant, or even if it possesses interests. If life in and of itself is considered to be a good, then loss of life could be seen as a profoundly negative event. If life, which is assumed to have meaning, is considered to be in the best interest of human beings, then in some cases it would seem acceptable to refrain from saving certain lives, because it is not in the interest of the person to live that life. The problem of uncertainty exists, for while there have been measurable and sustained advances in neonatal medicine, it is still often impossible to accurately predict with complete certainty the outcome for extremely premature infants. There is much evidence that points to the poor outcome of infants of 24 weeks gestation and less (Hack, Horbar, Malloy, Tyson, Wright & Wright 1991, p. 587; Whyte et al. 1993, p. 1; Synnes, Whitfield, Mackinnon, Lopes, Wong & Effer 1994, p. 953; Hack et al. 1996, p. 932; Battin et al. 1998, p. 469; Costeloe, Hennessy, Gibson, Marlow, & Wilkinson 2000, p. 670; Koh, Casey & Harrison 2000, p. 507; Lorenz 2001, p. 348; Chan, Ohlsson, Synnes, Lee, Chien, Lee, & The Canadian Neonatal Network 2001, p. 220; Lucey et al. 2004, p. 1559; Mikkola et al. 2005, p. 1391; Wilson-Costello et al. 2005, p. 997; Wood et al. 2005, p. F134), therefore at present it might not be in their best interests to be saved, and subjected to treatment when statistically they have a high chance of dying or being profoundly disabled. Nevertheless, even with the prospect of a poor outcome, it is difficult to know at what point on the treatment continuum the prognosis of the extremely premature baby becomes so poor that it is morally unacceptable to prolong its life (Doyal & Wilsher 1994, p. F67).

Prolonging the life of an extremely premature baby might be in others' best interest, but not in the baby's. There are benefits to the family in keeping the baby alive. Continued life support prolongs the baby's life and allows the family more time to experience a relationship with their baby and to find some meaning in the life and death. If the parents are hoping for a miracle it gives them more time for hope. Nurses who provide care to the baby whose life is being prolonged are likely to express feelings of frustration, confusion, anger and helplessness (Stutts & Schloemann 2002, p. 25).

Keeping the infant alive may have a positive outcome for the medical staff. While ever the infant is alive there is the possibility of gaining new knowledge about extreme prematurity by using experimental therapies (Mahowald 1986, p. 72). Keeping the infant alive might make the medical staff feel that they are doing something, rather than feeling helpless in the face of overwhelming odds. However, unless biological life is seen as valuable in and of itself, then maintenance of the baby's life for the benefit of others could be construed as exploitation, and the baby is being used for the purposes of others (Mahowald 1986, p. 77).

3.3.8 Sanctity of life

Belief in the sanctity of life is the moral conviction that all human life is sacred. Such life is seen as a divine gift, bestowed, sustained and then reclaimed by God (Kuhse 1987, p. 2). The view that all human life has equal value is a fundamental belief of a civilised society. Sanctity of life is firmly entrenched in laws and medical ideals. The Hippocratic oath admonished physicians to not give advice which might cause the deaths of their patients (Clark, 1993, p. 5). A striking difference is seen in the philosophy of the sanctity of life and the quality of life beliefs. Sanctity of life followers believe that human life is inviolable, and that the life has value regardless of the quality of the life lived, and that life and death decisions not be based on the quality or kind of life which is in question (Kuhse 1995, p. 104). The ability of technology to create life through artificial means, for example invitro fertilisation, and the ability of technology to sustain lives that would have ordinarily ended by natural means, suggests that the sanctity of life position is difficult to

maintain in the 21st century. One of the issues that seems to emerge from this debate is related to whether all human life has the same value. If the answer is yes, then this could lead to the indiscriminate preservation of life in an over zealous manner. If the answer is no, then humans should be respected because they have interests. Draper (1997, p. 166) has suggested that nurses see their work as promoting the quality of life of their patients while Sims-Jones (1986, p. 25) suggests that nurses who care for babies who have little potential for human happiness need to come to terms with their own views on the value of life.

3.3.9 Quality of life

Quality of life is featured in debates in medical and philosophical ethics. Quality of life is a difficult concept, and although much has been written on the topic, a universal definition remains elusive. Socrates (cited in Plato 1956) claimed "...we should set the highest value, not on living, but on living well". This statement implies that having a life (biological life) is not as important as living a life (quality of life). This is perhaps a simplistic view of a very large problem. There are authors who claim that quality of life is about definable characteristics or attributes that must be present before a person is worthy of moral respect (Fletcher 1972, p. 1), while others relate it to capacities such as self consciousness, rationality and the ability to relate to others (Kuhse 1985, p. 105). Regardless of the attributes required for quality of life, there is also a relational component, where relationships are important for human beings. It is difficult to know where extremely premature infants are situated, as they probably do not have these capacities at birth, but there is the potential for the capacities to develop. It is this potentiality that is of significance for the baby.

The problem with quality of life determinations is that they are ambiguous, and have been interpreted to mean a life with value to society (Mellien 1992, p. 131). The nature of quality of life is the value of the life to the infant, not the value of the life to society. Quality of life has major implications for extremely premature babies. When there are repeated intrusive, painful interventions that could prolong the infant's life indefinitely,

but are not associated with any satisfaction in life for the infant who is forced to endure it, and could deepen and prolong the anguish and grief of the family, then according to Mahowald (1986, p. 68) offering the family the opportunity to withdraw life support is a humane alternative. This is a quality of life decision, because although the baby might die, without withdrawal of treatment it is not likely to be in the near future.

The law in Australia is unclear on the extent to which an infant's quality of life can be considered when making treatment decisions. According to Skene (1993, p. 296) there is no legislation, which prescribes the care given to handicapped babies, and few cases have been decided in the courts. When making quality of life decisions about newborns, Rhoden (in Knepper 1994-1995, p. 39) suggests that "life span, prognosis, and potential for cognitive development and human interaction" are considerations, which should drive the decisions.

3.4 Decision making

Premature labour and delivery of a tiny baby represents a time of profound distress for many parents. The gestation period of 37 to 40 weeks is the time is required for the development of a mature fetus, but also for preparation both physically and emotionally of the parents for the acceptance of a new member into the family, and their new role as parents. When the mother gives birth to an extremely premature baby, parents are generally unprepared for what will happen to their baby, and to themselves in the process of the events. The emergent nature of preterm labour and delivery may make it impossible for the parents to participate in decision making for their baby, or to even articulate their desires and preferences. Physical and mental status is thought to limit a mother's ability to make rational decisions (Pinch & Spielman 1990, p. 712). Parents may not be able to assimilate the information about their baby's prognosis for surviving birth and the NICU experience. It is virtually impossible for neonatologists to give an accurate indication of survival and long term prognosis prior to birth.

The birth of an extremely premature baby can leave the parents with feelings of shock, anger, guilt and shame (Cohen 1990, p. 83). Profound ethical dilemmas related to life and death exist, and need to be addressed at a time when the parents are experiencing a crisis situation. Jellinek, Catlin, Todres and Cassem (1992, p. 24) state, "...grief replaces the family's hopes for a happy baby, their expectations of bringing a new baby into their home and the dreams which come with raising this child".

By law and custom parents are given huge scope in decision-making for their children. In the main, health care issues are left to the discretion of the parents. Parents act as surrogates because infants and children are not autonomous, and are therefore unable to determine what is in their own best interest. Parents cannot be expected to assimilate everything that they need to know, such as possible short term and long term prognosis, the benefits and burdens of treatment, to make decisions for their acutely ill extremely premature newborn. Such decisions include the most urgent one; should the infant be resuscitated at birth. Although parents may at first insist on treatment when they are confronted with a premature delivery, their opinions about treatment may change when they are able to understand the implications of the birth of an extremely premature infant (Fetus and Newborn Committee, Canadian Paediatric Society; Maternal-Fetal Medicine Committee, Society of Obstetricians and Gynaecologists of Canada, 1994, p. 547).

3.4.1 Communication with parents

Communication with parents at the time of delivery of a pre-viable infant allows for parental preferences to be known and acknowledged by health professionals. The presumed gestation of the baby may be the indicator for offering prenatal counselling. Prenatal consultation by a neonatologist is invaluable in helping educate parents about what is likely to happen when their baby is born (Halamek 2001, p. 116). Munro, Yu, Partridge and Martinez (2001, p. 276) found that at 22 weeks gestation, 24% of obstetricians counselled the parents, whereas at 25 weeks 77% of obstetricians counselled the parents about the survival at this gestation. This is a substantial increase in only three weeks, and shows how important one week extra in the uterus can be for the baby. Doran

et al (1998) found that physicians resuscitated extremely premature infants at delivery when they were very uncertain about the prognosis, and when the parents' desires about treatment were not known. Prenatal counselling of the parents about the likelihood of outcomes was not attended to in approximately one third of extremely preterm deliveries. With counselling the parents might have been made aware of the implications of aggressive therapy and the likelihood of a poor outcome. Previously neonatologists have been, "...accused of over treating infants, generating huge expenses and causing unnecessary suffering while merely postponing death, or prolonging lives with devastating disabilities" (Doron et al. 1998 p. 2), however Doron et al's (1998, p. 2) research suggests that parents may inadvertently be responsible for over treatment of their baby. Parents are understandably oblivious of the outcomes for extremely premature infants, therefore counselling by the neonatologist should provide the parents with choices in relation to the provision of life support therapy.

3.4.2 Decision making strategies

Decision-making regarding the newborn has traditionally been the domain of the neonatologist, with varying degrees of input from parents. In the main, decisions related to resuscitating an extremely premature infant at birth, or withdrawing life support are clinical decisions, requiring clinical judgement backed up by the results of research and wisdom. They are, however, also ethical decisions. These decisions are value judgements, not the value of the baby itself, but whether there was value for the baby just being alive. Decisions to resuscitate an extremely premature baby are overlaid with emotions, therefore the delivery room is not the appropriate place to be making these decisions (Cooper 1990, p. 327). Emotions can decrease the chance of informed decision making. It is difficult to determine how these decisions are made and whether there are frameworks used when making these types of decisions. The treatment decisions regarding extremely premature infants usually fall into two categories. These are those related to resuscitation and whether or not the infant should be resuscitated. Once resuscitated and attached to life support in the NICU the second type of decisions are those regarding discontinuation of NIC therapies and allowing the infant to die.

Rhoden (1986, p. 34) has described three different types of decision-making that she believes is being practised in varying institutions around the globe. In the ‘statistical prognostic strategy’ intensive care would be provided only for those infants who have acceptable survival statistics. A trial of intensive care is given in the ‘individualised prognostic strategy’, which gives all infants a trial of intensive care, but care is withdrawn when the infant’s prognosis is poor. The ‘wait until certain’ strategy is where all infants receive intensive care until death becomes apparent. The wait until certain strategy ignores statistical probability, it ignores information derived from tests and procedures, and it ignores the complex ethical issues involved in the situation. For Paris and Schreiber (1996, p. 597) this approach means that “technology takes over and controls the choices until no choice is left”. A combination of these strategies is used in NICUs, although as recognised by Rhoden (1986, p. 42), it was the ‘wait until certain strategy’ that was likely to carry the greatest risk for futile treatment. According to this approach, letting an infant die who may live an acceptable life is far worse than saving an infant who becomes profoundly disabled (Paris & Schreiber 1996, p. 578).

It is normal practice, in theory, to have the most senior member of the neonatal team present at the delivery of an extremely premature infant (Whitelaw and Yu 1996, p. 301). Unfortunately, the burden of decision making often falls to the most junior medical staff. Junior medical staff are not experienced sufficiently to make such difficult decisions (Stahlman 1995, p. 162). Maturity and experience are the best teachers, and medical staff can get caught up in the moment. Silverman (1992, p. 971) looks back on his career as a neonatologist and how his ideas have changed over the years.

The question never entered my head! And it never seemed to occur to my teachers. The baby was presented at grand rounds as a triumph of mechanism-guided treatment, and I was made to feel like a hero. My rescue fantasy was fulfilled...I was very disappointed that the parents did not share these joyous feelings of high adventure.....I tried to focus their attention on the miraculous present, and I was annoyed that their thoughts were fixed on an uncertain future.....the longer the baby lived, the more angry the parents became at the thought

that I, a young, childless house officer, with no personal experience in rearing a normal child (much less than one who might be disabled), now held in my hands an important determinant in the fate of this family.

Neonatologists consider the consequences of treatment for extremely premature babies. Singer (1985, p. 335) found that 38% of neonatologists in Australia would not initiate treatment on a baby of 24-25 weeks gestation, and not a single respondent in a study by De Garis, Kuhse, Singer and Yu (1987, p. 224) believed that the fact that the extremely premature baby was alive, should override considerations related to the quality of its survival. The NSW guidelines (Lui, Bajuk, Foster, Gaston, Kent, Sinn, Spence, Fischer & Henderson-Smart 2006a, p. 495) suggest it is acceptable medical practice not to initiate treatment prior to 26 weeks gestation.

There can be conflict between the staff and the parents about what they believe is in the baby's best interests, and whether or not treatment should be continued. Such conflict can be emotionally draining, ethically difficult and possibly have legal ramifications for the medical staff (Nelson & Nelson 1992, p. 427). Resolution of the dilemma will involve two options: the medical staff convince the family to withdraw the life support, or the family convince the medical staff to continue the life support. Nelson and Nelson (1992, p. 427) emphasise that parents should not dictate the moral values of paediatric practitioners, and that courts are reluctant to compel medical staff to perform medical acts that violate their conscience.

3.4.3 The parents as decision makers

Parents are seen as an integral part of the decision making team because they bear the legal responsibility for the baby. Perhaps their involvement is paramount because in reality they have the most to gain and the most to lose by any decisions which are made. Jameton (1984, p. 249) suggests:

It is important to consult the family about borderline infants, partly because they will be the most important factor in the infant's future

welfare, and partly because the infant's impact on the family gives them a significant interest in their child's treatment.

Although parents should be viewed as partners in the decision-making, decisions to withhold or withdraw life support are primarily decisions of a medical nature, of which the medical staff bear the ultimate responsibility (Campbell & McHaffie 1995, p. 340), and parents should not have to bear the burden alone (Duff & Campbell 1973, p. 891). Duff (1987, p. 244) emphasises that the exercise of responsibility can make people stronger.

Difficulties can arise with parents and decision-making. The parents are likely to make decisions based on past experiences and knowledge, cultural, moral and religious beliefs, guilt, knowledge of the law, fear of the death of their child, and fear of unknown consequences for the child (Saal 1996, p. 42), plus they may desperately want the child to live. The parents will be under emotional stress, they may disagree with each other, or may fail to understand the situation (Neal 1990, p. 95). Optimal communication is dependent on clear and unambiguous communication between the staff and the parents. Parents have requested "full and frank information with no false reassurances" (McHaffie, 2001a, p. 19).

While this is the ideal, parents in a study by Pinch and Spielman (1990, p. 712) did not appear to give informed consent. The same study found that parents had little understanding of the medical problems of their infant, therefore it could be assumed that the parents were not given adequate information. In this situation this was not the case as documentation existed in the hospital records that substantiated that this information sharing occurred. Nurses in the same study were frequently mentioned as sources of information for parents (Pinch & Spielman 1990, p. 712).

While few would discount the important role that parents play in decision making for their critically ill babies, arguments have emerged that suggest that parents should not be involved in the decision making process (Marchwinski 1988, p. 19). It is believed that

parents can become burdened by decisions to withdraw or prolong life support. The burden comes from their intense feelings of guilt if the baby dies, or if the baby lives in a seriously impaired state. One of the most important reasons that parents should be involved is they have to live with the consequences of their decisions. Medical and nursing staff have to live with their decisions, families have to be reminded of their decision and live with these decisions for the rest of their lives. Silverman (1992, p. 972) stated that many parents feared disability more than death. The best interest of the baby and family should be what drives the decisions making, not the best interest of the staff. A nurse participant in Hefferman and Heilig (1999, p. 175) summed up the experience:

MDs are making such choices for parents and when the outcome is disastrous they just expect parents to take home severely handicapped babies and deal with life-long problems.

For parents to make informed decisions they need accurate information about the possible outcome and prognosis for their extremely premature baby. Hurst (2002, p. 41) suggests that parents need ‘empowering information’, which is information that is readily accessible, pertinent and understandable. The internet has become a common place for families to start, however a mother of a 24 week gestation infant stated that she “looked on the internet, but I was overwhelmed with all the horror stories” (Richardson 2001, p. 1503). Parents accessing the internet may not understand how their baby differs from those in the stories. Parents would benefit by being directed to reputable sites, which contain a balanced view of what can happen to these babies in the course of their treatment. Another difficulty, according to Harrison (1986, p. 171) is that health professionals may speak about the uncertainties associated with care, amongst themselves, but rarely will they share these uncertainties with parents. NIC is not an exact science, yet parents can believe that more hope exists when it might not.

Information can be a valuable commodity for parents, and several books have been written that are designed to give parents an idea of what awaits them during the time that their baby is in the NICU (Kitchen, Ryan, Rickards & Doyle 1998; Linden, Paroli &

Doron 2000), to help siblings (Resta 1995; Lafferty & Flood 1998; Pankow 2004; Amadeo 2005; Maher 2005; Hogue Wojhan 2006), and what to expect when they take their baby home (Garcia-Prats & Hornfischer 2000; Bradford 2003), or help families deal with loss (Kay 2000; Woodwell 2001). Many of these publications are designed to give parents hope for the future, (Smith 1999, Powell & Wilson 2000; Taylor & Hoekstra 2000; Dickerson 2000; Davis & Tesler Stein 2004; Minton 2007), or to help parents who have decided to withdraw life support (Davis 1994). These publications contain stories of hope for parents, many of which are not realistic. Babies who survive in these stories are described as miracles (Ulrich 1998; Smith 1999; Powell & Wilson 2000; Lloyd 2001; Linnell 2001; D’Emilio 2002; Veitch 2002; Taylor 2003). Miracle babies also receive regular media coverage, which results in high public expectations of success (Gill 1994, p. 448). The use of the word miracle is not realistic, especially if a miracle is defined as “an event that appears to be contrary to the laws of nature and is regarded as an act of God” (MSN Encarta 2006). How the babies survive can be explained, therefore they are not miracles. Although some of these extremely premature babies survive intact, many more will suffer from life long physical and mental disabilities. Magazine stories and books may encourage parents to view the world with optimism. This implies that the parents live “in something of a fantasy world, seeing only the good things in life, choosing not to see or acknowledge anything unpleasant” (Daniel 2002). The parents may not fully comprehend the enormity of the situation with which they are faced. Pinch (2002, p. xxi) views the miracle baby stories and the reluctance of society to acknowledge the real dimension of neonatal health care, as the “shadow side of neonatal care”. Stahlman (1990, p. 167) emphasises that the medical staff may be to blame for the misperceptions because “...we have allowed the media to publicize our successes widely, and we have minimized our failures to the public”. Lucey (2004, p. 1819) states “these infants are not ‘miracle babies’. We are neither ‘miracle workers’ nor ‘techno crazies’”.

3.4.4 Overriding parental wishes

Parents are at liberty to refuse to consent to medical treatment for their children. They generally do so because their religious beliefs conflict with the medical advice, or they

would prefer to seek alternate advice because they disagree with the medical advice, or they wish no treatment at all for their baby (Knepper 1994-1995, p. 3). As they are the legal guardians for their children, this is their right. The medical staff might override parental wishes when the infant is considered to be less, or more viable than was anticipated (Lantos, Tyson, Allen, Frader, Hack, Korones, Merenstein, Paneth, Saigal, Stevenson, Troug & Van Marter 1994, p. F220; Peerzada, Schollin & Hakansson 2006, p. 1988). There have been situations (Stinson & Stinson, 1983; Lotter 1998) where parents had decided that they did not want their extremely premature babies treated, but their decisions were overridden by the attending neonatologists. Stinson and Stinson (1981, p. 5) described their son Andrew's situation as "the story of what can happen when a baby becomes hopelessly entrapped in an intensive care unit where the machinery is more sophisticated than the code of law and ethics governing its use".

The case of Miller versus Columbia HCA is an account of refusal by medical staff to accede to a parental refusal of resuscitation. The parents of Sidney Miller refused her resuscitation at 23 weeks gestation, however their request was overruled by the medical staff. The parents sued the medical staff and Columbia HCA. The court recognised the parents legal requirement to make decisions for their child, however, they did not award in favour of the plaintiff (Annas 2004, p. 2118). Sidney Miller during the course of her treatment suffered an intracranial haemorrhage. The parents requested life support be withdrawn, yet the medical staff refused. At the time of the trial Sidney was "seven years old and could not walk, talk, feed herself, or sit up on her own...was legally blind, suffered from severe mental retardation, cerebral palsy, seizures, and spastic quadriparesis in her limbs...could not be toilet trained, required a shunt in her brain to drain fluids, and needed care twenty-four hours a day" (Annas 2004, p. 2120) . At age 14 Sidney was considered to "lack the capacity for symbolic interaction" (Robertson 2004, p. 35).

The family of Sidney Miller sued Columbia HCA for wrongful life (Atkinson 2002, p. 1). Wrongful life is where the infant sues the mother or others for being born (International Centre for Bioethics and Disability 2004). In order for a wrongful life claim to succeed it

needs to be proven that someone has been damaged by having been brought into existence (Bell & Loewer 1985, p. 127). Even more recently, parents of extremely premature babies stated they were given very little information about probable outcomes and few, if any, choices about the treatment that their child received. Moreover, they stated “many of us were threatened and made to feel like criminals for questioning even the most extreme medical measures” (Culver, Fallon, Londner, Montalvo, Vila, Ramsey, Ramsey, Trebaol, Houle, Williams, Williams & Wolding 2000, p. 3201).

The most famous case of parental refusal of care for an extremely premature baby, is the Messenger case in the USA. Michael Messenger was born at 25 weeks gestation. His parents had been informed of the statistics on the prognosis for survival and possibility of cerebral bleed. His father was a physician and requested no extraordinary efforts to resuscitate the baby at birth. The baby was born in poor condition, but was nevertheless resuscitated by a physician’s assistant, and attached to life support (Peabody & Martin 1996, p. 473). When the baby was admitted to the NICU the parents requested some time alone with their baby, whereupon the father disconnected the baby from life support and he died in his mother’s arms. A jury returned a verdict of not guilty to murder (Paris & Schreiber 1996, p. 580; Pinkerton, Finnerty, Lombardo, Rorty, Chapple, & Boyle 1997, p. 283). These stories illustrate the difficult situations that families find themselves in, when their informed decisions are disregarded. Although the parents have the right to request non-intervention, it seems that once the infant is resuscitated and provided with intensive care the dynamics of the situation change. Withdrawing life support seems to be harder than withholding life support.

Medical staff might override parental wishes from the belief that they are making the correct decision. If the medical staff believe that parents will be burdened by decision-making then what they see they are doing is removing “the burden of freedom” (Mahowald, 1986, p.68), and making the decision for them. The other end of the spectrum is where the parents refuse to allow life support to be withdrawn even when the prognosis is demonstrably poor. Paris, Crone and Reardon (1991, p. 273) described the case of Baby E.T, who was a four month old infant of very low birth weight, whose

cerebral cortex had been eroded from a major intracranial bleed. The physicians, staff and ethics committee believed that the mother's request for continuation of life support was not warranted. In this situation the physician sought a court hearing. The baby died while waiting for this court hearing. There is guilt associated with the decision regardless of how it is made, and families need reassurance that allowing a loved one to die "is sometimes the most loving and caring alternative available" (Mahowald 1986, p. 68).

3.5 Withholding versus withdrawing life support

One of the difficulties surrounding the care of extremely premature infants is related to whether there is a difference between withholding resuscitation and not instituting life support, and the withdrawal of life support. There is no way of knowing at the delivery of the extremely premature infant whether that particular infant will live, die, or be profoundly handicapped (Ho 1992, p. 595). Different views abound. Selective non-treatment of the marginally viable infant is accepted if the baby will inevitably die in the short term (Doyal & Wilsher 1994, p. F66). The extremely premature infant is reliant on the technology of the NICU to sustain its existence, otherwise it would die in the short term. However, refusing to initiate intubation, resuscitation and life support on an extremely premature infant could be construed as indirect infanticide (Mahowald 1986, p.65). It could also be argued that there is little or no difference if the outcome is death, however Frohock (1986, p. 32), when discussing a theoretical case of a 24 week infant weighing 400 grams, argues that:

Suppose you don't ventilate a child because you presume nonviability. The evidence for nonviability is very different in that case than ventilating a child and then stopping the ventilator. The ventilator itself, to the courts, seems to confirm the impression that there was a chance for viability and you withdrew that support.....the physiology kills them, not the lack of support
(Wade, in Frohock 1986, p. 32).

There is a difference between not initiating life support because the infant is presumed to be pre-viable, as opposed to commencing and then withdrawing life support.

There is difficulty knowing if there is a moral difference between the two decisions, and if they easily distinguished. Hence, it is more difficult to stop a process that has already started (Binder 1994, p. 48). Ethicists see no moral difference between withholding and withdrawing life support, while clinicians see discontinuing life support as an act, which is morally preferable to not instituting the life support in the first place. Clinicians view the difference as withdrawal is an act, something which is done, while withholding is an omission, something which is not done (Mellien 1992, p. 132). Theoretically, it is easy to take a standpoint. However, when faced with the decision of whether to or not to resuscitate a preivable infant, with anguished parents appealing to the staff to do everything to save their baby's life, the reality is a different matter.

There will always be uncertainty about the infant's prognosis, and there is a risk of making the wrong decision (Peterson 1994, p. 380). This could result in the non-institution of life support or allowing nature to take its course, but the infant lives anyway. Life support is then instituted at a later stage, but the damage has already been done to the brain and other organs (Lantos 2001).

3.6 Futility

There are limits to what science and technology can offer extremely premature infants. Parents may feel entitled to expect everything that medicine can offer, even if it is futile. Futile efforts can be defined as those which serve no useful purpose, or are completely ineffective (Hylton Rushton & Hogue 1993, p. 180). Medical and moral dimensions of futility exist, and decisions need to be made about whether treatment for an extremely premature infant will be medically viable, or judged to have low probability of success, and therefore there is no obligation to provide them. While it is true that with experimentation the futile becomes efficacious, at present evidence exists to show that less than 24 completed weeks gestation and less than 500 grams will have a poor outcome, therefore aggressive treatment for extremely premature infants less than 500 grams and less than 23 weeks can be considered futile (Botkin 1990, p. 307; Stahlman 1995, p. 163; Lucey et al. 2004, p. 1559).

Futility is an ambiguous concept, because it is difficult to predict with certainty that therapy will be of no benefit to the patient. When faced with the dilemma of whether or not to resuscitate an extremely premature baby, it could be decided by the size of endotracheal tube (ETT) that can be inserted. The inability to site a 2.5mm ETT means that an infant is preivable, because at 24 weeks gestation the trachea has developed sufficiently, and is therefore large enough to accommodate a 2.5mm ETT. Frohock (1986, p. 153) suggests that at the birth of a preivable infant “a technical problem is facing the doctors. The baby’s trachea seems too small to accommodate the smallest intubation tube made (2.5cm). So the staff cannot intubate him without doing great harm to his trachea”.

Futile treatments are those considered by the neonatologist to be medically or ethically inappropriate because there are more burdens than benefits to the baby. The most difficult futility cases are, according to Lantos et al, (1994, p. F221) those where the parents seem to be emotionally unattached to the infant and yet demand continuing care. In these cases the health care team feel justified to be willing to try and protect the infant from pain and suffering because the parents are demanding over-treatment. The majority of deaths in the NICU are the result of selective non-treatment by neonatologists, with few infants receiving maximal support until death (Wall & Partridge 1997, p. 64). Deaths occur from a combination of non-initiation and withdrawal of life support decisions. Quality of life is taken into account, but the majority of decisions are based on the belief that treatment was futile (Wall & Partridge 1997, p. 64).

3.7 Allocation and utilisation of resources

The allocation of medical resources is an issue that generates substantial debate. When babies are involved the debate is likely to become highly emotional. The setting of priorities provokes a substantial emotional response, especially when priorities are being set on human life (Kirkley 1980, p. 873). The highly technological nature of the NICU makes it one of the most expensive health care options. The cost of NICU services are high for the extremely premature infant and it has been suggested that for every dollar

spent on antenatal care, there would be a saving of three dollars on NICU expenses (Walden & Sala 1993, p. 572). Antenatal care on average extends a high-risk pregnancy by two weeks, which provides substantial savings for the NICU and a better outcome for the infant (Rogowski 1998, p. 35). Extra time in the womb can mean extra growth. Even a small increase in the birth weight of these tiny babies can result in substantial and immediate savings (Schwartz 1989, p. 174).

Macro allocation of resources occurs when a budget is allocated to health care. It is, however, the micro allocation that is likely to be the cause of concern for neonatal nurses. The debate generally involves decisions about infants deemed to be too expensive to save. For the extremely premature infant the cost of intensive care increases with decreasing birthweight and gestation (Mugford 1988, p. 99; Petrou 2003, p. 18). These cost considerations will continue after hospitalisation depending on the degree of disability and the services required (Gorski 1985, p. 271; Petrou 2003, p. 19; Petrou, Henderson, Bracewell, Hockley, Wolke & Marlow 2006, p. 77).). The parents fund much of the care of the babies after discharge, so it is not only the initial hospital care in NICU that is considered in the cost equation. Many low birth weight children will reach adulthood with a disproportionate amount, in comparison to full term children, of health and developmental problems. Ongoing problems experienced by these adults are substantial in terms of increased morbidity, lost earnings and a greater demand for health care and social services (Lewit, Baker, Cormon & Schiono 1995, p. 48).

Prediction of which infants will live, die, or be profoundly handicapped is difficult. Cooper, Berseth, Adams and Weisman (1998) attempted to determine the future life expectancy of a group of premature infants. While survival of the smallest group improves dramatically in the first few days of life, there remains significant risk for a late occurring death, ie death beyond the 84th day of life, in those infants 500-700 grams (Cooper et al. 1998, p. 975). Most deaths of extremely low birth weight infants occur within the first week of life (Bohin, Draper & Field 1996, p. F110; Cooper et al. 1998, p. 975; Doron et al. 1998, p. 574) which suggests the utilisation of health care resources by non surviving infants is limited. The utilisation of health care resources by infants who

survive to 84 days of life is substantial. Ventilation expenditure for infants of 24 weeks gestation and less makes a small impact on available resources (Bohin et al. 1996, p. F112). The application of ventilation provides families with an opportunity to adjust to the situation. Most extremely premature babies die despite this support. The value of the time the family spent with the baby has been weighed against the costs to the NICU budget, and found to be worthwhile especially for the family (Bohin et al. 1996, p. F112). Tiny babies who die consume only a very small proportion of resources, making it difficult to ration resources (Stolz & McCormick 1998, p. 346). The rationing of resources to achieve modest savings can only occur with longer gestations, greater than 26 weeks. Babies of these gestations are more likely to survive with minimal handicaps, but rationing of resources would be unacceptable.

It has been argued that resource allocation decisions made about newborns should compare favourably with those for patients at other stages of life (Lantos et al. 1994, p. F222). The cost of preterm birth in Australia is in excess of \$100 million dollars, with \$64.5 million spent on the ventilator care of premature infants in the NICU (National Health and Medical Research Council (NHMRC) 2000, p. 23). In 1989 the daily cost of a level 3 intensive care bed for a neonate was \$1287 (NHMRC 2000, p. 20). It is estimated this cost would be closer to \$2000 per day in 2007. Campbell (1992, p. 158) suggests that the cost per survivor at 24 weeks gestation exceed \$250,000. It is difficult from an economic point of view to determine which extremely premature infants should be saved. Comparison between babies and adults is difficult. NIC is more economically favourable than many other health care programs (Yu 1997, p. 347). It is twice as cost effective as bone marrow transplantation, three times more cost effective than kidney transplantation, eight times more cost effective than liver transplantation, nine times more cost effective than renal dialysis, twenty six times more cost effective than coronary bypass surgery, and forty times more cost effective than coronary care. The main reason for the economic improvement is the improved survival rate without an increase in disability rate among survivors (Yu 1997, p. 347). The increased survival of these babies, however, has resulted in an increasing prevalence of children with disabilities. More tiny babies are born and survive, therefore the total disability rate has increased (Lorenz et al. 1998, p.

425). The cost of NIC has decreased since the introduction of surfactant for respiratory distress (The Victorian Infant Collaborative Study Group, 1997, p. 202), but it has been calculated that the lifetime earnings of babies less than 900 grams at birth might not exceed the total costs of their care (Congress of the United States, Office of Technology Assessment 1987, p. 60).

In Australia the public, through taxation, pays for most intensive care services for newborns. Singer (1987, p. 278) emphasises that saving the lives of tiny infants is not exclusively valued by society. If this was the case there would not be money for defence, roads, national parks and other areas of health care. Singer (1987, p. 278) is sceptical of the motivation of people who are outraged by the thought that extremely premature infants might not get treatment. These same people have not been forthcoming with support for higher taxes and more money allocated to health budgets that pay for short term and long term care for NIC graduates.

With increasing demands on the health care dollar there has been no reduction in the availability of NIC beds for sick babies (Freund 1993, p. 286). This situation exists because the NICU is seen as a worthwhile service by society.

3.8 The function of ethics committees

Deciding what is ethical in a given situation can be a difficult task. Bioethics is considered by many to be an ill-defined, abstract intellectual pursuit, with little clinical value (Southgate & Annibale 1995, p. 42). Ethics committees have evolved over the last decade. They are groups of suitable individuals who could be consulted when consensus regarding patient care could not be reached (Waltman & Schlenk 1999). Ethics committees provide forums where conflicts in professional and personal values can be raised and debated (Levine-Aruff 1989, p. 447). These committees function in an advisory capacity and do not make decisions. They are rarely consulted for the day to day decisions (Lantos et al. 1994, p. F222). It is thought that ethics committees may reduce the likelihood of hasty or unreasonable decisions (Tyson, 1995, p. 207). Potential

problems can arise with the use of ethics committees. Firstly, one of the cited reasons for their benefit is that their lack of involvement allows them a degree of objectivity, which may not be possessed by the caregivers and family. This objectivity however, does not give them an appreciation of the difficult decisions that need to be made in the delivery room and NICU (Southgate & Annibale 1995, p. 43). Secondly, they might not understand the intricacies related to the baby, its condition and the family. Ethics committees could help to establish health care policy, because very few NICUs have established guidelines concerning the termination of life support for neonates (Berseth 1987, p. 70). Thirdly, the ethics committee might be biased by institutional concerns and constraints. Annas (1991, p. 18) is highly critical of ethics committees, suggesting that the primary function of ethics committee is to provide protection for the institution, with the majority of the members researchers from the institution. It would be a mistake to think that objective outsiders could make policy decisions related to the life and death of extremely premature babies. Redman and Fry (2000, p. 365) found a low utilisation of ethics committees for decisions of an ethically sensitive nature. Leuthner (2001, p. 195) speaks of the odd situation in the USA where the medical staff caring for an extremely premature baby turned to an ethics committee for advice, before presenting the available options to the parents.

Ethics committees in the USA and Australia have different functions. In the USA infant bioethics committees were established after the Baby Doe regulations as a way of monitoring decision making, and to provide an avenue for discussion. An ethics committee should serve the institution, researchers, the patients and the wider community. In Australia, ethics committees have the best interest of all involved, however they mainly serve the needs of the institution. The NH&MRC (2006) states that ethics committees determine whether research proposals are suitable to be carried out on human subjects. Ethics committees are a misnomer in Australia. The majority of ethics committees in Australia are research ethics committees, and do not deal with ethical dilemmas (McNeill, Walters & Webster 1994, p. 487). In some situations ad hoc committees are convened specifically to discuss a particular case or issue. Difficulties arise when a quorum is needed to make decisions in the middle of the night, and

irreversible decisions have to be made before the committee can assemble (Kuhse, Mackenzie & Singer 1988, p.239). Schroeter (1996, p. 588) found that 44% of nurses who had consulted ethics committees found the ethics committee did not adequately address their concerns. The ethical dilemmas confronting nurses have been documented as being related to futility, withholding therapy, pain management, informed consent, capacity to consent, full disclosure to or honesty with patients, attention to advance directives, do not resuscitate orders and over-treatment (Ott 2000, p. 57). Currently, ethics committees in Australia are not used to solve dilemmas about extreme prematurity.

3.9 Conclusion

Babies born at the edge of viability present a challenge for all who care for them. Life saving interventions on babies that are not successful can have an impact on all those involved, however the loss of a baby who may have a future can be just as devastating. Although much uncertainty exists, the outcome for babies less than 24 completed weeks gestation, or less than 500 grams, is poor. It is, therefore, legally, ethically, medically and financially appropriate to withhold resuscitation at birth, depending on the condition of the baby. Conversely, once resuscitated, it is also acceptable to withdraw life support when the prognosis will be poor. Questions have arisen about whether extremely premature infants are saved babies, or “victims for life” (Murphy 1989, p. 285). Although the best interests of the baby should direct any decision-making by the caregiving team, babies do not exist in isolation. The best interest of the baby and the family will always be interdependent. Parents have a legitimate role in decision making, but they require an accurate and honest appraisal of the situation so their consent is seen as informed. There would need to be strong reasons for parental preferences to be overridden, especially if the baby is of marginal viability. Caring for tiny babies is a stressor for neonatal nurses, but they too have a place in the decision making process. Experienced neonatal nurses can offer another perspective on the situation.

The prenatal prediction of the chances of survival of extremely premature infants is a difficult task, and fraught with many challenges. It is, however, essential from a resource

allocation perspective that obstetricians and neonatologists are able to predict which infants at least have a chance of survival. On the one hand if the chance of survival is underestimated there are likely to be high levels of mortality and morbidity among these babies. However, on the other hand if their chances of survival are over-estimated this will result in the death of the infant after large amounts of resources have been used to save its life.

3.10 Summary of the literature review findings

Due to advances in technology babies of extreme prematurity are surviving with greater frequency. A baby's chances of survival greatly increase with each additional week of uterine existence. Estimates of fetal weight and gestational age can be inaccurate, making it important to see the baby at birth before making treatment decisions. Following birth however, it is unclear whether aggressive treatment is beneficial or prolongs the dying process. It is often impossible to accurately predict the chance of intact survival for these babies. Major complications can occur, sometimes necessitating discussions about treatment withdrawal. Parents have a role in decision making, but are often asked to make decisions at a time when they are vulnerable and grieving.

Neonatal nurses have begun to question the wisdom of saving all extremely premature babies, because of their concern for outcomes. Neonatal nurses have been shown to want extremely premature babies to have the best chance at survival, yet survival brings a different set of problems and rewards. At the margins of viability these problems can be experienced as ethical dilemmas by neonatal nurses.

The following chapter will explore the methodological issues related to the research, explaining in detail how the research was performed.