

<p style="text-align: center;">CHAPTER 6: IT'S ALL ABOUT THIS BABY</p>

6.0 Introduction

The neonatal nurses in this study held the babies, although extremely premature, to be individuals. They believed there should not be rigid generalised rules when decisions needed to be made about extremely premature babies. Seeing each baby as an individual meant that decisions about treatment would be based on the baby's condition at birth and its response to resuscitative treatment and not on arbitrary criteria such as birth weight and gestation. This means each baby is given every opportunity. The nurses recognised, however, that not all can or will survive and that a degree of robustness on the part of a baby was required for survival.

Babies of extreme prematurity present medical staff and parents with hard choices, however, for the nurses the focus of care was about recognising the individual nature of each baby. Giving the baby the opportunity to survive was important for the nurses. For them, giving the baby the opportunity to live allowed the baby to decide its own fate. In this chapter the dimensions of the theme, it's all about this baby are explored. The neonatal nurses were passionate that each extremely premature baby should be given expert treatment. They held hope yet carried expectations that the baby would not survive.

6.1 Confusion about this baby

There was confusion and uncertainty for the nurses about the decision making related to saving tiny babies. The nurses recognised that NIC medicine was not an exact science, yet they were sometimes confused about how different decisions could be made for babies of the same gestation. Different decisions could be made by different consultants. The nurses wanted to understand the decision making process, but the decision making processes was not transparent. Transparency was important.

6.1.1 Being confused about gestation

The nurses believed that one of the major difficulties associated with premature labour and premature birth was that the estimated date of confinement could be incorrect. Ultrasound estimations are accurate only within a two week time frame (Mongelli, Peek & Gardosi, 2007, p. 3), meaning it was possible that a baby thought to be 24 weeks gestation, could be 22 weeks, 24 weeks or 26 weeks gestation. This two week discrepancy would pose difficulties for clinicians. The nurses thought that neonatologists would inform parents they would assess the baby at delivery. There is a large difference in the potential between babies born at 22, 24 and 26 weeks gestation. The nurses emphasised the importance of the overall response of the baby to treatment, because, *'...we no longer look at gestational age as the be all and end all, because you know you've got two weeks'* (Nurse 1).

The anticipated gestation caused confusion and uncertainty for the NICU staff, particularly in situations where a baby was thought to weigh more than 500 grams. The nurses knew that the interpretation of gestation could be problematic. Their concern emanated from being told the baby was a certain gestation, and when the baby was born the gestation was lower. One nurse stated, *'We've been told they're 23 or 24 [week] and then they come around [to the NICU] looking like a little golf ball head with absolutely no features and very fetal'* (Nurse 14). The nurses were convinced gestation estimation was often very bad guesswork. One nurse explained:

When this child comes out, you get the call a 24 weeker weighs at least 550 grams, and you get there and you've got fused eyelids and you look and you think 'This is no 24 weeker'. (Nurse 2)

The nurses thought that obstetric staff did not want to make decisions about whether or not to treat the baby. By referring to the neonatal staff the decision about resuscitation and survivability was no longer the obstetric team's responsibility. The nurses made

reference to this issue several times and several nurses suggested that if the baby was born alive it became a neonatal statistic rather than an obstetric statistic if stillborn.

6.1.2 Being confused about birthweight

The nurses spoke of the difficulty of not knowing the weight of the baby until it was transferred to the NICU. They suggested personnel who made guesses, called “guesstimates”, of the baby’s weight were mostly incorrect. Oei, Askie, Tobiansky and Lui (2000, p. 357) found that birth weight was not considered important by 15% of their respondents. The birth weight was not available in the delivery room, however the majority of the respondents stated they would not have resuscitated infants less than 400 grams. The nurses in the current study thought this practice confusing because the medical staff would not know the birth weight if the baby had not been weighed. The nurses also understood that once intensive care was started, it was unlikely to be withdrawn because the baby weighed “x” upon reaching the NICU. This confusion continued for the nurses because if the baby was found to weigh 399 grams, they doubted life support would be withdrawn. One nurse spoke of the hypothetical situation of the extremely premature baby, resuscitated at delivery but not weighed, intubated and cannulated and taken to the NICU before it was weighed. According to this nurse each new piece of equipment added weight, albeit the increments are in grams only. When the baby was finally weighed the paraphernalia attached to the baby would contribute to the birth weight. The nurses considered birth weight an arbitrary figure. One nurse explained:

When we go to the low gestation labours, we don’t know the weight until we get back to the nursery. It is by sheer guess, and we are all really bad at guesswork. I don’t think anyone will admit you’ve only got 100 grams to guess on. (Nurse 1)

The nurses emphasised that birth weight was just as inaccurate as gestation when trying to determine if treatment should be commenced. They were acutely aware that babies could be small for gestational age, be ELBW, yet do well and require very little intensive care support. One nurse explained:

I've looked after a 29 weeker who weighed 500 grams and actually came out and needed no ventilation, needed 30% oxygen and he weighed 500 grams, and he was just the poor other half of a very fat twin. If you turned around in the old days and actually threw this child on the scales, you'd go 'Oh no sorry. Oh no that's it.' This child it was like 'Hey, I'm 500 grams. I'm puny, but I'm perfect'." (Nurse 1)

This situation provoked more confusion and uncertainty for the nurses. They were already confused about viability and questioned when a baby was truly viable and if legal viability endowed special options for care of an extremely premature infant. In some states of Australia babies are deemed viable at 20 weeks gestation and 400 grams, however the nurses' experience led them to believe there was no chance a 20 week baby would or could survive.

6.1.3 Being confused about withholding versus withdrawing life support

The nurses were confused about the difference between withholding and withdrawing life support. They believed they knew there was a difference, as did the nurses in McHaffie and Fowlie's (1996, p. 247) study. Withholding life support occurred when the baby was considered too immature to survive, therefore no attempt was made to resuscitate the baby. Withdrawal of life support occurred after the initiation of life support, when it was deemed the baby would have a poor outcome, or die regardless of treatment. Singh, Lantos and Meadow (2004, p. 1624) agree that treatment withdrawal seems more problematic than withholding treatment. Yet, there is no ethical distinction between not initiating life support and withdrawing life support because the outcome will be the same (Johnstone 1999, p. 324). Several nurses believed there was a moral difference and believed it was far worse to withdraw support than not initiate it. One nurse explained:

I know a lot of people think once you've started you can't stop, because that's different. Withholding is different to withdrawing. A lot of people have that emotional thing. Ethically they say there's no difference. (Nurse 16)

Whether there is a moral difference between withholding and withdrawing life support, several nurses believed a difference existed. Not initiating life support would indicate to the nurses that nothing could be done. Conversely, the nurses understood that initiating life support occurred if the baby had a chance of survival. Not initiating life support could have meant the baby was too immature, whereas initiating life support could have meant the baby had a chance of survival. For these nurses there was a difference. Perhaps they considered withdrawal of support different, because they had built up a relationship with the baby and its parents. For all the nurses interviewed, these relationships were important.

6.1.4 Summary

The nurses were confused about the fundamental criteria used to determine whether or not to treat extremely premature babies, namely birth weight and gestation and the difference between withholding and withdrawing life support. They perceived differences between babies of the same weight and gestation with a different clinical course. Perhaps the confusion surrounding birth weight and gestation is not necessarily negative. Hard and fast rules may mean all babies of 20 weeks gestation could be resuscitated, yet no babies less than 500 grams are treated. The approach in neonatal medicine that assesses individual babies would be lost.

6.2 This baby will decide

The nurses were convinced that extremely premature babies possessed personalities and they often attributed purposeful actions to the babies. The babies were credited with specific types of personality, moods, and the ability to decide to live or die. The nurses held that tiny babies were human beings who should be afforded all the protections their fellow human beings were afforded when it was obvious they would survive. In addition, the nurses wanted to know what the baby would choose if it could choose; such decisions revolved around whether they would choose to live or die.

6.2.1 This baby will decide its own fate

The nurses accepted that regardless of any intervention received, the extremely premature baby would decide its own fate. The nurses attributed adult type choices and autonomy to the baby. One nurse suggested:

It's every child for itself. They're going to stand up and wave the flag or they're going to say 'No sorry, I'm out of here! (Nurse 1)

The way the nurses spoke about the babies was as if they believed the baby would determine its outcome. This self-determination was probably more a reflection of the condition and vigour, the immature physiology, and the baby's response to treatment, rather than decision making capabilities. The nurses held the belief that when a baby made the decision to die, then treatment should be withdrawn. Nurses in a study by Schlomann (1999, p. 169) viewed babies as able to subvert or expediate plans by being able to choose to get sick, well or die. McHaffie and Fowlie (1996, p. 90) suggest that believing the baby makes the decision to live or die might make the nurse feel the responsibility for decision-making has been removed. It was not clear if the nurses in the current study reflected this explanation. They spoke about the baby making decisions, however, they took into consideration diagnostic results as well as the interactive cues of the baby. One nurse was convinced when she stated, *'If you give them a go and they've virtually said to you, "I can't take this any more," then you stop.'* (Nurse 12). The decision to stop could be related to deterioration in the baby's condition. Perhaps attributing decision making to the baby and wanting to know what the baby would choose were more about accepting the humanity of the baby, after all clinicians caring for older children and adults would consider these issues.

Neonatal nurses use interactive cues to assess the condition of the baby (Anspach 1987; Anspach 1993). Interactive cues were those that emanate from the interaction between the baby and the neonatal nurse and which elicit the patient's ability to interact (Anspach 1987, p. 215; Anspach 1993, p. 63). The cues include facial expression and eye contact,

among others, and were important for the nurses because they were seen as indicators of developmental changes. These changes must be observed over time, which make the nurses valuable, as they were with the baby for long periods of time. It was important for the nurses to interact with their tiny patients, because it was this interaction, or lack of it, that was fundamental to their relationship with the baby. It was during these interactions they thought they could determine which babies chose to live. Neonatal nurses in a study by Brinchmann (2000, p. 144) fervently believed that it was up to extremely premature babies to show a determination to live. The neonatal nurses saw it as a positive sign of vitality if the extremely premature babies in their care protested, were seen to be fighters, and have their own temperament (Brinchmann 2000, p. 144). This was described as a “resource phenomenon” (Brinchmann 2000, p. 144), where the baby was seen as having the resources to fight for its life.

It could be that attributing characteristics to the baby might make the justification of heroic life support measures easier. McHaffie and Fowlie (1996, p.9) suggest a baby who is seen as “clinging to life against the odds” might create the obligation to continue aggressive care even in the face of a poor outcome. Alternatively, Schlomann (1999, p. 169) suggests that the attrition of agency was a way to diffuse responsibility by extending it to the baby. Perhaps it is the personality of the “fighter” who clings to life, or attrition of agency to the baby that prompts continuation of treatment, but it is not evident in the data.

The nurses were convinced that babies even as young as 24 weeks gestation had personalities. The nurses spent many hours with the babies and were able to gauge their likes, dislikes and special quirks. One nurse explained:

When I first started working with these babies, people would hand them over and say, ‘This baby has been very naughty you know; it’s a very angry little personality.’ God, you know you’ve got to be joking, but in fact they have, they have got their little personalities. (Nurse 14)

It could be that the humanity of the baby was expressed when the nurse perceived the baby had a personality and would decide its own fate, making it easier to interact with the baby. The nurses considered the baby to be a human being who was able to perceive stimuli, and react in a positive or negative manner.

6.2.2 The baby's choice

Choice seemed to be important for the nurses. The nurses wondered what the baby would say, or choose if it had a voice. Several seemed desperate to know if the baby would choose to live or to die, or live with a severe disability. One nurse explained her concern:

If they had a voice, what would they say? Would they say, 'Leave me alone?' or 'Yes I want to live'. It's so hard when they can't speak for themselves. (Nurse 17)

Another nurse emphasised:

It's extremely frustrating because the baby can't say to you 'I'm in pain.' You think, they must be in pain, they must be feeling something. They must be saying, 'Please don't do this to me anymore.' (Nurse 16)

The difficulty for the nurses was that babies were unable to make their preferences known. Perhaps this was why there is a presumption in favour of life, unless the baby would be significantly impaired. One nurse who identified herself as having a strong Christian ethic stated:

I don't believe anyone has the right to decide what is a good life, even if the child ends up disabled. Well, we don't know whether they in fact are happy in their life. We just don't know that. (Nurse 13)

While it cannot be known whether the extremely disabled infant would prefer to live or die, Saigal et al (1999, p. 1991) found that disabled adolescents rated their own quality of life higher than health professionals. Decisions made for, and on behalf of severely

impaired infants, are made by able-bodied people. It is difficult to know whether or not the child would choose life over death, or whether he/she resented his/her existence. One nurse stated:

Because they're not going to turn around and say, 'Oh, thanks for saving my life so I can live in a bean bag for the rest of my life.' If they could talk, would they say that? (Nurse 12)

6.2.3 Summary

Extremely premature babies were considered by the nurses to have their own personalities. The nurses all attributed them the ability to make decisions about whether they would live or die, while recognising that the immaturity of the babies' physiology was ultimately linked with survival. Attributing personalities to tiny babies could be the equivalent of attributing the philosophical state of personhood to those babies who seemed to have the will to live.

6.3 The beliefs and values of neonatal nurses about this baby

There were times when the treatment decisions about extremely premature babies caused the nurses to experience ethical distress. This is defined as the psychological disequilibrium and the negative feelings that occur when people make moral decisions but are unable to act on their preferences (Johnstone 1999, p. 182). This ethical distress was either related to how the decisions were made, who made the decisions, and whether or not the parental input was truly informed. The nurses who were interviewed all believed that if the baby had a chance of survival it should be resuscitated and treated, until it was considered the baby would die, or be so damaged that treatment should be withdrawn. If the baby was deemed too immature the nurses believed it should not be resuscitated. The nurses held resuscitating an extremely immature baby was cruel and futile in the extreme.

6.3.1 To treat or let die

The extremely premature baby was seen by all the nurses who were interviewed as an individual. They believed the baby should be given every chance, but only if the baby's condition met certain criteria. Criteria in this sense related to vigour and robustness. The nurses were passionate that any baby not deemed overwhelmingly immature should be given every chance to survive. They held that if the baby was vigorous at birth it should be resuscitated. The need for CPR would decrease the baby's chance of survival (Lantos et al 1988, p. 91). The nurses were acutely aware of the mortality and long term morbidity associated with the need for CPR. Alternatively, to not resuscitate a baby whom the nurses deemed viable, and possibly have the chance of life, would have been unbearable for them as professionals. As professionals they adopted the ideal that each extremely premature baby be treated as an individual. McHaffie and Fowlie (1996, p. 246) found that neonatal nurses felt strongly that each neonate's life was precious, regardless of gestational age. The preciousness of life is an interesting concept, and no doubt extremely premature babies would be precious to their parents, but in this current study the baby's existence did not necessarily make them precious to the nurses.

It seemed to be important to the nurses to attempt to save a baby who made an attempt to live. Brinchmann (2000, p. 143) found that some extremely premature babies had more "spirit" and "vitality" than others, and this seemed to set them apart in terms of having a "fighting chance at life". Vitality was seen as a positive sign that the baby had the resources to survive.

The nurses were all committed to the belief that parents would want their extremely premature baby to have a chance of survival. They emphasised that parents were likely to want everything done. One nurse suggested that, '*...at 24 weeks you know you've got a bump, you can feel baby's kicking, that's a live person to that mother*' (Nurse 5). This is mirrored by Doran et al (1998, p. 574) who found parents' decisions to provide resuscitation for their extremely preterm infant were more frequent than their decisions to request non-intervention. One nurse explained:

When you're actually pregnant and you feel the baby moving inside and it's life...I think as a parent what you want to give that child is, if possible, a chance of surviving. (Nurse 3)

The nurses understood that parents and the public might have unrealistic expectations of technology, and assume that babies, no matter how small and immature, could survive. The nurses held that parents were probably unaware of the implications of extreme prematurity and unlikely to know the long-term issues for their baby.

The nurses were passionate that the baby be given a chance to live, but only if the baby made the effort to live. They had all seen tiny babies at birth attempt to breathe. They also stated they knew that tiny babies when born might have a heartbeat, gasp for air and attempt to cry, but were unable to sustain life. A difficulty arises because parents are unable to make a distinction between being born alive and viability (Macfarlane et al, 2003, p. F200). Realistically, the same could also be said of the nurses, particularly with their confusion related to birth weight and gestation.

The nurses all expected that if the baby made an attempt to live it should be resuscitated and admitted to the NICU. Decisions could then be made, and the care continued, or withdrawn following a thorough assessment. They emphasised how difficult and emotionally draining it was to have to make life and death decisions in the delivery room. This thinking is mirrored by Catlin (1999, p. 269) who found that the delivery room was not considered the proper site for resuscitation, and hence decision-making. Uncertainty in the delivery room led to the transfer of babies to the NICU where they could be examined in depth and a plan of action implemented (Catlin 1999, p. 269). One nurse emphasised, '*you've got to look at the actual baby, because if it's doing all the right things, like breathing and just crying, you can't just sit there and watch it die*' (Nurse 17). Krug (2006, p. 324) highlights the difficulty of "...doing nothing while a newborn is gasping". It is possible the issue could be about the social space of the NICU versus the delivery suite. Social space in this context suggests that the NICU is the legitimate place

for these decisions to be made. The reality is that decisions are not easier in the NICU, but not being hurried into making a decision in delivery suite could be crucial.

6.3.2 Leaving a baby to die

The nurses all experienced profound distress if they believed they were expected to do something that challenged their ethical or moral integrity. Several told stories from the past when they were midwives or midwifery students and had been requested to place extremely premature babies in kidney dishes, and leave them in the pan room to die. This experience was extremely distressing, particularly when the baby showed some signs of life. The nurses felt sad in this situation, because they knew the baby had little prospect for survival, but they recognised that here was a human being, forced to die alone. The issue was not one of sanctity of life, but rather the lack of respect and their belief that a human should not be left to die alone. The nurses were emphatic that these babies should have been wrapped and given to their parents to hold. One nurse told of her distress in a situation that occurred many years earlier:

To this very day I will take this to my grave. A preterm infant was delivered. I can't remember the gestation. It was this tiny little baby, it was back in the late 70's. This tiny little baby was breathing on its own. To compare it with these days it was a good-sized baby. We had to put it in the pan room to allow it to die. I will carry that forever. I don't think I could do that anymore. (Nurse 5)

The main concern for the nurses seemed to be that the baby was born alive. Had the baby been stillborn the nurses believed they would have been terribly sad for the parents, however they would not have had the distress of leaving the baby to die. Several nurses mentioned the philosophical issue that if the baby was deemed to be too immature to treat, would it not be more humane to ensure that the baby was not alive when it was born. Several of the nurses mentioned there had been suggestions of this in the literature. Due to the delicate nature of terminating the life of a tiny human deemed viable at 20-weeks gestation, it is unlikely consensus would ever be reached. One nurse explained her distress:

I can remember back when you couldn't do anything and you had the 26 weekers in the pan room on the steriliser and you kept them warm and they cried. That was even worse I think, now when I look back. (Nurse 23)

The distress this situation caused the nurses might have been a turning point in some of their careers. This was about lessons learned. The nurses knew there was nothing they could do to save the baby. They experienced sadness at the baby dying alone. One nurse spoke of her distress:

Oh I'd be crying. I can remember putting it [immature baby] in [the pan room] and thinking I need to cover it, keep the baby warm. Then I'd think but then it's going to prolong the baby's death and that's worse, and in the end I just couldn't cope. I ended up saying I had to get out of there. I had to move. I couldn't cope with that. It was the most awful thing. That's probably where I did start to want to do neonatal nursing. (Nurse 11)

These stories have a similar theme to Wolf and Zuzelo's (2006, p. 1191) "never again" stories where nurses were forced to betray their personal and professional values. The stories by the nurses in the current study mirror a sense of failed responsibility to tiny babies. It is clear they have ruminated over these events over time. These stories are full of regret, and "moral residue" (Wolf & Zuzelo 2006, p. 1204) has remained with the nurses.

Several nurses considered the difficulty of caring for extremely premature infants, and yet a termination of pregnancy could occur prior to 20 weeks. As explained by the nurses, *'it's a fine line between when you're actually allowed to legally get rid of them, to when you're actually saving them. It's a very small time'* (Nurse 13). This issue was not about abortion per se, it was about the small length of time between when a termination of pregnancy could occur, and when they were legally required to save a baby's life.

The majority of nurses spoke of difficult situations when a baby was left to die, expected to die, and yet does not die. Several nurses told stories parents in small country hospitals, or hospitals on the outskirts of the city without a NICU, who had been told their baby had

died, and yet 24 hours later the baby was alive. Todd (1995, p. 206) also spoke of this issue. The baby was then resuscitated and sent to a NICU in the city. The nurses understood the distress and confusion experienced by the parents, who had started to mourn the death of their baby. One nurse explained:

Both twins were left to die in the pan room, and the mother was told both babies had died. The next day they called the registrar [senior resident medical staff], and the registrar went down and had to tell mum that this baby [one of the twins] had survived and brought the baby back [to Sydney]. (Nurse 15)

The baby in this story survived, according to the nurse, because it was 30 weeks gestation, and small for gestational age. The baby eventually died, leaving the parents to grieve their baby's death again. The nurses understood that extremely premature babies left to die, yet still alive after 24 hours, were not in optimal condition. The babies were likely to have significant morbidities if they survived. These morbidities are associated with lack of adequate ventilation, respiratory acidosis leading to intraventricular haemorrhages, and cold stress. The case of *MacDonald v. Milleville* occurred when medical staff resuscitated a 23-week male infant, then withdrew treatment but the baby did not die. Although intensive support was reinstated the major damage had already been done (Paris, Goldsmith & Cimperman 1998, p. 302). Clearly, this baby did not fulfil the terminal prognosis allocated to it.

The nurses were convinced that parents experienced difficulty with the time taken for their baby to die. It was their experience that if life support was withdrawn the baby might die soon, or linger. This is confirmed by McHaffie (2001c, p.154-155). McHaffie, Lyon and Fowlie (2001, p. F10) found that 22 percent of families found the length of time it took for their baby to die to be a source of distress. It took between three hours to 36 hours for babies to die, even though the deaths had been predicted by medical staff to be swift. Davis, Doyle, Rogerson and Jacobs (2005) found that when treatment was not commenced the mean survival for babies of 20 to 25 weeks gestation was 41 minutes, ranging from three minutes to 327 minutes (5hrs 45mins). Anderson and Hall (1995, p.

17) emphasise that children removed from life support do not always die. The problem with protracted deaths is they make parents doubt the wisdom of decisions to withdraw treatment (McHaffie 2001, p. 9).

The nurses have made meaning from these distressing situations. It would appear that being placed in the situation of watching a baby die, and being powerless to do anything, had made the nurses resolve to give the viable baby a chance. This was not about the rampant use of technology, it was about giving the baby a ‘...*trial of life*’ (Nurse 15), and the opportunity to prove itself. The nurses were able to cope with a baby’s death if it had been given the opportunity to live, if only for a brief time.

6.3.3 Resuscitating a baby too immature to survive

All the nurses were convinced that it was unacceptable to resuscitate an extremely premature baby who was limp, lifeless and cyanotic, or fetal in appearance. It was the nurses’ belief that only extremely premature babies who were vigorous at birth should be resuscitated. Several nurses spoke of their disappointment when a tiny baby was admitted to the NICU, one whose condition at birth was not optimal. The reality is that no baby of a pregnancy interrupted at 24 weeks gestation or less would ever be in optimal condition. One nurse stated “*I think you come on [duty] and you think ‘Oh no, not another one.’ ‘Who was at this delivery?’ ‘Why did they resuscitate this baby?’*” (Nurse 16).

Providing care to what they considered to be fetal infants was distressing for the nurses. Providing physical care can present difficulties. One nurse explained:

The skin was so gelatinous, it would stick to the sheets and it would stick to anything that it came in contact with. The baby actually had fluffy marks from the sheep skin. It was actually being absorbed into the baby’s skin and there was nothing that we could put around or do anything with to stop this from actually happening. (Nurse 10)

The distress experienced by this nurse was extreme. It was clear to this nurse that the baby was too immature to survive. The nurse’s distress was compounded when the baby

was considered moribund, and the parents refused life support withdrawal. This nurse understood the parents' need to hold on to their baby who was born alive, however she was more concerned that the baby was being kept alive. The nurse explained the difficulty:

That baby was actually kept alive for 7 days at the parents' wishes. And in fact the baby, we all agreed that the baby was actually dead at the end of the ventilator for probably 24 hours, because the parents refused to let us take the tube out. (Nurse 10)

Several nurses spoke of being troubled by these types of situations, and gave examples, however they were at great pains to emphasise that when caring for the immature infant, '*...you're doing your best, you're treating them like a person anyway*' (Nurse 24), and '*I'll look after the baby as I would with any baby*'. (Nurse 18). Treating the baby as a person seemed to be important to all the nurses. In the situation previously described, a senior nurse convinced the parents it was time to remove the endotracheal tube (ETT). The senior nurse had developed rapport with the parents and at the end of the third day, she was able to say to them, '*this is what is happening with your infant*' (Nurse 10). The nurses considered this a major achievement. McHaffie (2001b, p. 87) found nurses were an invaluable support to parents. The nurses knew the baby and the circumstances, which reassured the parents that withdrawal of life support was a permissible option.

The nurses all understood the parents' desire to hold on to their baby, however Weir (1992, p. 211) believes nurses may harbour feelings of resentment towards the family for requesting care that prolonged death. The resentment of some of the nurses in the data was at times almost palpable.

Providing care for an infant they believed to be '*dead at the end of the ventilator*' (Nurse 10) was troubling for several nurses, and they perceived it to be contrary to their professional goals and values. The emotions evoked in the nurses during this situation may have long term and profound effects upon them (Cameron 1997, p. 280). The nurses practice their profession within an established code of ethics, which has respect for humans as a basic tenet. For these nurses, caring for this baby was seen as disrespectful,

and perhaps akin to what would be deemed as disrespectful actions on a corpse. Murphy (1994, p. 35) confirmed the difficulty for the nurses by stating that “daily nursing care of a permanently unconscious patient to be a grotesque distortion of what it means to be a nurse”.

At a deeper level perhaps the difficulty in this situation seems related to when a person or human exists or ceases to exist in the eyes of the staff. Schlomann (1999, p. 166) suggests the difficult situation faced by the nurses could be one of ambiguity of “humanness”. Ambiguity relates to physical appearance, characteristics such as cognitive status and responsiveness of the baby, suggesting that humanness is the ability to relate socially. The nurses in Schlomann’s (1999, p. 165) study were not sure if they were caring for a person when they cared for babies with severe disfiguring anomalies. One nurse asked, “how do I give good care, what does it mean to care for something that’s not really a person”? (Schlomann 1999, p. 165). Situations where the staff perceived ambiguity of humanness tend to be problematic (Schlomann 1999, p. 166). One physician commented on a baby with poor cognitive status, stating “he really died a long time ago” (Schlomann 1999, p. 166). Cognitively impaired babies were considered to be “nonreclaimable to a human state” (Schlomann 1999, p. 168). For the nurses in the current study, the human status of infants too immature to survive could be ambiguous (Preston 1979). The goal of intensive care is to restore their human status, but this could be impossible. When there is little or no feedback from the baby to the nurses the baby becomes the object of work. Such objectification and depersonalisation could be necessary for the nurses as it helps them distance themselves from ethically troubling situations.

6.3.4 All or nothing

There is debate in the ethics and neonatal literature about the type of intensive care support provided to extremely premature infants at birth (Richardson 2001; Leuthner 2001; Oei et al. 2000; Silverman 1992; Walden & Sala 1993; Gill 1994). All the nurses were convinced that if extremely premature babies were to be given any chance of

survival they must have maximum treatment. This included intubation, ventilation, haemodynamic support, fluid therapy and invasive lines for physiological parameter monitoring. One nurse stated, *'If you give minimal care to 24 weekers, you're actually damaging the ones that survive'* (Nurse 7).

The nurses were all emphatic that intensive support should be an *'all or nothing'* (Nurse 10) phenomena, and decisions should be made to either treat maximally, or not treat at all. Several nurses found it worrying that ethicists were in favour of minimal support, yet ethicists were unlikely to have seen an extremely premature baby struggle at birth, nor made the decision to allow a baby to die. This could be the difference between distant and close up ethics. With distant ethics, issues are resolved simply using rules, such rules could be birth weight or gestation. Close up ethics requires orientation toward family, religious, philosophical or social conditions (Duff 1987, p. 245). In this situation distant ethics would provide a clear cut answer using rules, however it "imposes a state of helplessness on persons most affected by the decision" (Duff, 1987, p. 245). Close up ethics by comparison would take an individual approach to the situation and judge each case on its merits, or treating each baby as an individual. Minimal support is clearly not in the baby's best interest. If there is a decision to treat then all or nothing gives the baby the best opportunity to survive. One nurse emphasised:

You can't deliver minimal support. It's either all or nothing. In a baby that's 24 weeks gestation, you either make the decision beforehand that it's futile and you don't progress, or you pull out all stops. There is no grey area, because the infant needs every single ounce of support in order to survive the first 24 hours, which are absolutely crucial. An infant of that gestation will not survive without ventilation, will not in most cases survive without some kind of haemodynamic support. Will definitely not survive without some kind of fluid management. (Nurse 10)

This all or nothing approach was important for the nurses, because they saw this approach in keeping with giving the baby the best possible chance of survival.

6.3.5 When the honeymoon is over

The nurses all accepted they were non committal about the survival of babies less than 24 weeks gestation until the '*honeymoon*' (Nurses 5, 11, 12 & 13) phase has passed, or specifically they observed something to be optimistic about. This included a head ultrasound that did not reveal a large cerebral bleed. As stated one nurse, '*You always have a honeymoon period with these babies. Always*' (Nurse 5).

The honeymoon phase referred to a time frame, usually two to three days where the condition of the baby following resuscitation and initiation of life support was stable. During the honeymoon phase the infant had an excellent clinical course, despite discouraging chest X-Rays and the certainty of clinical deterioration (King 1992, p. 18). The baby is adequately supported with technology, however the baby's survival was dependent on the body functioning, for example making urine and passing urine. During the honeymoon phase the nurses understood the parents' hopes for survival of their baby would be high. The nurses had all witnessed babies rapidly deteriorate following the honeymoon period, therefore they were reserved in their judgements about potential survival. One nurse explained the difficulty:

It's usually within the first two days. Everything looks good, you can ventilate quite easily, blood pressure is OK, head ultrasound is fine, everything is fine and then for some reason they crash [deteriorate]. It's usually either an infection or something else goes wrong. (Nurse 12)

The honeymoon phase as described by the nurses is not documented extensively in the literature. Meadow et al (1996, p. 636) found that approximately 80% of deaths of extremely premature infants occurred in the first 3 days, therefore if the infant survived to day 4 the likelihood of survival was dramatically increased. Birth weight as a predictor of survival was high at birth, but had decreased by 72 hours. Using Meadow et al's (1996) research, it could be seen that the nurses were not likely to become optimistic about the survival of the baby until they came to believe the baby would survive. The nurses had all

seen many tiny babies die in the first few days of life, making them reluctant to invest time, energy and emotions in a baby who was likely to die. The nurses lamented the difficulty of keeping parents' hopes up for the survival of their baby, when they were not feeling hopeful. The nurses tried to explain the significance of the honeymoon phase to the parents. One nurse explained:

You know it's going to happen. For a 24 weeker, they're not going to get through without anything happening. I mean a 28 weeker may will these days, but not a 24. So there's going to be something, so you are on your guard. I guess that's why you say to the parent, 'You know you have to take every minute as it comes'. Because they change so rapidly and you know that it's not going to last, that honeymoon phase. (Nurse 11)

Wilshire-Warren (2000, p. 5) and Bright (2000, p. 14) spoke about the honeymoon period and the eventual deterioration in their respective children's conditions. Although they had been prepared, Bright (2000, p. 11) believed the focus on the negative, although necessary, made their experience more distressing.

The nurses in this study all believed the honeymoon phase represented uncertainty about survival. During this time they were on tenterhooks because they attempted to temper the parents' hope with the reality that the baby might not survive. For many nurses the honeymoon phase was difficult to bear, and they distanced themselves emotionally until a clearer picture of the baby's future emerged.

Hope has been described as one's future imagined reality (de Sales Turner & Stokes 2006, p. 364). Hope is when the temptation to despair is overcome (Fitzgerald Miller 2007, p. 13). During the honeymoon period the nurses used hope promoting strategies with parents. Hope is "a dynamic inner power that enables transcendence of the present situation and fosters a positive new awareness of being" (Herth 1993, p. 544). The nurses recognised that parental hope is made possible through the development of a trusting relationship between the nurses and parents (de Sales & Stokes 2006, p. 363). The nurses were all convinced that for hope to be believable it must be founded on reality. Giving the parents false hope was seen as unacceptable by all the nurses. They believed that

reality must be respected and acknowledged (see footnote). Parents in a study by Kavanaugh, Savage, Kilpatrick, Kimura and Hershberger (2005, p. 355) stated they did not want “to hear false hope”. It seemed that the facilitation of hope by the nurses was tempered with kindness.

6.3.6 Being brave

The nurses were all convinced the baby should be given a chance to live. They hoped that the medical staff and parents would be brave enough to make decisions. Bravery related to decision making seemed to be about the notion of moral or clinical courage. Bravery was needed according to the nurses when there were catastrophic complications like grade IV IVH with bleeding into the brain, or NEC where the bowel had infarcted or perforated. These two conditions were considered by all the nurses severe enough to offer withdrawal of treatment. One nurse explained:

I just believe you give the baby a chance. We’ve gotten to the point that we know indicators that will tell us whether to pull out or not. We’ve come to the point that you say ‘OK if the baby develops NEC, if it has an IVH greater than 3, then pull out’. (Nurse 12)

Being brave according to the nurses, meant health professionals had to display courage, and allow the baby to die. Several nurses considered themselves able to cope if they knew everything had been done to save a baby, who had shown signs that it might live. One nurse stated, *‘I just think give them a go, if they don’t work out then you have to be brave enough to say, ‘Well we gave the baby the best chance we could and it wasn’t enough’, so we have to be brave’* (Nurse 12). Another nurse stated, *‘I just think, give the baby a chance, if the baby is showing signs [that things are not going right], then pull out. Have the decency to pull out on the baby’* (Nurse 12).

It was the understanding of many the nurses that brave parents were ones who made the hardest decisions of their lives. Brave parents were prepared to make decisions, rather than let others make them. The nurses all recognised how hard it was for parents. They were convinced there could be nothing harder than making life support decisions for a much loved baby. One nurse related a story of parents she considered brave, and who made, what she believed, was a courageous decision. She stated:

They [parents] looked...and thought 'God I don't think the two of us can survive this. Should we take a child home who in maybe in 5 months time we're not even going to be a couple'. (Nurse 1)

This situation was difficult and sometimes pitted nurse against nurse in the NICU. Some nurses in the unit believed, '*...that was a very reality thing that they were looking at. Some people thought it cold, some people thought it hard*' (Nurse 1). Other nurses in the unit believed parents should be admired for making hard decision because, '*...it was the hardest decision they ever made*' (Nurse 1). The parents reflected on their life and thought, '*...are we going to be thankful for every day of our lives that we have this child?*' (Nurse 1), and for these parents the answer was no.

A couple of nurses spoke about parents who made decisions based on how the life of the child would impact on them. These nurses saw this as parents making difficult, yet brave decisions. One nurse spoke of a difficult situation:

They [parents] thought that 'If we can't bring up a child in a life as we know it now, we'd rather not have that child in such a disrupted lifestyle.' ...They've turned around and said, 'Well no I'm sorry. This child is going to skew our entire life perspective'...They turned the child off [withdrew life support]. That was their decision. They just thought 'This child was going to come into our lives. We were not going to step into this child's life', and they chose to turn the child off. They were given the poor prognosis of a 23 plus weaker, and they went away and were left three days with it. Eventually they just came in and said 'We've made the decision. We've jointly made the decision'. (Nurse 1)

It is interesting the nurses saw this type of parental decision making as being 'brave', and yet Bopp and Coleson (1996, p. 1) would see this as a violation of the incompetent baby's rights, because the family have put their interests above the interest of the baby. It needs to be remembered that if being brave was about the parents making the decision, and not allowing someone else to make the decision on their behalf, therefore, being brave would also apply to those parents who made the decision not to withdraw life support. There is evidence that parents tend to favour intensive care rather than withdrawal of treatment (Hentschel, Lindner, Krueger & Reiter-Theil 2006, p. 568), and would choose treatment at any cost (Brinchmann, Forde & Nortvedt 2002, p. 394). Bravery and courage could also be considered to be a problematic framing of what is required of parents during decision making, regardless of the decisions they make.

6.3.7 Competing demands

All the nurses held that every baby was an individual, yet there were times when they felt pressured to make choices between the competing demands of babies. The nurses all spoke about the difficulties of finding resources for larger, sick babies who were potentially more viable and had a greater chance of survival. One nurse spoke about the situation of having no available NICU beds:

If our unit was turning away other children, perhaps then they would start to feel pressure. They're [staff] asked to take other babies, and they just can't because we've got blocked beds. We've had to turn away patients. (Nurse 24)

Turning away more viable babies caused distress for the nurses, especially if the larger baby was transferred to another NICU, possibly interstate. One nurse explained her anxiety:

I look at times when you've got beds...full of babies that are 23 weeks. No space. A mum comes in who is 29 weeks...have to transfer her out with that baby in utero. When you think, why am I saving this [extremely premature baby], when I could have had that nice little baby in here that's going to do well and be normal. (Nurse 19)

The competing demands for the resources of the NICU presented the nurses with difficulties, especially when faced with the hypothetical scenario of deciding who should be treated. One nurse in a focus group stated, *'It's awful to have to play God,'* (Nurse 7), while another stated *'...play God and say, 'Can we afford this or not?'* (Nurse 9). Deciding between patients is a value judgement, and one nurse stated *'...well ultimately, I wouldn't like to be the one making that kind of decision'* (Nurse 17). The nurses were all acutely aware they were not making those decisions, they had to care for the babies once decisions were made, however it provoked anxiety. For one nurse:

It's overwhelming. How do you make a decision like that? How are you going to go in and say to...parents, 'Well I'm sorry but we've decided to cut funds today and your baby has been selected'. Who's going to do it? I don't know of anybody that would want to. (Nurse 21)

This situation was difficult for that nurse, however, none of the nurses believed that if NICU beds were available, all babies should be saved. They all emphasised that all babies deserved the best, but turning away a baby of greater gestation requiring intensive care for a shorter time period was more difficult. If confronted with this situation, one nurse stated, *'I think you'd probably be praying that something would happen that would take the decision out of everyone's hands'* (Nurse 24). This meant this nurse hoped the extremely premature baby declared itself and improved or died, or alternatively the larger baby improved and did not require the level of support anticipated. While this seems harsh perhaps the reality is as stated by one nurse, *'We will always find that bed and we will always find that nurse'* (Nurse 2), while another emphasised there would always be funds for babies, *'...because babies are small and cuddly and nice'* (Nurse 18).

It was the belief of all the nurses that extremely premature babies should not have to compete for resources. They also recognised that sometimes comparison and competition was inevitable, as there is a large difference in babies even of the same gestation. This difference could be a source of surprise and amazement for the nurses. One nurse explained:

Who's to say that the dates are right. You look back at some 25 weekers and you think, 'God they're amazing,' and then you look at some and you think, 'Well the 24 weekers that I have looked after have done better than what we thought was a supposed 25 weeker.' It is sometimes hard to draw the line, because it is always that element of surprise where you know a baby will do better than another one for no apparent reason. (Nurse 17)

The nurses all accepted the baby should be given the chance to survive. One nurse stated:

They should get the treatment that they deserve and then let the baby make the decision. If they're not going to survive with the treatment that they need, they're not going to survive. (Nurse 8)

Giving the baby the treatment they need is linked to the ethical principle of justice, where the baby should be given the opportunity to live, or as stated by the nurse in the previous quote the babies '*should get the treatment that they deserve*' (Nurse 8). The nurses were all convinced treatment should be instituted or continued if, and only if, the baby made a determined attempt to live. Ultimately it was the physiology which determines survival. The lack of maturity of the organs of the extremely premature baby is the deciding factor for survival. If the extremely premature baby does not have the necessary organ maturation, the technology of the NICU cannot make the baby live and grow normally. Providing intensive care until the baby's physiology made the decision seemed to be important for the nurses.

Several nurses experienced difficulty understanding that the value of a baby, even an extremely premature one, was considered to be less than an elderly adult. Three nurses in a focus group related an incident where an extremely premature infant had perforated its intestines and required immediate surgery. At the same hospital in the adult intensive care unit was an elderly gentleman of 90 years. The elderly patient was to have surgery before the baby. The nurses had great difficulty accepting this judgement. The nurses explained:

Where do you balance life, like that guy? In my personal belief...sure that man

might have had a huge bleed in his head, but he's 89 or 90 years of age. (Nurse 7)

He's probably going to die. (Nurse 9)

He's had a whole life. I mean this little baby had his whole life ahead of him. (Nurse 7)

The nurses in the focus group could not comprehend why the elderly adult had preference to available resources. It was hard for them to reconcile competing demands for access to resources, but in justice-based ethics, getting what is owed, they believed the baby should have been treated first.

Further inequities in treatment were described by other nurses. Nurses from another focus group made comparisons between an adult patient and an extremely premature infant. These nurses believed a severely burnt adult patient with profound lung disease would be analogous to the extremely premature baby with major problems. The burn patient compared to the extremely premature baby is a good analogy, because for the extremely premature infant the combination of friable skin which allows very high evaporative losses and enormous metabolic demands of 150kcal/kg/day is akin to a severe burn (Richardson 2001, p. 1502). The nurses in the focus group believed that perhaps the most humane treatment for this adult patient would be to allow him to die. Yet they spoke of the inconsistencies of treatment. The focus group explained:

If we make the absolute leap to the other end of the spectrum. If you had your father brought into Casualty with half his brain missing, half the myelination missing, his lungs absolute crap, you know perhaps burnt...burnt is the only damage that might even equate to something like a 24 weeker. He's been horribly burnt beyond repair and therefore has a degree of scarring, perhaps BPD [severe lung disease] the baby might have, to basically being asphyxiated by the fumes and to a degree where they've had permanent brain injury. You're standing there beside him. What would be the best treatment for your father? (Nurse 1)

There is no treatment. (Nurse 2)

There is no treatment because you know that he would want to live with Quality of Life should he survive. (Nurse 1)

Exactly! So why do we do it? (Nurse 2)

Why do we choose what we think is right for a 24 weeker? (Nurse 1)

Probably because her life has begun. (Nurse 3)

Is that a reason why people are looking at it so differently? On one side of the spectrum, you've got a life that your father who has had a life and then there is this life that's just beginning. (Nurse 3)

The analogy was difficult for the nurses in the focus group because they saw inconsistencies in treatment between the extremely premature baby and the adult. They had difficulty understanding why the adult would be allowed to die, yet the extremely premature baby would continue to be treated. These nurses could not see justice being done.

6.3.8 Summary

All of the nurses held strong beliefs about extremely premature babies. It is clear the nurses had an overwhelming need to give each baby the best possible chance of survival, yet for babies deemed too immature, they believed that survival was not in their best interest.

Belief in the philosophy of treating extremely premature babies as individuals could mean competition for valuable resources. This could see baby against baby, or baby against adult compete for available resources. In today's current health climate it was an ideological, although somewhat naive belief, on the part of the nurses, that there should be equal access to health care. The nurses showed they would fight to ensure equitable treatment and resources for the baby until such time the baby would have what was considered to be a poor outcome.

6.4 Desperately seeking parenthood

The nurses all encountered parents who professed their desperation to become parents, and have a baby of their own. Many of these parents had suffered multiple reproductive losses and the nurses believed the parents' desperation might influence their ability to

make decisions. The nurses all picked up the desperation of the parents to have a baby but were powerless to give these parents the outcome they craved.

6.4.1 The biological imperative to become parents

It is difficult to know whether there is a biological imperative that makes couples desperate to become parents. All the nurses had encountered parents who told them of their desperation to have children. Many of these parents had been through numerous attempts at assisted reproductive technologies in order to conceive a child. All the nurses had encountered parents who had endured many invitro-fertilisation (IVF) cycles. One nurse explained:

It's some sort of imperative that is beyond reason. I don't know if it's a biological or psychological. But I think...IVF... it's just so awfully artificial and weird. Being on IVF...your entire focus is on producing a baby at the end. (Nurse 14)

It seemed that IVF babies are framed within a context of desperation and this context plays out in the NICU. The nurses all encountered parents for whom this pregnancy was their final hope of having a child. Albritton (1998, p. 27) spoke of agony at the thought of losing yet another baby when she went into premature labour at 24 weeks gestation. Having lost three previous babies, all at the same gestation. Schrinner (2004, p. 94) a neonatal nurse spoke of the extraordinary efforts undertaken to keep her from delivering at 25 weeks gestation. The nurses in the current study seemed to understand the difficulties faced by the parents, as stated by one nurse:

It's their one and only chance of having a child. I think they can only see that immediate sense of having a child. That's what they want to see, they want to take home a baby. (Nurse 1)

The nurses all stated they understood the parents' desperation for a child, but they deduced from previous experience that babies from assisted conceptions were more likely to have a poor outcome. There is some evidence for this. Helmerhorst, Perquin, Donker

and Keirse (2004) and Ombelet, Martens, De Sutter, Gerris, Bosmans, Ruysinck, Defoort, Molenberghs and Gyselaers (2006, p. 1025) found that babies from assisted reproduction had a significantly worse outcome than from non-assisted pregnancies. Gould (1992, p. 262) suggests that for pregnant couples the ideal is represented by a positive outcome, but for parents with a history of fertility problems the real can be an unfavourable outcome.

The nurses all spoke about attempts to resuscitate extremely premature babies when, given other circumstances, the parents would have been counselled about the poor outcomes. It was the understanding of these nurses that babies of parents with poor reproductive histories would be resuscitated. One nurse explained:

The family situation...there are women who have been desperately trying with multiple IVF attempts, and quite often these babies are saved as a last ditch to provide these parents with a family. (Nurse 6)

Wilshire Warren (2000, p. 1) a parent of a 23-week gestation baby, was informed that ordinarily the staff would not attempt to resuscitate a baby so immature, but due to their nine year history of infertility their baby was resuscitated.

Several nurses described how judgements were made about the “preciousness” of babies, usually related to whether there was a history of infertility. These nurses considered the comments unrealistic, because, for them, every baby was precious to the parents. Yet judgements were constantly made about “preciousness” when referring to the baby of the IVF pregnancy. One nurse explained:

We give report and say, “This is a precious baby.” To me that’s always a silly comment, because isn’t every baby precious? That usually means that those parents have had infertility and great difficulty falling pregnant. (Nurse 11)

One nurse told of a situation that she faced:

The neonatologist went around to delivery suite, came back around and he said, 'We'll do everything to save this baby. The mother is 42.' And this was her first baby, bad obstetric history, no more chances. And I'm thinking, 'That's not really a good reason'. (Nurse 19)

The nurses all understood that pregnancies conceived through assisted reproductive techniques were precious to an infertile couple. They were several, however, who were convinced it would be a mistake to think they were more precious than babies who were conceived naturally. A couple of nurses spoke about the subtle, and not so subtle, attempts to inform them that IVF babies conceived through in-vitro fertilisation were precious. One nurse stated:

The request forms do come around from delivery suite with IVF on them. I don't think they should. I don't think it makes any difference one way or the other, whether it's an IVF baby or it isn't an IVF baby. If it's 23 weeks, whether or not you're IVF, the outcome on the other end is the same. (Nurse 19)

This could mean there was an assumption that babies should possibly be treated differently because of the difficulty associated with conception. The nurses held to the belief that all babies were precious. They did not like to treat babies differently based on their conception history, often related to their socio-economic status.

6.4.2 The desperation of wanting a child

The desperation of parents to have a child of their own was a cause of anxiety for the nurses. One nurse spoke of what she believed was the myth of parenthood,

...sold as this wonderful experience. It completes and rounds your life. There is an awful lot of hype that isn't really true to raise people's expectations of what being a parent is all about. I really think there is an awful lot of people who have fallen for that trap who seriously believed that to be a complete and fulfilled human being you must be a parent. (Nurse 6)

It was the understanding of all the nurses that infertility treatments have helped couples to realise their dream of parenthood, however, there is a substantially increased risk of preterm delivery with assisted conception (Slattery & Morrison 2002, p. 1491).

Reproductive technologies are a major contributing factor to the increased number of multiple pregnancies (Kauma 1997, p. 355). Multiple pregnancies are a major risk factor for preterm delivery (Slattery & Morris 2002, p. 1491; Roze & Breart 2004, p. S31).

The majority of nurses told stories of parents with poor obstetric histories who had used assisted reproductive technologies to help them conceive. One nurse stated, *'IVF parents, this has been not the first try and they've had other losses, so I think that they are more desperate'* (Nurse 13). These nurses emphasised that while parents had their quest to take a baby home they should not lose sight of the needs of the child. One nurse explained:

I think certainly IVF are more desperate to have anything. I still don't think that should cloud the decision...putting the baby through what it has to go through for maybe no outcome. Parents do often say, 'I want everything done.' (Nurse 13)

Most nurses spoke about the desperation of parents to take home a child regardless of the outcome. One nurse explained:

As hard as it is for us to understand, they are happy to have a child of their own regardless of what it is. They're happy to suffer the consequences, so to speak, just to say that it's their own; that it's something that they can love. (Nurse 3)

It was the experience of three nurses that some parents believed it was important to have a child, even if that child was disabled. This could be related to the self image of the couple needing to see themselves as parents. One nurse stated:

It wasn't up to us to say what was quality of life...because parents might think that even if the child was disabled, that it was better than not having a child at all. (Nurse 13)

Most nurses had encountered parents who were desperate to take a child home, they emphasised that not all parents would feel that way. It could not be assumed that all parents would '*suffer the consequences*' (Nurse 3), regardless of their level of desperation. One nurse explained:

As for accepting damage, I would say that is probably a very individual thing and certainly in my experience, I can probably only remember very seldom seeing parents who would accept a damaged child as recompense for having a baby. (Nurse 10)

Wilshire Warren (2000, p. 4) described how she and her husband agonised over the decision to save their 23-week gestation baby following their nine-year history of infertility. They "desperately wanted this baby we had been trying so hard to have, but we didn't want him imprisoned in a body that wasn't able to function" (Wilshire Warren 2000, p. 4).

Imeson and McMurray (1996, p. 1015) found that infertile couples described a cycle of alternating feelings of hope and disappointment. They experienced social isolation that was intensified by dealing with the responses of others. One nurse in the current study empathised with parents about the desperation of wanting a child at all costs. This nurse had been on the IVF programme. She explained:

If you went through the IVF programme, because it's not easy, it's very difficult. To have something that's alive, I can understand that. I can understand somebody saying, 'I want that infant in preference to nothing at all'. (Nurse 8)

It seems the nurses were dealing with parents who had suffered cumulative reproductive losses. Not all of the losses are related to reproductive technologies. McHaffie (2001b, p. 87) found that of mothers dealing with neonatal death, 41% had suffered a previous obstetric loss, while 19% had a history of infertility. The nurses believed that all societies value the birth of children (Van Balen & Bos 2004, p. 245). Several nurses suggested that fertility could be central to a woman's identity. Multiple causes of infertility exist, and there is no simple causality. The situation of childlessness is culturally defined (Van

Balen & Bos 2004, p. 247), and several nurses understood that even with reproductive technologies only 50 to 60 percent of couples will achieve a pregnancy (Garner 1985, p. 58s). Infertile couples could become desperate for a child because of discrepancies with their perceived and actual self image. Infertile men and women perceive themselves as “failures,” “damaged or defective” (Garner 1985, p. 59 s). The nurses’ empathic understanding might have arisen because the nurses were all female and may have understood the biological imperative to have children. Ten of the nurses were mothers. They had all seen many families have this experience, so they may have been more attuned to the complex realities and dilemmas faced by infertile couples with a premature baby in the NICU.

The nurses all hoped the parents’ desperation for a baby would not make them continue treatment keep when the benefits of treatment were outweighed by the burdens imposed. Four nurses experienced distress when they considered a baby was treated to provide the parents with a baby. They stated it was hard, *‘to nurse those babies when they want a baby no matter what’* (Nurse 9). These nurses were caught between understanding the parent’s situation and the baby’s best interest. The distress for one nurse was apparent:

I think it’s more horrifying and upsetting that you have to put something [baby] through that just for the sake of the parents giving them maybe their last chance at having a baby. Acceptance is a hard thing. (Nurse 17)

The nurses were all convinced that when parents requested *‘everything’* (Nurse 13) to save the life of their baby, they would not know what “everything” meant. They knew the baby would experience pain and suffer from intensive care therapies. Their experience led them to understand that parents could suffer as a consequence of seeing their baby suffering. It might be important for parents to witness their baby suffering as it could increase their receptiveness to ceasing treatment (Schlomann 1999, p. 167). The nurses all believed they were also affected by the baby’s suffering, because it was *‘agonising for the staff that have to look after them’* (Nurse 17).

Several nurses found that medical staff were reluctant to override parents' wishes about the maintenance of life support. They understood there were cases where this had occurred (see footnote). This reluctance is confirmed by van der Heide et al (1998, p. 414), who found 17% of medical staff were content about having continued treatment because parents did not consent to withdrawing treatment. None of the parents in van der Heide et al's (1998, p. 413) study regretted their request for continuation of care. This is mirrored by one nurse who stated '*I don't think further down the track they change their mind. I have seen parents like that who say, "Well, you know, we don't care. We just want a baby"*' (Nurse 16).

6.4.3 Summary

The nurses all understood the parents' desperation to have a baby and experience parenthood. They believed on the other hand that such desperation should not be the sole determiner of whether the baby survived. The nurses all hoped the best interest of the child would determine the outcome and not parental desperation. There was recognition by several nurses that a disabled child would be welcomed into many families.

6.5 The neonatal nurses as caregivers of this baby

The neonatal nurses were the primary caregivers to these tiny babies. The nurses were responsible for providing care to the baby and helping the parents. They all considered themselves to be in a quandary. They wanted to be optimistic about the survival and outcomes of the baby yet they were unable to commit to being positive because of what they had seen in the past. This was usually death within first week of life or a poor long-term outcome.

6.5.1 Personal philosophy on life and death

The neonatal nurses revealed from time to time a personal philosophy about the life and death of extremely premature babies. They were all aware of the survival statistics as well as the potential for long-term morbidities. Many of them cited literature during the interviews. They emphasised that some extremely premature infants had anatomy and physiology too immature to survive even with optimal intensive care. One nurse explained:

It is important that you put things into perspective, and one way for some to cope is to have a positive attitude and think, 'Well this is this baby, every baby is an individual. You know we'll give this baby a chance and we'll see what happens'. (Nurse 10)

It seemed that all the nurses had developed a philosophical approach to caring for extremely premature babies. The nurses in an earlier phenomenological study on the effect of neonatal death on neonatal nurses (Green 1995, p. 70) were committed to giving the baby every opportunity, but they were concerned when babies with poor or uncertain prognoses were kept alive. The neonatal nurses in this previous study (Green 1995, p. 67) could accept the death of an infant if they were assured everything possible had been done for the infant. Knowing that everything had been done justified the many painful procedures.

Every baby that is born has the right to live, but if he or she can't make it, well they can't make it, they've tried. I don't agree that they're continually pushed especially the really premature babies, pushed and pushed and pushed until they've got so many abnormalities wrong with them, with their brain and their eyes. They are not going to have any quality of life anyway. I disagree with that. I agree that what has to be done has to be done. I don't agree that they push and push and push till other things go wrong. (Green 1995, p. 70)

The nurses in the current study all needed reassurance that everything possible had been done to give the baby a chance, and the baby's humanity considered and treatment

withdrawn if necessary. It can be said that the personal philosophy of the nurses was the lens by which they interpreted their care of extremely premature babies. The nurses all found meaning in caring for tiny babies by giving the baby the opportunity to survive, yet recognising their role in relieving pain and suffering and ensuring a peaceful death. For the nurses in the current study this philosophical approach came with years of experience. The nurses would be heartened that thoughtful and compassionate neonatal end of life palliative care protocols have been developed (Catlin & Carter 2002, p. 184; Gale & Brooks 2006, p. 37).

6.5.2 Optimism dependent on outcomes

All of the nurses' optimism was related to their previous experience with extremely premature babies. Their optimism was dependent on whether they had seen good outcomes in the past. They were acutely aware that extremely premature infants could survive with long-term morbidities including major disabilities. The long-term outcome was important to how the nurses perceived themselves as professionals. They knew that major problems like severe cerebral palsy might manifest early, however, they knew other problems might not manifest for several years. Nurses who had encountered a good outcome early in their career were more likely to feel optimistic. One nurse explained:

Seeing one go through well in my early experience changed my judgment a little. If it turned out to be more of a problem, I might have looked on them worse in the future. I started off with a good experience and so I kept a good feeling going the whole time.
(Nurse 24)

Technology influenced the nurse's optimism. The positive and negative responses of the nurses were influenced by the head ultrasound that detects bleeding in the brain. The head ultrasound is a routine screening test, performed on all babies at risk of neurological impairment. One nurse explained:

With 24 weekers or less...one of the more deciding factors is the actual head ultrasound results. These are not usually attempted until 24 hours of age. When you have a 24

week, you have 24 hours of non-commitment to start with, before you even begin to either be negative or positive in your feelings. (Nurse 1)

Head ultrasound findings document the presence of brain injury (Hack & Fanaroff 1999, p. 193). The nurses all understood that lesions associated with future neurodevelopmental disability include grade III or grade IV IVH, periventricular haemorrhage, periventricular infarction, periventricular leukomalacia and persistent ventricular dilatation (Hack & Taylor 2000, p. 1973).

It was troubling for the nurses when they believed they knew the likely outcome. They had all experienced many similar situations. Lantos (2001, p. 127) suggests “we see so many bad things, we can’t help imagining the worst”. It was difficult for the nurses to remain optimistic when they had seen few or no positive outcomes. Previous experience made the nurses non-committal until there were indicators of a positive outcome, for example a grade 2 or less IVH. The nurses all believed low grade IVH’s were associated with a good outcome, as opposed to grade 3 to 4 IVH’s which are often associated with devastating neurological consequences (Ward & Beachy 2003, p. 9). One nurse explained her dilemma:

Nurses...they are not very positive, not very committal and very unemotional because they really don’t want to get into the situation until they at least see probably what they are expecting as a result. (Nurse 1)

The lack of optimism seemed to be part of the nurses’ distancing behaviours. They searched for signs of a positive or negative outcome even though they were optimistic in their day to day lives. This was not a group of pessimistic people. They demonstrated positive psychological strengths and capacities required for balancing cognition and emotions. Theories of optimism suggest that optimism in nurses is linked with high workplace performance. Optimists are believed to formulate plans of actions for difficult situations, are less likely to give up, and have a more positive outlook in stressful situations (Luthans, Lebsack & Lebsack 2004, p. 5). Perhaps Seligman’s (1998, p. 292)

“realistic optimism” is more insightful and useful for the nurses, because it recognises the downside of too much or false optimism.

The nurses all stated they were aware babies of 24 weeks gestation and less often died or had poor outcomes. They were also aware that babies, even at the same gestation, were not the same in relation to management and clinical courses. There were many intra-uterine and extra-uterine factors influencing the outcome. One nurse explained:

You nurse the 24 weeker that requires no Survanta [surfactant], minimal ventilation, no inotropic support and blisses through and you're...shaking your head in wonderment. You acquire the child that requires everything but still comes through without a problem. Then you get the child who needs a little bit of this and a little bit of that and comes out with a major handicap. (Nurse 1)

The uncertainty about outcomes kept some of the nurses somewhat optimistic. They believed that if all outcomes were considered to be negative, they would have lost their optimism years ago.

A nurses' previous experience could determine their optimism before they had even glimpsed the baby. When an extremely premature baby was born, the neonatal nurse and medical staff went to the labour ward to resuscitate the baby. The nurses could form an attitude before they arrived:

When you go around [to labour ward]. Word goes out there's a 24 weeker being born and you go around there with that attitude. You don't even wait for a child to be born, the first glimpse, the first view or the first Apgar. You look at predictors of survival. You actually go around there knowing the gestation. (Nurse 1)

The nurses all judged tiny babies by what they had observed in the past. One nurse stated, *'that's because of the sum of your experience and what you've seen other babies withstand and the outcomes. Unfortunately so many very negative outcomes'* (Nurse 4). The nurses all imagined the life the baby would have if it survived. Most nurses had not

seen many positive outcomes, making them question the value of intensive care for extremely premature babies. One nurse explained her dilemma:

What's the point of that much pain...and that much resources going into a baby that is very rarely normal. Sure there are the odd occasional ones. I think in honesty, all honesty, that you could count them up on your hands the number that you actually see come through unscathed or minimally scathed, that are going to have a life that's not handicapped and be having major problems for the rest of their life. (Nurse 9)

6.5.3 Knowing who to give up on and who not to give up on

The nurses were all optimistic about what the NICU could offer sick babies. Their previous experience led them to be less optimistic about extremely premature babies. Such lack of optimism was related to their conviction that something would go wrong. This was not an ability to predict the future. Most nurses spoke about waiting for something to happen to the baby. These nurses did not know what or when, just that something would happen to the baby. One nurse elaborated:

As your experience gets a bit more, you're very guarded. You are hopeful at the start when everything is going well, but you're...guarded in your hope. You think, 'Oh the baby is doing really well so far, but when is it all going to happen?' When is it not going to be so good. (Nurse 11)

The nurses might know something would happen to the baby, yet they were also hopeful this baby would be the one to defy the odds. Several nurses had seen some good outcomes from babies 24 weeks gestation and less, however, most continued to focus on the poor outcomes.

The nurses all believed they knew which babies would die, '*...we know who to give up on and who not to give up on*' (Nurse 12). It was difficult for them to care for the baby when they were surrounded by extreme optimism. One nurse explained her dilemma:

The doctors and the parents are saying, 'No, keep going, keep going.' I think that's quite depressing when you've got the feelings of death around you and people are just going, 'Oh but no you know the baby's eyes are opened,' and all these positive signs, but you know, through your experience that this baby is going to go [die]. I think that's why a lot of us have got negative attitudes. (Nurse 12)

The nurses emphasised their difficulty in remaining optimistic, yet they tried to be optimistic for the sake of the parents. They explained they all experienced difficulties in, *'dealing with the parents and sometimes dealing with the doctors that don't want to stop'* (Nurse 18). The nurses found it difficult to maintain a cheery facade. One nurse explained:

It's sad when the parents come along smiling and you think you've got to keep smiling and saying nothing because they want this baby so much. (Nurse 18).

Sometimes it was the parents' continual hope or optimism in the face of a poor prognosis that was difficult for the nurses. One nurse explained:

I found it very difficult...she [mother] was just so optimistic and we kept having to say to her 'No. No, No, No, this, this and this.' She'd just bounce back up like she didn't hear you.... You're saying things and they shut off because they don't want to hear what you're saying, unless you're saying what they want to hear. (Nurse 16)

This nurse found herself in a quandary. She did not want to shatter this mother's hope, but she wanted her to understand the current reality as it stood for the baby. This nurse was attempting to transform the mothers' hope into something that was grounded in reality (Baergen 2006, p. 482). It was the understanding of several nurses that some parents could be "too hopeful" and "unreasonably optimistic" (Baergen 2006, p. 482). Just as uncertainty keeps the nurses hopeful, it contributes substantially to parental optimism, meaning where "there is room for error there is room for hope" (Baergen 2006, p. 483). They considered an error might be a possibility, but it was unlikely. The nurses understood that when some parents were presented with bad news, they responded with

denial. They might not have understood that parents who are unable to acknowledge the reality of their baby's situation are unlikely to give up on treatment (Baergen2006, p. 483).

6.5.4 Do as I say, but not as I do

The nurses all made it clear they would not have their own baby treated if they delivered at 24 weeks gestation and less. This issue was noted in the questionnaire when approximately 25% of respondents wrote unsolicited comments, for example, '*every neonatal nurse I know would go bush rather than go to a tertiary centre if they were in prem labour with a pregnancy of 24 weeks gestation or less*' (Q/A 106). This was interpreted to mean they would not allow others to do to their babies what they did to other people's babies in the NICU. Only one of the 24 nurses interviewed stated she would have her baby treated, but only if treatment would be withdrawn if the baby suffered a large intracranial bleed. This could mean the nurses held a belief but did not want others to hold the same belief. The nurses all considered treatment a personal autonomous choice. One nurse claimed her decision was an educated one, based on her understanding that an extremely premature baby breathing at birth did not equal sustained life. The decisions the nurses made were seen as recognition of the reality parents faced during treatment. The nurses all claimed that just as they had the right to choose, the parents had the same rights. It was accepted that parents might make decisions based on how the information was presented to them. One nurse explained the difficulty:

I don't know what they [Doctors] tell them. They must tell them survival. I don't think they tell them intactness [intact survival]. If someone told me that, 'Yes at 23 weeks you've got a 50% chance of survival, but a 99% chance of being abnormal,' I don't think I'd want my baby resuscitated. (Nurse 19)

This was a hypothetical situation. The nurses would not know in reality what they would do until they were in that situation. It was interesting they wanted other people's babies to have the opportunity to live, yet not want that for their own child. Sanders, Donohue,

Oberdorf, Rosenkrantz and Allen (1995, p. 494) found the opposite for neonatologists. They found 61% of neonatologists would want their child treated with the same level of aggression with which they treated patients, while 34% would want their child treated less aggressively. Streiner, Saigal, Burrows, Stoskopf and Rosenbaum (2001, p. 152) found physicians were more optimistic than neonatal nurses about the outcomes of extremely premature infants. Eighty eight percent of nurses and 85% of neonatologists in a study by Oei et al (2000, p. 357) would almost always resuscitate 24-week gestation infants, these clinicians were more optimistic about survival than the long-term outcome. McHaffie and Fowlie (1996, p. 263) found neonatal nurses would not want their own child to go through the painful therapies when the benefits were questionable. The outcomes for extremely premature babies are a major concern to neonatal nurses.

The nurses were all in agreement that it would have been unbearable for them to deliver an extremely premature baby. They held that this was not about not wanting a child with a disability. Rather, it mirrors McHaffie and Fowlie's (1996, p. 263) finding that nurses did not reject imperfection, they rejected pain and suffering for their own baby.

6.5.5 Give each baby the best

For the majority of nurses extremely premature babies were a challenge. At times they considered it difficult to care for these babies. The nurses were all committed to the belief that experienced nursing staff should be looking after these babies. The nurses all understood that infant mortality was related to staffing levels, and an association existed between nursing specialisation and decreased mortality rates (Callaghan, Cartwright, O'Rourke & Davies 2003, p. F96). The nurses were all adamant that medical or nursing staff should not be learning or practising on these babies. Staff not familiar with the medical and nursing needs of these babies should be supervised by experienced staff. One nurse stated:

Learning and I'm sorry, but that's what happens. That's probably what happened when I was learning about it too, but they weren't as small and as desperately ill as they are now.

It's not the fact that this person needs to get experience; it's what is the best thing for the baby. (Nurse 13)

When neonatal nursing evolved as a nursing specialty, practical learning was considered important often without a theoretical base. While times have changed, memories ran deep for many nurses. One nurse explained how she started looking after sick babies:

I did my midwifery. You really have no insight into looking after babies anyway before you're thrown in. Back in the dim dark ages, I was actually stuck with two ventilated babies on the Birds ventilator and told just suck them [suction the ETT] when you want to. You had no feelings for those babies because you didn't know what you were doing. (Nurse 18)

The nurses all highlighted a need to give the best care to all of the babies. One nurse emphasised:

Whatever comes in that door, we give the best possible care to, for however long that baby is here. Most of us know a lot of them don't survive, but you give them the best that you can while they're here, especially the little ones. (Nurse 7)

The nurses were all convinced the extremely premature baby was worthy of respect. They wanted the baby to receive the best possible care from the most skilled nursing staff. They perceived skill and expertise came with experience. The nurses could tolerate the baby dying if the baby had been cared for by experienced nurses. The nurses were in a quandary because they knew many of their experienced nurses colleagues had gained experience from caring for sick babies in often sub-optimal educationally supportive environments.

6.5.6 Comfort for the baby and the nurse

The relief of pain and suffering is the domain of the professional nurse. It was important that the baby's pain was adequately managed. In discussing the importance of pain relief the members of a focus group said:

It's a comfort thing and not just for the babies sometimes. (Nurse 21)

Sometimes it's a comfort thing for us too, because we know that we've done everything we can possibly do. Now we're going to let this poor little baby die, but at least we're going to give it a chance to die peacefully, rather than be in agony. (Nurse 21)

I don't think they gasp and go on for as long if they've had morphine. (Nurse 23)

They don't. I mean sometimes it's days. It's awful. (Nurse 21)

It's traumatic for everyone when it's like that. Not just parents. (Nurse 22)

While the morphine was important for the baby it held importance for the nurses. Several believed morphine was consoling for them and the family, because they did not have to witness the baby's suffering. Observing a baby suffer might emphasise their powerlessness in a fundamental role of nursing, the relief of pain. A baby could live for several days following withdrawal of treatment. Several nurses became anxious and seemed to count every breath as life faded from the baby.

The nurses needed to know that the baby was not in pain or suffering. Several nurses spoke of colleagues who were reluctant to give a baby morphine in case it hastened the dying process. One nurse stated:

I think a lot of people feel that if you give morphine and anything happens and it goes to court, you're going to be questioned about why you gave morphine to this baby that was dying. (Nurse 21)

The nurses inferred a strong association between narcotics and respiratory depression. Zerwekh, Riddell and Richards (2002, p. 87) suggest nurses fear being accused of over medicating, therefore opiates are avoided and feared. This response is referred to as

“fearing to comfort” (Zerwekh et al 2002, p. 83). It seems the nurse’s colleagues might have been confused about “killing versus comforting” (Tarzian 2000, p. 141). The doctrine of double effect is often invoked to explain the permissibility of an action that causes a serious harm. This harm could be death as a side effect of promoting some good end (McIntyre 2004). As long as the intention of giving the morphine was to relieve pain, and not to end a baby’s life legal ramifications for the nurses are unlikely.

6.5.7 When the baby suffers

The nurses were all passionate that babies have the right to receive pain relief. Most spoke of the problems in getting some medical staff to order pain relief medication for babies. It has been many years since Anand and Hickey (1987) exploded the myth that neonates do not feel pain. Babies of 24 weeks gestation are capable of feeling pain as cortical and thalamic connections are complete (Bildner, 1999 p. 511). It was the understanding of all the nurses that pain is harmful to the premature baby and is linked with an increased morbidity and mortality (Mitchell, Brooks & Roane, 2000, p. 60). When the premature baby is in pain, the resources required for growth and healing are diverted into coping with the stress response. This stress response produces increases in heart rate, respiratory rate, blood pressure and intracranial pressure. There is a possibility of intracranial haemorrhage. During the stress response arterial oxygen saturations are reduced, adrenal hormones released, and there is impaired functioning of the immune system (Mitchell et al, 2000, p. 60).

It was intolerable for all the nurses to think a baby was suffering. Even so, with all that is known about neonatal physiology, pain receptors and the pain response in neonates, these nurses encountered medical staff who did not believe that babies could feel pain. One nurse explained:

It’s amazing...you have all these talks [lectures] that babies do suffer pain but it’s taking forever for the doctors to realise this. They don’t give anything [pain relief]. You say, ‘Hey I want to give some morphine’, then they’ll just say, “No”. ‘It’ll drop their blood pressure.’ So what? (Nurse 18)

Several nurses could not accept that the side effect of morphine, hypotension, was a valid reason to withhold pain relief. Simons, Roofthoof, van Dijk, van Lingen, Duivenvoorden, van den Anker and Tibboel (2006, p. 2419) found that even in premature infants, morphine has minimal effects on blood pressure and is not associated with negative outcomes. The nurses spoke about some medical staff's fear of medicating the babies especially when the baby was going to die regardless. The nurses all wanted the baby to be free from pain and were passionate about this outcome.

The nurses were committed to the belief that the relief of pain and suffering was the domain of their profession. They all believed a baby could be overwhelmed by pain and suffering. The nurses experienced extreme powerlessness caring for a baby who was suffering. One nurse reflected, '*...the baby suffering, even though you are sedating them, you wonder how much suffering they're going through*' (Nurse 18).

These nurses were all compassionate and did not want the extremely premature baby to suffer. It was hard for them when much of what they did to the baby caused it pain. One nurse explained:

I believe that they suffer. They have the physiology. I know the researchers said that babies don't suffer pain because the nerve tracts aren't myelinated. Don't tell me that 24 weekers don't suffer. Just because they don't remember it and they don't have the language skills to remember pain, doesn't mean that they don't suffer. It's just that they can't communicate. (Nurse 12)

Pain and suffering in a baby affected the nurses. They all wanted to treat the baby with respect and withdraw treatment. The degree of pain and suffering inflicted on tiny babies could be seen to have a profound effect on the nurses. For these neonatal nurses their mandate was to prevent, or at the very least, minimise pain and suffering in babies.

I look at the pain that we inflict on them, even for the short time that we keep them alive, before we decide that there's no hope. We do create a lot of distress. There's no doubt about it. (Nurse 13)

Caring for a baby in pain threatened the professional esteem of the nurses, being at odds with a fundamental goal of nursing, which is to alleviate pain and prevent suffering. The nurses learnt to cope, in part, with inflicting pain on babies. Knowing they were harming a baby in trying to save its life represented a dilemma. Several used rationalisations, however, a time came when they could no longer believe their rationalisations. They were forced to admit to a different reality. They spoke of leaving neonatal nursing and finding a job that did not require the soul searching and philosophical questions about the nature of human suffering.

6.5.8 Summary

The nurses had developed a personal philosophy that was about giving the baby the best chance of survival, yet recognising that not all babies can survive. They wanted the baby to have the most experienced nursing staff caring for the babies to ensure the best possible outcome. The nurses were not generally optimistic, and the nurses' optimism was determined by the outcomes of tiny babies they had seen in the past. Their past experience also led them to believe they knew which babies would survive, do well or have a poor outcome.

It was difficult at times for the nurses to provide care to a baby that was in pain and suffering. Providing pain relief to the baby effected the nurses and enhanced their professional esteem. Conversely, being unable to relieve pain eroded the nurse's ethical integrity and caused them to experience ethical distress and distance themselves emotionally from the situation.

6.6 The collision of best interests

At times the nurses had difficulty in understanding whose interest the staff were obliged to act. They all understood that the best interests of the baby and parents were inextricably linked, and sometimes it was difficult to separate those interests. The best interests of the baby were paramount for the nurses. They were convinced that interests

were not served when a baby had no hope of a meaningful future. Defining a meaningful future was more complicated, but involved awareness of self, being happy to be alive and minimisation of pain and suffering.

The nurses all understood that babies required a surrogate to make decisions on their behalf. The surrogates are usually the parents. Parents are given legal responsibility for decisions. It is generally assumed that parents have their baby's best interests at heart. Parents also have an emotional bond with the baby which develops during pregnancy. The nurses were convinced that best interests could collide when the baby was being kept alive when the prognosis was poor. This collision could occur when medical staff would not offer the withdrawal of treatment, or the parents had been offered treatment withdrawal, and refused. The nurses, as suggested by Gribbens and Marshall (1982a, p. 135), viewed themselves as the moral defenders of the baby, even though they had little formal authority to influence the decision-making.

It was hard for the nurses to understand why parents refused to withdraw treatment when given a grim prognosis. The desperation of wanting a baby, loving their baby, not fully understanding the implications of the prognosis, or not being able to live with the guilt associated with withdrawing treatment were all reasons discussed by the majority of nurses. They saw some parents as having exclusive regard to their own interests, resulting in the baby's needs not being met. One nurse stated:

It's hard looking after a baby where it's being kept alive just to meet the needs of the parents, because they want a baby. They want to take home something, regardless of how it's going to be. (Nurse 17)

Another nurse stated:

Wanting something so badly, they [parents] don't see that that it's not right that the baby, you try and make it survive, for their sakes. (Nurse 17)

Several nurses concluded that parents could not imagine their future. One nurse explained:

I think they see a baby in the bed. I don't think they truly see the outcome of that baby's survival, of how it will be. Even when they're told that neurologically this baby is so damaged, I still don't think they can really imagine. (Nurse 17)

There were times when the nurses were convinced the baby's best interest collided with the parents' interest. Several nurses told of situations where the best interests of the family superseded those of the child. One nurse told of an incident that was extremely perturbing to her and her nursing colleagues. The story involved parents who did not tell the truth about the gestation of their baby. The parents knew the NICU was conservative in its approach to extremely premature infants. The nurse explained:

The parents wanted everything done for the infant and so they actually lied, I guess, for want of a better word. I hate to use that word lied. They informed the front desk that the woman was actually 28 weeks. (Nurse 10)

The parents were adamant the baby was 28 weeks, refused an ultrasound and biophysical profile to assess size prior to delivery. When the infant was delivered the care dilemmas began for the staff.

The infant was delivered and was fetal, it was definitely fetal. Eyes were fused, skin was just like jelly. It only weighed 400 grams. It was obviously very much a 23 weeker. It certainly wasn't a 28 weeker. When the parents were confronted about this baby being this gestation, they were still adamant that the baby was 28 weeks. It then became the consultant's task to explain that they knew. They could tell gestational age assessment using the Ballard's [gestational score chart] that this baby was definitely 23 weeks. When that was presented to the parents, the parents then agreed that, yes, the baby was 23 weeks exactly and that they had lied about this, so that they would actually get treatment for the infant (Nurse 10)

This situation provoked stress for this nurse even though she understood why the parents lied. These parents had a tragic reproductive history. This was an IVF and ninth pregnancy. No pregnancy had survived to 23 weeks gestation. If the parents were going to lose this baby, deceiving the staff was the only way they would get an opportunity to consider themselves parents. The nurse explained:

Come hell or high water, they were having this baby and it was actually going to stay 'alive' until they could actually say that they had had a baby and felt comfortable with it.
(Nurse 10)

It was understood that there were times when parents needed time to come to the conclusion their baby would not survive. One nurse explained:

We've had babies, basically dead babies on ventilators until parents can come to the decision that, 'Yes it's hopeless. My baby is going to die no matter what we do, and let my baby go.' (Nurse 19)

Several nurses spoke of understanding the need for parents to accept their baby's diagnosis and eventual death, but questioned if this was in the baby's best interest. It could be argued that the baby was unlikely to feel pain or suffer in the usual sense, however, the nurses suffered in providing care. Such suffering held elements of hopelessness and powerlessness. The existential suffering of nurses relates to their ability to demonstrate respect for human beings (Hylton Rushton 1995, p. 367).

The nurses all believed the needs of extremely premature babies were not served by being kept alive at all costs. They were also aware there is no requirement in Australian law for neonatologists to provide futile care. They believed too that parents did not have the right to request futile treatment. Avery (1998, p. 216) proposed that parents may view one chance in a million worth taking. They may believe that a miracle will happen. Miracles are unexplainable events or actions that challenge the limits of human beings and technology (Hylton Rushton & Russell 1996, p. 64). Claims of miracles were likely to engender negative responses in the nurses, especially those who did not hold strong

religious beliefs. The nurses all said they knew that religion played an important role in the lives of many families in the NICU. They also understood that while the free exercise of religion needed to be considered in the light of parental autonomy, parental autonomy could not be absolute. The nurses, who held to a Christian based philosophy, but not necessarily strong religious beliefs, found it difficult to comprehend what could be done to a baby in the name of religion. They realised many parents drew hope from religious beliefs and could anticipate divine intervention. It was their understanding that parents who expect a miracle are unlikely to be swayed by medical science (Baergen 2006, p. 484). Several nurses realised that praying for a miracle was about hope, but recognised that a baby's best interests could be denied in waiting for a miracle.

6.6.1 Summary

The nurses all acknowledged the difficulty in deciding what was in the best interests of a baby born at the edge of viability. They did, however, believe the best interests of the baby were not served by living a life of pain and suffering. On the other hand they acknowledged that parents needed time to spend with their baby and to be able to hope for a positive outcome or divine intervention.

6.7 The value of this baby

Extremely premature babies were valued by the nurses. They recognised that the baby was somebody's child, a human being and, as such, was afforded respect. The majority of nurses struggled with the value of the baby when making comparisons between extremely premature and full term babies.

6.7.1 Lack of tangible memories of this baby

When an extremely premature baby died there were often no tangible reminders of the baby for the parents. The nurses stated they all understood the difficulties faced by

mothers, who a few weeks ago had felt their baby move. They spoke about how important it was for parents to mourn their extremely premature baby.

As a consequence all the nurses were committed to a belief that parents needed mementos of their baby's existence and took steps to provide them. At this early gestation, parents were unlikely to have personal mementos of their baby. Mementos could include Polaroid photographs of their baby, locks of hair if present, footprints, handprints, the cord clamp, name cards, name bands, booties and bonnets. Personal mementos can become sacred to the family (Yoder 1994, p. 476). Three nurses had heard stories in which houses burnt down and the mother saved only the mementos of the baby. These mementos were her most precious possessions. If parents did not take the mementos home they were left in the baby's medical records. It was the experience of the nurses that many parents retrieved them at a later time. One nurse spoke of such a situation:

Parents may not accept the death of their infant initially. Sometimes in the future, they may want the memories of the photographs and the blankets of love [blanket made by hospital volunteers] and the booties and the bonnets and the lock of hair. Six months later that mother made a secret visit to the nursery and claimed all of the memories booklets, the blankets, the gloves, the booties, the bonnets and all the things the baby had been in when it had died. (Nurse 10)

It was an indication of the nurses' empathy when parents claimed the mementos of their baby. The nurses were acutely aware that resolution of grief was needed in order for parents to move on from this tragedy. Many parents, as the nurses told it, were extremely appreciative of their efforts in providing these memories. There was, for many nurses, some professional satisfaction out of an incredibly sad situation.

6.7.2 Term infants more valued than extremely premature infants

The majority of nurses considered full term infants of more value than extremely premature ones. Full term babies were fully matured. They could become acutely ill following a difficult labour and delivery. Extremely premature babies were valued, but

most nurses did not expect an extremely premature baby to survive. One nurse stated, *'The higher the gestation, the less likely it is that you're going to die'* (Nurse 10). The difference was that, *'in general you don't expect a full term 38 weeker to die. Whereas you do expect a 23 weeker to die or have a very large possibility of dying'* (Nurse 10). It was more difficult for most nurses to accept a poor outcome in a term infant than in an extremely premature infant. The term infant had survived the long gestational weeks and had the ability to live, grow and develop. There was sadness and bewilderment for the nurses when a full term infant died. One nurse stated, *'...for this person [term infant] to sustain injury because of the immediate antepartum, intrapartum or post partum experience it was difficult to take on board'* (Nurse 5). Another nurse explained, that *'...with a term baby dying, you just think 'Why, why has this happened?'' And it seems so much worse'* (Nurse 13). This response is confirmed by McHaffie and Fowlie (1996, p. 105) who suggest the devastation is about "what should have been". The nurses in the current study all expected something to happen to extremely premature infants. They spoke about how they expected them to succumb early to a massive cerebral bleed, NEC or sepsis. One nurse stated, *'I'd be waiting for the baby to die... I think it would only be a matter of time'* (Nurse 17). Another nurse explained that in her experience babies of 24 weeks gestation or less *'...survived a day or two and then they've just died practically on the end of the ventilator'* (Nurse 17). Another nurse added:

Those infants, none of whom I have seen survive,...have probably lingered on for maybe a week, and have usually died or succumbed to a Grade 3 or 4 IVH. It's usually a haemodynamic problem...secondary to a massive bleed. (Nurse 10)

It seemed that the nurses' perceived value of a baby was based in part on its appearance. The extremely premature baby looks different in comparison to their full term counterpart (Budreau 1987, p. 13; Budreau 1989, p. 38). Several nurses described how full-term infants were capable of eliciting nurturing behaviours in adults, essential for their survival. These nurturing behaviours include feeding and protection until the infant was able to do these things for himself/herself. Premature infants attached to life support can be seen as a violation of this ideal by nurses (Frey 1995, cited in Whittier 1999, p. 217),

thus making them ambiguous (Schlomann 1999, p. 168). Extremely premature babies might be unable to elicit nurturing behaviours in adults. Shahan (2000, p. 29) aptly described her babies (twins) as being attached to a “mechanical mommy”, and to her the sight was scary and overwhelming. It could be argued that the tiny baby should not have to elicit nurturing behaviour in adults, the issue is about the difference in appearance between the immature infant and its full term counterpart.

The nurses who considered full-term babies more valuable than extremely premature babies also accepted that parents could value their baby regardless of gestational age. While the nurses could value extremely premature infants they could accept its death because it was more likely than with a full term infant. Neonatal nurses have been found to experience difficulty in accepting a terminal diagnosis in particular infants, usually full term infants. The nurses in that study believed that when full term infants with no visible abnormalities were dying they were more distressed than when a premature infant died (Green 1995, p. 72).

I find it harder when they are big fat term babies than I do when they are premature, because big fat term babies it shouldn't happen to. Premmies, there is a reason why they have come out early. (Green 1995, p. 72)

It was as if these nurses understood that extremely premature babies died, however, it was more devastating for them when a baby who had made it to the end of gestation died. To the nurses it seemed a waste of a new life.

6.7.3 Summary

Babies are valued and seen as special by the community. The nurses were all aware of the value that is placed on babies by society. They believed this was an emotional issue because babies represent the future. The majority of nurses considered full term babies as more valued by them than extremely premature ones, which was related to maturity and the ability to sustain existence.

6.8 The cost of sustaining life for this baby

Much has been written about the resources, particularly money, required to keep extremely premature babies alive (McCarthy, Koops, Honeyfield & Butterfield 1979; Yu & Bajuk 1981; Hernandez, Offutt & Butterfield 1986; Murton, Doyle & Kitchen 1987; Schwarz 1989; Lewitt, Schuumann Baker, Corman & Shiono 1995; St John, Nelson, Cliver, Bishnoi & Goldenberg 2000), and whether or not such money is deemed well spent (Boyle, Torrance, Sinclair & Horwood 1983; Murphy 1989; Battaglia & Battaglia 1992; Paneth 1992). In the NICU there is very little comparable data in which to rank funding decisions (Chance 1988, p. 945). What is known is that caring for extremely premature babies is expensive, and the costs on average increase with decreasing birthweight (Mugford 1988, p. 107; Petrou 2003, p. 18).

6.8.1 Money and services

The nurses were all convinced that neonatal intensive care was one of the most expensive areas of health care. They were acutely aware that large quantities of public money was needed to treat extremely premature babies. The cost is directly related to the length of hospitalisation (Petrou 2003, p. 19). One nurse observed:

There's no two ways about it; it's astonishingly expensive to maintain these kids, whether they be term babies in an NICU or whether they be 24 weekers. The 24 weeker is obviously going to need a bed for a hell of a lot longer than a term baby. (Nurse 4)

Another nurse explained:

When you consider the cost of maintaining a 24 weeker in an NICU from the beginning, to discharge, to adulthood. I just hate to think what it would cost the economy. (Nurse 14)

Access to neonatal services increases the likelihood of survival, however, it does not seem to increase the likelihood of a positive outcome at extremes in gestation. The

survival of extremely premature infants has increased though increased survival has resulted in more children with disabilities (Lorenz, Wooliever, Jetton & Paneth 1998, p. 425). One nurse told of the dilemma faced by NICU's in relation to finances:

Our hospital is in debt...Certainly in the NH&MRC [National Health and Medical Research Council] preterm birth guidelines, when they were quoting millions that were spent on neonatal units for a 12 month period, 66 [percent] of that was spent on level 3 units, which actually make up a relatively small percentage of neonatal beds within NSW/ Australia. That's an incredible amount of money to spend on a very small specialty and a small number of beds. Between 50-60 beds in NSW... small numbers of beds in other states. That's an incredible amount of money to spend, particularly if the infant is actually going to die or be damaged and require ongoing support in the community through Developmental Disability Services. (Nurse 10)

The nurses all disliked thinking about the finances associated with saving extremely premature babies. They wanted to separate their caregiving activities from a budget. The nurses were not unrealistic about the allocation of scarce resources. McHaffie and Fowlie (1996, p. 2) suggest the justification for expenditure on NICU varies with the position of an assessor. An administrator is likely to appreciate the financial implications differently from clinician. The initial cost of NICU and the ongoing costs both require consideration.

The nurses could all see that saving extremely premature babies was at a huge cost. They tried not to think about the costs. The nurses were convinced it was worth the exorbitant cost if the baby had a chance of intact survival. Money was well spent if a baby survived intact. One nurse stated:

For 24 weeks and less, I think the dollar, if you look at that almighty dollar, that is something to do with whether or not you should treat those children. You know that way back in the deep recesses of your mind. The cost of it when you do see one that comes through, who's done extremely well, you feel it's worth it. You just push it right to the back of your mind, because you do see the odd occasional ones that do so well. You think well it's probably worth at least waiting and seeing. (Nurse 9)

The nurses all knew that extremely premature babies required months of intensive support. Though there were no guarantees the baby would not have any lasting or ongoing problems. If babies did survive they required ongoing hospital services (Petrou 2003, p. 19; Petrou, Mehta, Hockley, Cook-Mozaffari, Henderson & Goldacre 2003, p. 1290; Catlin 2006, p. 742). They were more likely to be re-hospitalised during their first year of life and if admitted were more acutely ill (Mitchell & Najak, 1989, p. 29).

6.8.2 Justifying money spent on this baby

With the health dollar subjected to ever-competing demands, most nurses understood that other specialities might be allocated less funding in order for NICUs to receive optimal funding. The nurses all knew full well that babies of greater gestation and full term infants benefitted from NIC. They were convinced that NICUs should not have to relinquish money to fund other areas:

There's only so many dollars going around. I don't think that the onus should be on the NICU's to cut their spending. It should be allocated to everybody in reasonable proportions. (Nurse 14)

Costs for individual extremely premature babies are purported to be high (St John et al 2000, p. 170), though the cost for extremely premature babies is only a small component of total neonatal costs. Intensive care is more cost effective for babies weighing greater than 1000 grams, and less favourable for those weighing less than 1000 grams (Boyle et al 1983, p. 1330; Petrou 2003, p. 18). Murton et al (1987, p. 78) have suggested that 80% of the resources in their NICU were utilised by low birthweight infants, yet they comprised less than 50% of the total admissions. Clearly, the extremely premature infant impacts on the resources of the NICU and could account for the vacillation experienced by the nurses as they tried to justify NICU expenditure:

A lot of people would say, 'The amount of money spent on keeping one of your babies alive in intensive care, could make up for say five hip replacements or a couple of heart operations. Can you justify that?' (Nurse 17)

Another nurse offered:

The health dollar is finite. If we put more into saving micro-premmies, we rob from another area of health spending. We are entitled to ask if we achieve a good outcome for our expenditure, but also if it was worth short-changing other areas. (Nurse 6)

The nurses all held that economics should not be the basis for decision-making, yet several nurses emphasised they should be concerned about the cost of NICU, because, *'...you can't just go on and on and not have any regard to money'* (Nurse 20). All the nurses discussed how their managers underscored the costs of the NICU. One nurse discussed her anxiety:

We always have it rammed down our throat, because whenever we have to cut back, paediatrics have to cut back money. First place they hit is the nursing staff because that's the biggest group of people. No one says. 'Ok what we're going to do to cut the budget is we're not going to admit any babies in the Nursery less than 25 weeks gestation.' That never comes into it. But we're not going to have any staff to look after them. (Nurse 19)

At the time of the interviews there were protests about the poor treatment of elderly patients. Elderly patients in a nursing home were placed in kerosene baths to treat scabies, a treatment phased out over 50 years ago (Willacy 2000). Several nurses experienced difficulty reconciling what happened to the elderly patients, people who had made a contribution to society. One nurse explained:

We haven't got infinite money to go around. I think you've got to try and be as fair as possible, because you've got your ageing population. Medicine has come so far technologically, that we're prolonging everybody's life, as much as the prems. Older people are living longer, so you've got to decide what you want to focus the money on. (Nurse 16)

This issue was not about preferential treatment of the elderly, it was about balancing the health care budget to ensure equitable access for all Australians. Several nurses spoke of

their fear of being the recipient of sub standard health care when they became elderly and infirm.

6.8.3 The question of spending money on babies

The nurses all questioned spending money on babies who were not viable, probably not survive, or be severely handicapped. One nurse was philosophical in her comments about the use of funds:

Major support costs lots and lots of money. In the quieter moments, you would have to question yourself whether spending a couple of thousand dollars a day for an infant that may have a sudden demise on Day 5 or Day 7. Is it worth it? (Nurse 10)

Another nurse observed:

There's plenty of evidence around that babies with poor gases [arterial blood gases] just don't make it. How much money should you spend on babies who you know according to research have almost no hope, whether society can afford to spend this sort of money on babies who don't stand a chance. (Nurse 14)

Several nurses were convinced the money would be better spent on babies 26 weeks gestation and greater. Although the nurses believed that each baby should be treated as a valued individual, there was consensus that 23 completed weeks (ie 24 weeks) should be the cut-off point for treatment. One nurse expressed her concern:

The infant may have an enormous amount of money spent on them... and then die. Everybody knows that economics are finite within our particular health system, and that perhaps we should be directing certain cut-off points towards viable gestation. (Nurse 10)

One focus group discussed the initial and ongoing costs associated with babies less than 24 weeks gestation and believed the money could be better spent.

23 weekers you probably don't, [spend a large amount of money] I reckon. (Nurse 20)

Yeah they die real quick. (Nurse 19)

There's only the odd one here that survives. (Nurse 20)

But it only takes one or two to come through to chew up a big pile of money. (Nurse 19)

Oh yes that's true. (Nurse 20)

Long stay, 100 odd days. You're looking at afterwards going home and any special schools. (Nurse 19)

There was frustration as the nurses spoke about their experiences with babies of extreme prematurity. The frustration was focused on the same issues related to outcome. They thought about the babies who would not contribute to society in a financially viable way. They recognised that extremely premature babies would require long term support.

Perhaps the most significant issue here is that it was important for parents to spend time with their baby, to come to terms with realities. Such time may not make a great difference to the NICU budget, because, '*...the majority of them are only a few days. It's only a few thousand dollars*' (Nurse 19). McCarthy et al (1979, p. 760) found that most non-survivors died during the first few days of life, therefore a large amount of money was not spent on them.

The nurses were all emphatic that if extremely premature babies were saved, money should be allocated to help the families provide for the ongoing needs of their children. One nurse explained:

The money could be better allocated to looking after the people [babies] that do survive. You know the families. That's where the money should be going, since it's limited, rather than keeping babies going who are going to die anyway. (Nurse 14)

The allocation of finances was an ongoing cause for concern. The majority of nurses knew that allocating funds to babies who would probably die, or if they survived, might require lifelong care. Such use of funds in their opinion was not optimal, yet they wanted the baby to have a chance. There was, in addition, vacillation on the part of many nurses.

They considered that treating extremely premature babies could be not cost effective but believed it was inappropriate to make decisions based largely on costs. Their emotions seemed to pull them in opposing directions. One nurse stated, '*...we're going to be burning up a lot of money basically to keep them alive*' (Nurse 17), while in another breath the same nurse stated:

Health does cost a lot of money, and maybe one day it will come down to cost, but that would be a worry for me if that ultimately was a significant factor. (Nurse 17)

The nurses all agreed that they would find it worrisome if decisions about treatment were based on costs.

We don't think money should come into the issue of treating. I don't think cost would come into it while we were trying to treat them. I wouldn't like thinking that money played a part in whether we should treat a baby or not. (Nurse 17)

Decisions made on the basis of cost were considered unacceptable. Many made comparisons, questioning how society could find money for entertainment and visits by dignitaries, yet could not afford intensive care for babies. Nurses in a focus group discussed this issue:

We spend 1.5 million dollars to say hello to the Queen this week. (Nurse 2)

Fireworks cost hundreds of thousands of dollars. (Nurse 4)

You've got years and years worth. Work out the budget. OK we have beautiful fireworks, but I'm sorry we lose 5 neonatal beds. We can have the Queen out here, well there's another 5 neonatal beds. (Nurse 1)

I was at the Opera House for New Year...and I thought 'My God we could feed Africa.' (Nurse 2)

With that money that was going up in smoke. (Nurse 4)

Other nurses compared the money needed for NICU and that spent on other things not deemed as important. They believed, '*...it's [NICU] a pittance really compared to the*

billions that are spent on Public Works' (Nurse 21). They could not reconcile some public expenditure when they believed health was more important. There should be no competition between health and other expenditures, health was always far too important.

The nurses all held their role to be carers, not budget administrators, therefore they saw their role as carers for the baby, not feeling responsible for treatment costs.

People think you're cheapening the life...you're putting a price on the life. We should be not worried about economics, we should be out there just to heal people. (Nurse 16)

One nurse was particularly clear:

These are little lives, they need to be helped and we're there to help them. If you've got a problem with the money, then don't come here and tell me. I believe we're more carers. I think if you ask any neonatal nurse...about dollars and cents, they will show you the door. (Nurse 2)

None of the nurses were concerned about cost while there was hope for a positive outcome. This position reflects a justice ethics perspective, in which the subject received what is rightfully owed. When it became obvious to the nurses that a baby would have a poor outcome, or was being subjected to futile treatment, the nurses spoke of voicing their concerns about financial costs. Until that time the costs were justified. The nurses would then question resource allocation and lament how little money other areas were allocated. On reflection, such thinking was related to the frustration of keeping a baby alive. The nurses all seemed to justify the costs spent on these babies, while knowing the shrinking health dollar was impacting on all health care.

6.8.4 Summary

The nurses all were convinced there should not be a price on the life of extremely premature babies. If the baby were to live money should be available for treatment. The nurses found it troubling that other areas might not be as well funded, but they held firm

to their conviction that money from NICU should not be diverted to other areas. They, however, were concerned about cost when treatment was futile.

The allocation of scarce resources raises questions and provokes emotions and the funding of extremely premature babies is no exception. The nurses' emotions seemed to swing between wanting everything done, not being worried about the costs to being concerned about the cost of care, and recognising the competing demands for health care resources. The nurses at times were all ambivalent yet used ethical reasoning to identify that spending money of extremely premature babies likely to have a poor outcome, could both enhance and diminish the wellbeing of other members of the community.

6.9 Conclusion:

In this chapter, *It's all about this baby*, the baby, as an individual, has been shown to be a fundamental belief and a motivating force for the neonatal nurses in this study. They believed that each baby should be treated as an individual and given the opportunity to live if it was vigorous and active at delivery. The nurses recognised that not all babies would live or survive, but when a baby was resuscitated they wanted it to receive the best available treatment. This standard enabled those who survived to have the best possible outcome, while others would be given every possible opportunity and care. The nurses understood clearly that not all babies would survive. The nurses were hopeful but not optimistic. The nurses demonstrated a commitment to the baby and their practice in the challenging NICU environment.

The following chapter 'having a voice' explores the experience of the nurses related to the decisions about the extremely premature baby, and how such decisions impact on the babies, their parents and the nurses themselves.