

CHAPTER 7: HAVING A VOICE

7.0 Introduction

The decision to resuscitate an extremely premature infant is a complicated one, and because of the issues involved it can never be taken lightly. Treatment decisions are difficult because if a baby is resuscitated with little hope of survival it becomes hard to withdraw life support, particularly if there are objections by the parents. Conversely, if a baby was not resuscitated, survival and a promising future could be lost. These are the decisions that confront neonatologists and neonatal nurses. The nurses all understood it was not members of the health care team who had to live with the outcomes of these decisions. Rather, they knew it was the parents who would live with the consequences. This was their most compelling dilemma. The nurses were “caught up in the personal tragedy of a given family facing these momentous choices” (McHaffie & Fowlie 1996, p. 3).

In this chapter the theme ‘having a voice’ is explored. Having a voice is about the nurses’ belief that they and parents should have a voice in the decisions involving extremely premature babies. Having a voice will offer an understanding of what it is like to hold these beliefs and implement the decisions of others, often without input. It was the view of the nurses that they had the experience to be involved in decision making. The nurses considered themselves to be in a unique position. They were in possession of knowledge of the baby and family not possessed by other members of the health care team.

The treatment decisions regarding extremely premature babies are usually one or other of two categories. The first category concerns those related to initiating resuscitation. Once resuscitated and given treatment in the NICU, the second category of decisions are those about continuation/discontinuation of treatment. The decisions that were problematic for the nurses were those concerning resuscitation and the management of babies with a poor prognosis. Decisions related to babies with a good prognosis were seldom the cause of anxiety for the nurses.

All the nurses had experienced what they believed was authoritarian and autocratic decision making. The nurses had encountered medical staff whose determination to make unilateral decisions for extremely premature babies could make the NICU an oppressive environment. Boosfeld (1995, p. 21) has questioned whether parents and nurses can ever be accepted as equal partners with medical staff in the decision making process.

Deciding what was in the best interest of an extremely premature baby was difficult. It was the understanding of all the nurses, that under normal circumstances, babies are born at term and taken home and nurtured by their parents. Extremely premature babies, by comparison, are resuscitated, attached to life support and treated with aggressive neonatal therapies. The babies are intubated, ventilated and supported with inotropes until they recover, or complications occur necessitating withdrawal of treatment. The nurses were convinced the baby could be burdened by treatment. The nurses were all passionate that when the burdens of continued treatment outweighed benefits for the baby, then treatment should be withdrawn. Several nurses spoke of situations where a baby might have treatment continued while an adult could refuse treatment. Willmott, White and Howard (2006/7) agree that a competent adult has a right to refuse life-sustaining medical treatment, but this issue has not yet been tested in Australian law.

The nurses were all emphatic that decisions to save an extremely premature baby were not easy decisions. They believed decisions should be made at birth, on the condition of the baby, using objective criteria like the Apgar score and the baby's response to treatment. The Apgar score alerts the clinician to the level of assistance needed by the baby at one and five minutes respectively after birth (American Academy of Pediatrics, Committee on fetus and Newborn, American College of Obstetricians and Gynecologists and Committee on Obstetric Practice 2006, p. 1444). The nurses were all clear that if a baby was vigorous and active at birth, it should be resuscitated. Once resuscitated the condition of the baby and its response to treatment could be evaluated. It could be argued that nurses in other areas of health care are involved in difficult situations related to their patients' decision making. In many other areas patients are able to make their own decisions. All babies in the NICU require advocates to decide their best interests. Many

decisions need to be taken at a time when parents are vulnerable and struggling with grief. These decisions relate to whether the baby will be given the opportunity to live. Decisions at the beginning of life could have a lifelong impact.

7.1 Helping parents have a voice

The nurses all believed the parents were an integral part in their baby's life and an important part of the decision making team. It was imperative that parents be informed of all possible outcomes. The nurses believed parents had the most to gain and the most to lose from any decisions about their baby.

7.1.1 Informing and honouring the voice

Premature labour and delivery are a shock for parents. It was the understanding of the majority of the nurses that parents are required to make decisions about their tiny baby at a time when they are physically and emotionally overwhelmed. They believed that becoming parents at 24 weeks gestation and less would be difficult, because all of their expectations and dreams had been shattered. Over half the nurses were convinced that parents, particularly mothers, grapple with the crisis of premature birth. There are psychological tasks associated with premature labour and delivery that need to be accomplished (Caplan, Mason & Caplan 2000, p. 25). Wilshire Warren (2000, p. 4) spoke of the delivery of her extremely premature baby. There were many people in the delivery room to resuscitate the baby, however "there was no joy or anticipation on anyone's face" (Wilshire Warren 2000, p. 4). One nurse told of going to the labour ward to assist with resuscitation of 25-week gestation twins. She wondered if the parents understood what the next few months would hold. Several months later the mother of one of the babies still in the NICU said to the nurse, '*I always remember your face in labour ward. You looked so sad*'. The nurse explained that, '*...it was probably because I knew they have such a long road ahead of them*' (Nurse 11). The mother agreed that the nurse was right.

It was the belief of all the nurses that parents at risk of extremely premature delivery would benefit from antenatal counselling by the neonatologist about the chances for initial and long term survival. Sanders et al (1995, p. 494) found that virtually all neonatologists counselled parents that 100% of infants less than 23 weeks gestation would die. Mulvey, Partridge, Martinez, Yu and Wallace (2001, p. 269) found that obstetricians in Australia were likely to discuss resuscitation with parents at 23 to 24 weeks. Similar results were reported by Partridge, Freeman, Weiss and Martinez (2001, p. 27) in California (USA). Munro et al (2000, p. 275) found that 95% of neonatologists spoke to the parents about mortality and morbidity. It was troubling for the majority of nurses when a pregnant woman arrived at the hospital in the late stages of labour, making it impossible for the neonatology staff to discuss treatment options.

The nurses all believed that decisions to resuscitate should be made at birth and be dependent on the baby's condition. They understood that if the baby was in good condition at birth, it had a better chance of a positive outcome. One nurse explained that, *'...you know not do the heroics, but be there to have a look. Vigorous, pink, active. The bruised battered baby, you're in trouble'* (Nurse 13).

Several nurses emphasised the importance of the baby being born in optimal condition. They spoke about how other professionals used the word 'optimal'. The nurses held that pregnancies that needed to be terminated for maternal or fetal reasons at 24 weeks gestation and less could never be optimal. 'Optimal' referred to a baby born in the best possible condition, regardless of gestation. One nurse elaborated:

If the baby on the first day has started with pHs of 6.8 [on arterial blood gas analysis] and then blown their gut [perforated intestine with NEC] within 24 hours, then you don't give it [continued support]. But if they've started in an optimal position then you give the ventilation and the treatment they need. (Nurse 8)

The nurses were all convinced that treatment issues were never black and white. They would be happier if the medical staff explained in detail to the parents about treatment, non treatment and treatment withdrawal. One nurse suggested:

We can do things if the baby is looking vigorous and healthy. I would feel much happier if the doctors just spelt out a), b), c) to the parents. 'If this baby starts showing any sort of difficulty, if there is any sort of major problems with it, then we are not going to keep persevering'. (Nurse 9)

7.1.2 Giving a voice during labour

Confusion arose from the questionnaire results when many nurses believed it was inappropriate to discuss extreme prematurity with expectant parents during labour. They understood it was a, '*...very emotional time for parents*' (Q/A 137). This thinking could be viewed as paternalism. All nurses interviewed were adamant that expectant parents in labour needed information. This approach seems dogmatic, but the nurses considered imparting information to expectant parents important. The nurses recognised that labour was not the most beneficial time to discuss the delivery, neonatal management and outcomes of extreme prematurity. The information needed to be imparted if consent was to be informed. The nurses were convinced that information was essential because labouring before 24 weeks gestation would be traumatic.

The nurses held that labouring women and their partners should be given information, unless they chose not to be informed. The amount of information taken in would depend on the stage of labour, as suggested by one nurse:

In later stages of labour there's no use talking then, because you can't think about anything. In the early stages you can talk...you're [the mother] going to be worried. You're going to want information. You're going to want to do the right thing. You've come into hospital, you're worried sick because you've gone into labour. I think you should be given all the pros and cons. (Nurse 11)

Labour was not considered the optimal time to speak to expectant parents, yet one nurse emphasised, '*You're not stupid in labour. While the contractions are going don't worry about talking, but in between, you can carry on a normal conversation. And you're*

thinking alright' (Nurse 11). Conversely, several nurses were not sure whether expectant mothers could take in information. One nurse who had experienced labour stated:

How many women would get through it [labour] without an alteration in their ability to sit up and think about their ethical preference? Is she able to consider a discussion of outcomes of 24 weekers and statistical outcomes while you are labouring? If I think about my level of awareness while I was labouring I would say not. (Nurse 6)

The nurses all knew that not all extremely preterm labours proceed to delivery. There were women whose labour could be stopped or suppressed for 24 hours. During this time important discussions could occur. One nurse stated:

They've got time to think. They've got time for people to talk to them. Not every extreme preemie suddenly delivers at 24 weeks. There's often the opportunity for someone to sit down. They're a human being, it's frightening and they are entitled to that information. (Nurse 5)

The nurses all stressed the importance of ensuring the parents' decisions were informed. Several nurses explained how perinatal centres had a visitation programme for those likely to deliver prematurely. A neonatal nurse and neonatologist visited the labour ward or antenatal ward and discussed potential outcomes. They spoke about the NICU and if the baby appeared viable the expectant parents visited the NICU.

The process of information giving was important regardless of when it occurred. The nurses all showed empathy and seemed to project themselves into the position of the expectant couple and they were passionate they would want to be told what was happening. Labour at the edge of viability would be traumatic, regardless of the best intentions of the staff to try to protect the expectant parents from the reality.

7.1.3 Not wanting to traumatise expectant parents

The nurses all had a view that antenatal classes for expectant parents were not realistic. They were convinced that many expectant parents were not informed of the possibility of premature birth. This is confirmed by Catlin (2005, p. 169) and Keogh, Sinn, Hollebhone, Bajuk, Fischer, Lui (2007, p.273) who suggest this lack of education has meant that parents are unprepared, and have given little thought to what they would do in the event of extremely preterm birth. The nurses were all passionate that expectant parents should be informed about the risk of preterm labour and birth yet they stated this rarely happened. One nurse stated:

They don't cover it in the antenatal class at all. Premature birth isn't at all. When do these people then get the information? When they get pregnant, the doctor isn't going to talk. The GP isn't going to talk to you about premature birth. Nobody is. Either you read it through the media or you've had a friend that's gone through it, or you don't know what's going to happen. So when do you discuss it? (Nurse 12)

The nurses were all convinced that antenatal classes did not adequately address the possibility of preterm labour and delivery. If they addressed it, they glossed over it, suggesting it would not happen. The nurses all thought the nursery tours for parents in danger of a high-risk delivery were not realistic, because little emphasis was placed on the baby being sick, instead the focus was on the baby being well. One nurse explained:

They [pregnant couple] have a look through Level 3 [NICU] and see a couple of 'Ohhh!' babies with all those attachments and they take them to Level 2 [step down nursery] and show them some nice cuddly, chubby ones in cots. All of a sudden well that's my baby that looks normal up there. That's how you progress through. You start off here and you look really sick like this and then 6 weeks down the track, you look like that. They forget what's in the middle and that their one might never be that one. (Nurse 19)

Several nurses emphasised that expectant parents were not given a realistic tour of the NICU, because no one wanted to traumatise them. It could be theoretically possible that

in an antenatal class of 20 expectant couples that at least one of the couples could have a baby requiring intensive care. Most nurses were passionate that antenatal classes should be run by midwives, because of the reality orientation which was required. Antenatal classes might not be realistic, but as stated by one nurse *'I don't know anyone who has found a good way to make them absolutely realise what a 23 weeker is going to do to you'* (Nurse 20). Regardless of the difficulty, expectant parents need to be informed of the possibility of premature birth. Several nurses recognised there were limits to this approach. Out of concern they wanted expectant parents to be exposed to the idea of possible premature delivery in a realistic manner, but could see no way of preparing them for the experience.

7.1.4 The window of opportunity

The nurses all understood that when the baby was resuscitated and its condition evaluated, decisions could be re-evaluated when problems arose. They believed it was imperative that decisions were made early during, *'...the window of opportunity'* (Nurse 19), and were convinced this window of opportunity lasted for a short period of time. One nurse stated:

The longer things go on, the better chance of survival. If the decisions are made very early...before catastrophic events, that could be a quicker decision for either withdrawal or continuing support. (Nurse 15)

There was some desperation in several of the nurses at this time. They held it to be crucial that parents were informed of their baby's condition, given the prognosis, and options for treatment. Information giving needed to occur early, and it needed to be given with sensitivity and compassion, but time was of the essence. Arthur-Burto and Tarlos-Benka (1997, p. 333) discuss the importance of 'go slow' decisions for the parents because it offers them control over time, which diminishes the sense that they are pressured into a decision. This 'go slow' approach important for the parents, created a dilemma for the nurses. Most nurses had seen treatment withdrawn and an impaired baby

survive. They could understand that parents needed time, yet timing was of the essence once the decision was made to withdraw treatment. Several nurses stated they tried not to convey their anxiety to the parents. Most told stories of seizing the moment, where they requested medical staff to keep the treatment withdrawal dialogue open with the parents. One nurse stated, ‘...we just keep working on them [medical staff]. Start working on them’ (Nurse 19).

The nurses were all acutely aware that time was critical. It was concerning for the nurses when ‘...the open window of opportunity was missed’ (Nurse 19). It needs to be remembered that when medical staff speak to parents they have often made up their minds about treatment. The family does not have the benefit of the team’s knowledge and experience and are unable to immediately come to the same conclusion. King (1992, p.20) suggests that parents take longer to grasp the situation than the team anticipates. McHaffie and Fowlie (1996, p. 247) agree that the “window of opportunity is sometimes only briefly open. Delays can mean that when equipment is removed the child is able to sustain life unaided.”

7.1.5 Summary

Parents need to be informed about issues related to extreme prematurity. The nurses all understood that parents would be confused about viability, gestation and birth weight, and the effect these will have on their baby’s outcome. They lamented the situation where decisions were made by parents without an understanding of the ramifications of survival. MacDonald and the Committee on Fetus and Newborn (2007, p. 1024) have suggested information should be given to parents in small fragments at frequent intervals, however, this does not take into account the urgency of the situation. All the nurses were concerned about the time taken to make the decisions, because if treatment was not withdrawn before a certain time, there was a chance the baby would survive in a profoundly impaired state.

7.2 Parents making difficult decisions

The nurses were all committed to the belief that parents have the legal right to make decisions for their babies, regardless of gestation. Shared decision making is considered important (Hussain & Rosenkrantz 2003, p. 466). Yet, there is evidence (Penticuff 2005, p. 199) that mothers are less than satisfied with their level of decision input. Catlin (2005, p. 174) has even recommended an advance directive that would outline treatment decisions.

It was the experience of the majority of nurses that the involvement of parents in decision making could be a positive experience. They also understood that the decisions had the potential to violate the baby's rights. Violations occur from the emotional turmoil facing the family, lack of sufficient information to partake in decision making, and the inability to separate the interest of the parents from the interest of the child (Bopp & Coleson 1996, p. 133). It remains difficult to know what is in the best interests of babies. The language of interests is abstract and seems to suggest that separating the parents' interest from the baby's interest is paramount. The idea that emotional and familial bonds can be broken between baby and parents can be challenged. Decisions about the best interest of the baby will always impinge on the best interest of the family.

7.2.1 A legitimate voice

The nurses were all convinced that parents should be welcomed into the decision making team. Several stressed that parents were disadvantaged, in that information was essential for participation, as was the ability to understand the significance of the information. The nurses all recognised the parents as the legitimate decision makers for their babies. Legitimacy is ascribed from the familial, emotional and legal bonds that tied the parents to their baby. One nurse stated:

I firmly believe from a legal viewpoint and a moralistic viewpoint that it is right for parents, these people who created, who had genetic input into that child, having the right to have the decision, about what happened in terms of outcomes. (Nurse 6)

In emphasising the importance of the parents' role in decision making the nurses demonstrated their understanding that parents had the most to gain and most to lose in terms of outcome. One nurse made this clear by stating:

They're [parents] going to have to look after the child. It's easy for me to turn around and say 'Oh you should have the child no matter what.' But I'm not going to clothe it, I'm not going to feed it, I'm not going to be the one who's going to have to pay for the special schooling or the physiotherapy or the special shoes or the glasses. So you know I have no business in that decision. (Nurse 12)

Parents were seen by all the nurses as an integral part of the decision making team but they believed the parents should not make the final decision to withdraw treatment. While this belief appears to contradict other statements, all the nurses wanted the parents to understand the neonatologist bore the ultimate responsibility. Several nurses in the current study held that parents would be traumatised if they believed they were solely responsible. One nurse emphasised:

I think it's wrong to just ask parents 'Do you want to turn the baby off the ventilator?' Can you imagine how those parents feel forever like they killed the child? (Nurse 11)

Another nurse did not want parents to live with the guilt of withdrawing treatment on their own baby. She explained:

If you leave it to the parents, I see that's a terrible burden on them for the rest of their lives. They know that they're the ones that said 'Turn off'. (Nurse 18)

What seemed to be important for most nurses was that parents must be supported in their decision making.

You've got to get that balance between supporting them and giving them the information, but also acknowledging that it's their child, and they've got the right to make that decision. (Nurse 6)

This support was essential otherwise the parents, '*...are going to carry that burden as a very real, heavy burden...grieve over it*' (Nurse 6). There was conviction in most nurses that involvement in decision making came at a price for parents. Parents would carry their decisions for the rest of their lives.

They've [parents] got to live with it. We might forget eventually, but they won't. They're never going to forget the fact that they took their baby's life virtually. It's a terrible decision to have to make. (Nurse 21)

Parents in a study by Brinchmann et al (2002, p. 396) wanted to be included in the decision making, but they did not wish to take the final decision because it "...would be too heavy a burden to live with later". One of the most important reasons parents should be involved in making decisions was that they had to live with the outcomes (Brinchmann et al. 2002, p. 397). There are accounts of parents who have pursued legal action if kept out of the information and decision making loop. The parents who have sued were making the point that they should have been involved in the decision making, rather than seeking monetary recompense (Lantos 2001, p. 87).

7.2.2 An informed voice

The nurses were all committed to the belief that parents should be able to choose non-intervention for babies 24 weeks gestation and less. One nurse reasoned:

I don't think I would personally have a problem. I really think that anything under 25 weeks you've got a hard battle on your hands. I wouldn't have a problem. (Nurse 18)

Parents needed to be informed about extreme prematurity by the neonatologist but staff should assess the information had been understood. The nurses emphasised that consent must be informed.

When a person is fully aware of the consequences and have made an informed decision not to go ahead, then nobody should go ahead. We know that physiologically the baby stands a poor chance less than 24 weeks...with this very extreme prem, I have no problem with the parents not wishing to start. (Nurse 12)

The nurses all held that if parents made informed decisions, those decisions should be honoured by the medical staff. They emphasised that the baby must be assessed at birth, and if found to be too immature then the parent's decisions to withhold treatment should be honoured. This is in contrast with Catlin (1999, p. 269) who found that 45% of neonatologists would treat regardless of parental wishes, and one respondent believed that parental wishes for withholding treatment should never be honoured. Peerzada et al (2006, p. 1992) found that 75% of neonatologists would resuscitate despite parental requests to withhold treatment. Pinkerton et al (1997, p. 285) emphasised that parents who choose non intervention need to understand that the "...paediatrician will have a strong urge to treat and initiate resuscitative attempts", (Pinkerton et al. 1997, p. 286). Neonatologists strongly favour the ethical tenet that physicians "...ought to opt for life" (Pinkerton et al. 1997, p. 285). The difficulty for most of the nurses was the baby had to be resuscitated to enable a full assessment.

The majority of nurses reported that neonatologists would inform parents that their decisions for non-treatment would be honoured if the baby was too immature. If the baby was a greater gestation and/or made an attempt to live then the baby would be resuscitated. This situation created confusion for several nurses. They wanted parents to understand that all decisions were open to change, or as one nurse stated, '*...we have to look first before we make the decision*' (Nurse 13). One nurse suggested:

That's a decision that they [parents] can have and yet...it's based on what the baby actually does when it's delivered. If it's lusty and crying and looking if it wants to live,

then you could hardly not do something to help it. You'd have to explain [to the parents] that that's what you would have to do [start treatment]. (Nurse 14)

The nurses all considered themselves caught wanting the parents' decisions respected, yet wanting the baby to have the opportunity for life if not deemed too immature. They were upset if the parents' wishes were overridden when the baby was too immature to survive. Most nurses stated they had observed this situation.

The nurses were all sure that for babies of 26 weeks gestation and greater, parental decisions about non-intervention should not be honoured. One nurse stated, '*If it was an older gestation then that's totally different altogether*' (Nurse 12). The nurses were all aware the outcomes for premature infants of increasing gestations had improved dramatically.

7.2.3 Afraid the parents will change their minds

Parents are at liberty to request non-intervention for their extremely premature baby at birth, however the majority of nurses believed medical staff feared parents would change their minds. This was about parents accepting an extremely premature baby not be resuscitated, yet change their mind when the baby was born. One nurse explained the difficulty:

I think it comes down to the doctors being frightened of being sued if they do what the parents say and then the parents turn around and say, 'No I didn't.' (Nurse 18)

Most nurses were convinced that the risk of litigation in neonatology in Australia was low. There is still much scope for individualised decision making. They were however, convinced that when the legal system became involved, neonatologists might leave the profession. One nurse stated:

There's a little grey area in the Australian laws that they're still working through, and once that gets closed up they won't be working in the neonatal field in any longer. (Nurse 15)

Several nurses spoke about those decisions, made in consultation with parents, not to resuscitate the baby at delivery. They had been requested by the labour ward midwives to wait outside the delivery room in case the parents changed their mind and requested resuscitation. One nurse found this practice distressing:

If the parents say they don't want anything done, the labour isn't monitored. When that baby is delivering, delivery staff ring you to come around. 'Why are they ringing me if those parents don't want me to ventilate that baby?' The parents didn't ask, or the parents will say 'Oh I still want you there.' Why? (Nurse 19)

Confusion and uncertainty were experienced by this nurse. If the labour was not monitored, the obstetric staff would not know if the unborn baby had difficulties or know when to intervene. Yet, the neonatal staff had to be available when the baby was born. Clearly, this baby would not be born in optimal condition. Most nurses understood why they needed to be available because if parents saw their '*child was probably struggling to survive maybe they'd want to do something*' (Nurse 24). It seems that seeing their baby at birth had a bigger effect than antenatal counselling. One nurse noted that with parents, '*...once the baby is born, all reason goes out the window*' (Nurse 14). It was the belief of all the nurses that this situation could be avoided or minimised with support and counselling from the obstetric and neonatal staff.

If the nurses accepted that parents had the right to choose non-intervention, they also had the right to request resuscitation. Sometimes the parent did change their minds about resuscitation. Several nurses considered themselves powerless, and as one nurse explained '*it's like your hands are tied*' (Nurse 20). She believed it was her job to resuscitate the baby, even though it caused her much discomfort. The powerlessness persisted, as explained by another nurse:

When they get the baby to the unit, your hands are still tied because it's the neonatologist that's ruling, whereas before you're doing it for the parents and then you're doing it for neonatologist. (Nurse 19)

It is fascinating that parents were seen to make the right decision only when they agreed with the wisdom of the medical and nursing staff. The staff might believe they were the only ones whose primary concern was the best interest of the baby. It is difficult to know if the nurses were wrong in this estimation, but the issue was about freedom of choice, and if society gives parents the autonomy to decide on behalf of their child, then the staff had to accept the parents' decisions. Most nurses understood this, yet it did not seem to make it any easier for them. The limits of parental autonomy are not absolute, and the medical team is not obliged to provide treatment if it is seen to interfere with individual professional goals and standards. The interests of the family are taken into consideration, but these interests should not override the fundamental respect for the best interests of the baby.

7.2.4 Giving information

It was the conviction of all the nurses that parents required information to help them make decisions. The information parents needed was the probable outcome, and the predictability of that outcome for their baby. Parents need to know the outcome for their baby's gestation from cohort studies, and the probability of the outcome for their baby. The nurses all knew that this information could sway the parents' decisions. If the neonatologist imparting the information was optimistic about extremely premature babies, the parents might opt for treatment. Conversely, a neonatologist who was realistic, taking a view based on evidence, his/her view might encourage the parents to opt for non-treatment. This could be misconstrued as coercion. Coercion by definition is to compel by authority, without regard to the individual's wish or desires, (Collins Dictionary 2001 p. 288) therefore some parents might believe there were no choices. One nurse explained:

If it's someone with a belief that 24 weeker does well, comes and talks to you, you're going to get a different view than if someone who is really pessimistic comes. (Nurse 11)

Most nurses understood there were obstacles for parental involvement in decision making. There was the potential for coercion, and the use of euphemistic and technical language, which could impinge on the parents' understanding (Zaner & Bliton 1991, p. 22). These nurses hoped that information about the probability of success would be imparted to the parents without personal bias. Medical staff have been found to be more likely to use coercion than nurses (Lutzen, Johansson and Nordstrom 2000, p. 525). Several nurses balked at the idea of coercion, yet they had hope that a neonatologist would speak honestly and realistically to the parents, to ensure a realistic picture of extreme prematurity and their situation. This is probably benign influence rather than coercion.

It was the nurse's desire that parents be given all the information about their baby. Information could help "parents to restore order in a chaotic existence" (Starke & Moller 2002, p. 245). The nurses all knew the internet had changed the way people access health care information.

We've had a few fathers who are on the Internet. They leave the unit, get onto the Internet and then come back the next day with all this information. (Nurse 13)

The nurses all knew that internet information could be inaccurate and misleading (Lewis & Behana 2001, p. 245). Several spoke about families who had suggested treatments based on their internet search. The parents were invited to bring their internet information to the NICU and discuss it with the neonatologists in order to assess its relevance and possible benefits. The nurses agreed that there are reputable internet sites for parents of premature babies, and they encouraged them to use these sites.

The nurses all emphasised the importance of presenting information to parents in a manner that could be understood. One nurse stated:

The issue is how it is actually delivered. There are many ways to talk about statistics and...outcomes. The issue is that it's presented honestly and that it's presented realistically. It's all very well...to baffle the parents with a whole series of figures, but it must be presented in a realistic manner so the parents are fully aware of what they can expect from an infant at this particular gestation. I think it's how it is said, not what is said. (Nurse 10)

Consistent information was considered to be important. All nurses emphasised that information should be clear and given in a timely manner. They welcomed the case conferences that happened with parents, neonatologists and neonatal nurses. The case conferences were effective because:

All the cards are laid on the table. All the goods and the bads are told to the parent and the nurse, so that everybody knows what's actually been said. (Nurse 10)

One nurse spoke of an excellent method of ensuring parents understood information. She spoke of a neonatologist who audiotaped interviews related to withdrawal of treatment, and he gave the cassette tape to the parents. This nurse believed this was an excellent idea:

After the pain has gone and the baby has gone, you forget a lot of the hard parts that you went through. When you're certain that everything is quiet, they could go back and listen to that tape and say 'Yeah, he did say there's nothing else. He did say that this has happened.' (Nurse 9)

This nurse was convinced this method of communicating was helpful for parents to not be left with unanswered questions. It was clear that communication between staff and parents was an important issue. It was the nurses' experience that discussions surrounding withdrawal of life support were never taken lightly, and only occurred when it was believed the baby would die or survive with major impairments. They all approved of this realistic and compassionate approach.

On the whole most nurses were content with the way most medical staff imparted information to parents. One nurse stated, '*...for the most part, medicos, I would say, would explain things extremely well. I've always been very impressed by them*' (Nurse 10). There was concern however, that parents might not be able to express themselves during meetings with medical staff.

Parents talking to doctors can't really express themselves...the doctor is on a bit on a pedestal and they're more likely to express how they feel to the nursing staff. (Nurse 24)

Most nurses spoke of parents being present during discussions, not voicing their concerns, nor asking questions, but returned to the NICU and asked the nurses their questions. A nurse being present during the meeting could be helpful for those parents. The nurses seemed to believe they had a responsibility to help clarify information for the parents.

7.2.5 Keeping secrets

The nurses were convinced that secrets kept from parents created difficulties for them. They were often privy to information about the condition of the baby including the recent test results. It was difficult when the nurses knew something the parents did not and had to hold this information unto themselves. An example cited concerned a baby who had a head ultrasound, and it was discovered the baby had sustained a major intraventricular bleed. The nurses knew the test results, but were not able to inform the parents. In NICUs it is the responsibility of the neonatologist to inform the parents of the test results. The nurses managed this situation by pretending the tests results had not been made public, or were still being interpreted. In acting as if they had not been informed the nurses found themselves feeling guilty. Their stories have a remarkable similarity in that they felt they were betraying the parents. One nurse's account contains a vivid example:

The morning routine head ultrasounds would be attended on the very tiny infants, those that are ventilated and meet the criteria for head ultrasounds... The parents aren't present. The ultrasound will be done at 10 in the morning, the parent may not arrive until 6

o'clock in the afternoon. They may live 2 hours from the hospital. At 10 o'clock in the morning we may find the infant has had a Grade 3 IVH . There are times when nurses have to hold that knowledge to themselves, for perhaps the entire length of their shift. They may even have to hand it over to the oncoming shift, because the parents aren't going to be present in the nursery until many hours later. (Nurse 10)

The time frame between the staff finding out the results and the parents finding out may be short, but for the nurses, '*...it's only a matter of hours or so. But then they're the longest hours*' (Nurse 15).

In this example the parents arrived in the nursery and the first person they spoke to was generally the nurse caring for their baby. They were expecting to be told the results of any tests.

When they [parents] come in and say 'Well what happened when the baby had the head ultrasound',... they know that the baby's having a routine head ultrasound...will come in expecting you to tell them the results. You must, as part of your role, say 'Yes your baby has had an ultrasound and yes the doctor wants to talk to you this afternoon.' As soon as you say those words, 'Yes the doctor wants to talk to you this afternoon', the parents immediately assume the worst. Knowing that perhaps it is very bad news, you then have to say in a very diplomatic way, because as nurses...we are not allowed to take on the responsibility of informing parents about the fact that their infant has a terrible cerebral bleed. (Nurse 10)

Keeping information from the parents was stressful for all the nurses. They noticed that parents usually knew something was wrong, even though they had not been told. They wondered about this, even if it was a sixth sense.

In my experience I would say that the majority of parents have a sixth sense about being told bad news. (Nurse 10)

Quine and Pahl (1986, p. 58) suggest parents knew something was wrong when the nurses behaved oddly, or differently, or evaded or ignored questions. Perhaps it might

have been that when results were normal the parents were informed, and they know this time it was different.

If you're lucky enough to find a note that says a normal, you can say, 'Well, unofficially, I can tell you it's normal, but the official result hasn't come through'. (Nurse 15)

If the nurses gave unofficial normal results, the parents would realise something was wrong when the nurses wanted the doctor to talk to them about the results. One nurse stated, '*...if I was a parent and the nurse says, "Oh, you'll just have to wait to see the doctor about it." You'd know there's something wrong*' (Nurse 11). It is possible that parents knew something was wrong because a rapport had been established with the nurses. One nurse emphasised, '*...they know when you're keeping something from them, because they've either known you for six hours or six days, so they can tell*' (Nurse 15). It might possibly be easier for nurses to keep this type of information secret if there had not been rapport. The nurses knew parents could interpret their responses. One nurse said, '*...they can read things off your face or off your demeanour that something is wrong*' (Nurse 15). One nurse described her experience.

We were told no one was to say anything in front of the parents because the neonatologist hadn't had time to talk to the parents...and those parents knew something was wrong. Everybody went really edgy and stilted with conversation. The parents had been here for a long time. Nobody went over and had a chat with them like they normally did. The atmosphere changed, they knew something was wrong and nobody would tell them because we had our hands tied. (Nurse 19)

Parents generally do know when they are not being told the full story. Smith (2000, p. 50) knew the nurses were keeping information from her, because they became very guarded, and stated, "...the doctors would have to compare it with his last one". This mother attempted to find out the head ultrasound result from the nurses, but was told, "I shouldn't worry about it now", (Smith 2000, p. 50). For this mother "this kind of advice from the nurses drove me crazy" (Smith, 2000, p. 51).

The nurses knew that holding on to information made them behave differently with and around the parents. Astrom, Jansson, Norberg and Hallberg (1993, p. 183) describe a “hide and seek” phenomenon that occurred with cancer patients who wanted to know their prognosis. This hide and seek approach was known to the nurses in situations where they feared leaking information to the parents. Being on tenterhooks was difficult and tension-filled and one nurse explained:

You're very guarded and you have to watch everything you say because if they don't know and then it slips out you really feel bad because then they're upset and you create big problems. (Nurse 12)

It was not easy for the nurses to keep secrets mainly because they believed parents had the right to know everything about their baby. They accepted the direction about keeping such information to themselves, but they were caught in a problematic situation. One nurse explained:

You're keeping secrets...and you think 'Oh, I've got to watch exactly what I say'. I think twice about what I'm saying and make sure that it doesn't come out by accident. (Nurse 12)

This issue is related to who is authorised to give information to parents. Traditionally the relationship between parents and physician has been seen as exclusive and nurses have been encouraged to preserve that exclusivity (Quine & Pahl 1986, p. 58). In the current study, the nurses' role in communication was limited to re-explanation of information given by the medical staff. Nurses have always known things about their patients that others did not. This situation clearly caused the nurses much anxiety. One nurse told of a situation in which she accidentally leaked some information and tried to extricate herself.

I think I said something which let the cat out of the bag but then I quickly covered it up. 'Oh, no, I've got you confused with somebody else', but then later it comes out and it's really hard, because they say 'Well you knew, why didn't you tell us?' And you say 'Well I'm not at liberty to tell you.' It's really hard because you know what's going on,

but they don't know, and they've got to wait for the...consultant to actually tell them.
(Nurse 12)

It was not easy for the nurses to hide information from parents. For one nurse it, '*...makes you feel sick to think that you are hiding information ... information that they should have*' (Nurse 19). The length of time it took the neonatologist to speak to parents bearing on how the nurses coped. One nurse told, '*...incident was probably 4 or 5 days down the track before he [the neonatologist] spoke to the parents*' (Nurse 19).

The nurses all found it difficult to maintain a positive demeanour when they knew bad news needed to be imparted, '*...it is difficult if you know that something horrible has happened, and the parents are still coming in and being really optimistic*' (Nurse 16). They felt guilty because they could not inform the parents of the true nature of their baby's condition. Although they accepted it was not their role to impart bad news, they experienced guilt because of their lack of openness in a trusting relationship. One nurse said, '*...you feel a little bit guilty because you're not telling the parents everything. But then it's not my responsibility to tell them this bad news*' (Nurse 16). One nurse was very matter of fact when she stated:

Parents are not told because all the definitive results are not in yet. It is not possible to carry the burden of angst for every parent and survive well and do the job well. (Nurse 6)

Most nurses told of being criticised for giving too much information to parents, placing them in conflict with the medical staff. One nurse spoke of this problem:

Sometimes you just really want to tell them the truth. Depending on who the doctor is, you know that sometimes isn't possible, because they'll end up having a fight with you, because you've told the parents too much. (Nurse 17)

One nurse related a story in this regard. She had stumbled into a situation with parents of an extremely premature baby where she thought, '*Oh I put my foot in it here*' (Nurse 21). This nurse had assumed the parents had been told their baby was likely to have a poor

outcome. The baby's condition was poor because the primitive reflexes of sucking and swallowing were absent, functions vital for survival.

The baby had no gag, suck, swallow, nothing. You could suction as much as you liked and it didn't blink an eyelid. (Nurse 21)

At this time the nurse was speaking to the parents about the statistics related to outcomes of extremely premature babies.

I just happened to say that 'babies less than 26 [weeks], there's an 85% chance of a major disability.' And mum said, 'What do you mean?' And I said, 'Well cerebral palsy, deafness, hearing problems or blindness.' Nobody had even mentioned that to them. And they actually withdrew care after that, after they had spoken to the neonatologist. (Nurse 21)

This nurse perceived the parents had been given false hope about the long-term outcome of their baby. The nurses despaired when parents had been given false hope. For all of them it was crucial that parents be informed of the realistic situation. One nurse explained:

You just say as it is and say, 'We're just going to do what we can do.' It's certainly not a good idea to say, 'Oh he's going to make it.' That would just be totally wrong. You're just giving them false hopes. (Nurse 17)

The tension about who gives information, when and in what context has been previously described. McHaffie and Fowlie (1996, p. 260) noted medical staff can regret nurses' compulsion to give information to parents.

The majority of nurses in the current study found themselves in no-win situations. One nurse stated, '*...we often get in trouble for telling the parents too much*' (Nurse 15). They were however, convinced they were right to give the parents this information at times. The issue of parental trust seemed to surface when parents found out the nurse had not

been completely honest with them. When parents perceived staff were holding back information, they would wonder what else they were not being told. The nurses were all committed to believing trust as a core component in the relationship between the parents and nurses, but they knew trust could be eroded. One nurse explained, *'I think the parents have to trust the nurses, because they're actually looking after the babies, otherwise they wouldn't go home at night'* (Nurse 16). The nurses were required to cope with secret-keeping, but for them it was a professional burden.

You're made to feel guilty that you're not being totally honest and that's a burden...You think that if they find out later that you haven't been honest, then you've lost their trust. (Nurse 20)

Another nurse emphasised:

There is a burden because until they're told, you've got to skirt around it...the parents might wonder why there was some hope in your speech before, suddenly you've gone negative. They must be guessing that we know something that they don't. There is a burden of knowledge. (Nurse 24)

Secret keeping can damage the nurse-parent relationship. McHaffie and Fowlie (1996, p. 26) emphasise that, "...the hurt parents can show when they subsequently learn of the deception is in turn wounding for the nurses". The nurses in this study were committed to the belief that the parent-nurse relationship was essential for the baby's care and did not want anything to jeopardise this relationship.

There were times when the nurses tried to persuade the medical staff to speak to parents. This persuasion was not common but it had been experienced by most. The despair of the nurses was evident as explained by one nurse:

Who's going to talk to these parents? We often know that these babies are definitely going to be that bad. You're banging your head on the wall trying to get the doctor to talk to the people and that seems to be the biggest hassle. (Nurse 9)

Her colleague backed up these comments:

You just have to wonder how honest and upfront they are with some of these parents. A lot of the time they never get time to sit down with them. (Nurse 7)

The nurses were convinced that medical staff should speak with parents. The nurses held themselves to be in a difficult situation, when they knew they could tell the parents what they wanted to know.

7.2.6 Protecting the parents

All the nurses in the study were passionate that parents needed support and guidance from the staff to help them make decisions. They understood some of their colleagues wanted to protect parents from making difficult decisions, yet, protecting the parents was not seen as helpful by the nurses. Sharing the decision making was seen as more important.

We should share the decision making with the families...If they decide to withdraw support then they can walk away and say, '...well we made this decision, but we made it because these people supported us with the decision'. (Nurse 5)

Most nurses understood their colleagues' desire to protect parents and thought they had admirable and well intentioned motives. One nurse explained:

It's nurses wanting to protect, nurture that person and stop them from having to experience something that's ugly, disappointing or distressing, and to have to make that decision is extremely distressing and ugly and grim. (Nurse 6)

One focus group emphasised;

I can see some people thinking that as a medical person you feel useless because you can't help...their baby to survive...Try and protect them by trying to make that decision for them. (Nurse 3)

Or cushioning the blow? (Nurse 1)

Perhaps both. It's your way of trying to feel better in yourself by trying to take that hurt away from them. (Nurse 3)

We're all rescuers. (Nurse 2)

Several nurses told of how they had tried to protect parents early in their careers, but realised parents could not be protected from reality. It was the understanding of all the nurses that decision making was difficult for parents, yet they were passionate that parents needed to be involved. Parents would like the opportunity to be involved in the decision making and the dying process (McHaffie 2001a, p.19). Studies have consistently failed to confirm the harmful effects of participation by parents in life and death decisions. In a study by Walwork and Ellison (1985, p. 14), parents involved in treatment withdrawal showed no evidence of prolonged or pathological grief response. The parents accepted responsibility for their decision and believed they had made the right decision to withdraw life support. McHaffie (2001, p. 19) found no evidence of residual guilt among parents who took responsibility for their decisions to withdraw life support. One nurse reflected:

I don't see what you're protecting them [parents] from. Taking the decision away from them and not letting them decide, all that's going to do is compound guilt, compound the negative feelings. We can't protect them, we can't. They may not understand and in all the fugue [grief] they live in...they may not fully comprehend, and they certainly won't for a long time. But you can't protect them. If they feel that they were given no part in the decision, they'll be stuck in anger mode. They won't be able to grieve, they won't be able to resolve, because they'll be stuck in this mode of 'It was my child and I had no choice'. (Nurse 1)

The nurses all emphasised their concern that if parents were not involved in decision making they might not come to an adequate resolution of their grief, which could be

detrimental. They did not want to protect the parents, because, for one, they believed that if they were in the parent's position they would not want to be protected. They all understood that making decisions would be hard for the parents, however, they emphasised that involvement was associated with more positives than negatives for the parents.

7.2.7 Different capabilities

The nurses all proposed that parents differed in their ability to make decisions about their extremely premature babies. They understood that decision making could be affected by emotions or intellectual capabilities, and that no two sets of parents approached decision making in the same manner. Difficulties were experienced by several nurses when they believed parents were unable to make difficult decisions, and one nurse stated, '*...they really need to be assessed as to whether they can make those decisions*' (Nurse 12). They had experiences in which some parents allowed others to make the decisions. Several nurses spoke of situations where the mother had a severe developmental disability that precluded her from decision making. One nurse told a story of a mother who sat by the bed of her 23 week gestation baby and played with dolls, while another nurse told a similar story about a developmentally delayed mother of a 23 week gestation baby, '*...so long as she had her chips and her cake. She walked in the nursery with her crisps and a drink and every time that ran out, she'd been at the machine to get some more*' (Nurse 22). The mother, '*...had no idea about the baby. She told the ward [staff] she was bottle feeding it*' (Nurse 22). Independent, informed decision making was not evident in these situations.

Even so, there was never a suggestion from any of the nurses that parents with a developmental disability should automatically be precluded from decision making. Nevertheless, some difficult situations arose for four nurses. Four nurses in one focus group related a story about an extremely premature baby whose mother was fourteen and had a developmental disability. The baby had been given a poor neurological prognosis. The neonatologist suggested the baby would have a poor quality of life and offered treatment withdrawal. The father wanted the baby to live. This situation caused the nurses

in the focus group to experience severe anxiety and anger, because although the parents had rights, the mother was underage and developmentally delayed. These nurses believed the best interest of the baby was not being served. These nurses showed extreme concern for the future of the babies, ‘...*I just hoped the child wouldn’t survive so we wouldn’t have to make a decision about where it was going to go when she left here*’ (Nurse 23). For this nurse the idea of death of the baby came as part of her ethical reasoning, because death of the baby would have removed the ethical dilemma.

7.2.8 Differing voices

Most nurses found it difficult when parents could not agree about treatment, as stated by one nurse, ‘...*so what do you do when one parent says, ‘This is what should be done’ and the other parent says, ‘No!’*’ (Nurse 2). It was the belief of several nurses that parents would eventually have to come to a consensus. One nurse stated:

In the end they are going to go home as a couple. They are going to have to face life’s consequences and we’re not going to be there as a sounding board. The doctors are not going to be there supporting one, discussing with the other. They have to in the end go home and live the rest of their lives, hopefully together. (Nurse 1)

Several issues emerged in relation to the fathers of extremely premature babies and decision making. The nurses all noticed that fathers were generally guided by the mothers. One nurse stated. ‘*I think guys tend to take the backseat and get guided by what the mother wants to do*’ (Nurse 15). They also noticed that, ‘...*fathers give up before the mothers*’ (Nurse 15). “Giving up” meant fathers came to accept that treatment should be withdrawn sooner than mothers. Several nurses thought this might be due to the bond developed during uterine life between the mother and her unborn baby and also to the postnatal bond developed between them. The nurses all observed that maternal visits were usually more frequent than paternal visits. Paternal feelings of attachment for the baby have been found to develop when the father knew the baby would survive (Sullivan 1999, p. 38).

The nurses were convinced that parents experienced grief when they delivered an extremely premature baby. Mothers grieve the loss of a normal full term pregnancy, and ‘...*the loss of a normal term infant*’ (Nurse 10). It has been suggested that grief can block effective participation in ethical decision making (Arthur Burton & Tarlos-Benka 1997, p. 333). The NICU, as well, thrusts new parents into situations where they feel powerless. Parents in feeling helpless and unable to cope are likely to find hard decisions difficult to make.

One situation several nurses found troubling occurred when the father was protective and did not want the mother to be told bad news. This was often a cultural issue, yet these nurses felt uncomfortable. They feared they would accidentally leak information and strongly believed that neonatologists and neonatal nurses should not be placed in this difficult position. One nurse told a story where a neonatologist refused to accede to a father’s request.

We have a very multicultural clientele and there’s a lot of times where the fathers don’t want you to tell the mothers any bad news. We had this case...the neonatologist said ‘Look I can’t do that, we have to let her know what’s going on with this baby.’ (Nurse 16)

Australian guidelines states that doctors should strive to ensure good communication regardless of the cultural background (NH&MRC 2004b, p. 4). Information should not be withheld from patients except in cases where the patient expressly directs the doctor or another person to make the decisions (NH&MRC 2004b, p. 11).

It was not surprising the nurses experienced ethical conflicts when caring for babies and their parents. Redman and Fry (2000, p. 36) believe that nurses are individuals with personal and professional values who work with patients who will have different religious and moral values. To be asked to lie, or not tell the truth by omission was particularly difficult for some nurses. They understood that sometimes there were cultural factors associated with decision making, yet they experienced ethical distress when

mothers were not informed about the ramifications of treatment. The nurses could accept situations in which the mother told them she did not want to know what was happening and that she preferred others to make decisions. They found it difficult to comprehend others making decisions on her behalf without consultation.

7.2.9 Bewildering the parents with statistics

All the nurses were committed to the belief that effective communication between the staff and parents was essential, and that communication involved a realistic appraisal of the possible outcomes. It was their understanding that medical staff often used statistics to convey potential outcomes. Parents needed to be given information prenatally and postnatal about survival and outcome, and what this might mean for them as parents. They understood that there were problems with outcome statistics related to extreme prematurity and worried about how they were portrayed to parents. One nurse commented:

Outcome studies are very subjective. They don't really tell you the full picture with these tiny ones. They haven't really been saving that long to get some long-term outcomes...a lot of it is just guesswork. There's an uncertainty about it. (Nurse 16)

The nurses all believed that parents did not always understand outcome statistics. Shaw and Dear (1990, p. 520) found parents, particularly mothers, had difficulty interpreting expressions of probability. The statistics related to extremely premature babies are presented in cohort groups. To extrapolate cohort statistics to the outcomes for individual babies is problematic (Simeoni, Vendemmia, Rizzotti & Gamberre 2004, p. S34). Although all the nurses believed parents should be offered statistics, they knew problems could be encountered. One nurse explained:

If I didn't have any medical knowledge, that [statistics] would mean absolutely nothing to me. Someone coming along to me and saying 'Well this is all the statistics, you know these kids are going to have this, that and the other.' And it wouldn't mean a thing unless I actually saw it. (Nurse 13)

Several nurses had a view that pregnant women and new mothers would try and protect themselves from things that were potentially problematic. Mothers could deny the risks of premature labour and delivery or the ongoing problems of prematurity by believing these things could not happen to them. Pregnant women, especially those who have had a perinatal loss, fear bad news and will try and protect themselves (Cote-Arsenault 2001, p. 132). Pregnant women have used avoidance to cope with the uncertainty of being high risk for poor pregnancy outcomes (Giurgescu, Penckofer, Maurer & Bryant 2006, p. 363). These women are hoping they will beat the odds and “maintaining hope amid fears” (Cote-Arsenault, Donato & Earl 2006, p. 356). One nurse stated:

Even though you might tell them, they're going to say, 'Well, that's not going to happen to me.' Because that's what you do, isn't it? When you're pregnant and you're having a baby, you think it's not going to happen to me. (Nurse 13)

Although all the nurses knew about babies of smaller gestations who had survived, they had not seen an appreciable decrease in morbidity particularly as it related to neurological deficits. One nurse explained:

The morbidity hasn't changed a lot with these babies, the tinier ones. The older babies...28 weeks and above, they've changed dramatically. You can say to the parents usually with a lot of confidence, 'Your baby will probably do well'. With these ones [less than 24 weeks], you really can't say that. (Nurse 16)

Several nurses were troubled when they read medical journal articles reporting success with extremely premature babies. These nurses believed that these so called, '*one offs*' (Nurse 17) contributed to the unrealistic expectations of the NICU. One nurse explained:

I've never seen any babies less than 23 weeks who've ever survived. You read all these things in some journals...about 280 gram babies. I really have to wonder whether that's true, because I just can't see them surviving that way. (Nurse 16)

The publication of outcome studies troubled several nurses. One stated, '*...the literature it's still a bit weighted to make things look really good*' and, '*...there would probably be hardly any babies on the end of any study that came out unscathed*' (Nurse 19). These nurses struggled with literature findings as they did not match their experience. They, therefore did not always trust the literature. One nurse explained:

With research...you would have nurses working in the units. They have all been looking after these 23 weekers and they see them going home deaf, can't see, bad cerebral palsy. I don't know whether we've actually had anyone come through that's completely normal. (Nurse 19)

Three nurses were confused by the statistics in research articles on outcomes of tiny babies when compared with what parents told them about their individual children. One nurse explained:

They're a bit unbelievable. They [statistics] say 60% of them only have none or mild [disability] and what you're hearing from the parents is that they've had their lives destroyed. (Nurse 14)

The nurses could not reconcile these differences. They understood the importance of outcome statistics in determining the effectiveness of a given treatment. When they encountered parents who told them they, '*...had their lives destroyed*' (Nurse 14), they could not marry the two concepts. They seemed to believe they were being manipulated by statistics and were reluctant to accept such statistics at face value. The nurses all emphasised the need for parents to have an accurate understanding of the ramifications of their decisions. Several nurses told of not wanting to be seen as practising subterfuge, however, they took advantage of available technological age and referred parents to reputable internet sites. It was their belief that this information was in the public domain and as advocates they considered it their responsibility to the direct parents to accurate information.

The nurses all believed survival and outcome statistics should be presented in a meaningful way to parents. Parents needed to know in everyday terms the ramifications of their decisions on them as a family. One nurse stated:

I don't think the statistics are very meaningful, unless someone says, 'This means you will not be able to have a job. You will not be able to go out to dinner without major eruptions, trying to find someone who will look after a disabled child.' If you look at the effect it's going to have on your life, it means you'll have no money for holidays, it means your other child won't be able to go to the school you thought they'd go. If you point out the real realities of changing your life, as well as the statistics and you emphasise that once they make a decision, they've got to go with it and stick with it. (Nurse 14)

The use of language to explain statistics could be problematic for the nurses. The use of nice words to describe conditions such as cerebral palsy could be the equivalent of using euphemisms to describe death. Euphemisms are used when there is an attempt to soften starkness (Wood 1986, p.727). This softening was a cause of concern for most nurses:

At the end of the day, they [parents] don't really see that picture, because I don't think it's ever fully spelt out to them. They use nice words to make it sound nice. (Nurse 9)

The nurses would prefer the medical staff to use words such as brain damage instead of technical terms such as cognitive impairment. The use of terms such as brain damage might be more likely to give the parents a more realistic view, as most parents understood this concept.

7.2.10 Being affected as a family

The nurses were all committed to wanting parents to understand how their lives could change when they took their baby home. One nurse spoke of how she asked the parents whether they understood their baby's condition.

‘Do you really understand cerebral palsy and what these difficulties are going to be?’
They just think, ‘Oh, you know we can cope, the baby won’t walk very well, but I’ll still have a nice baby.’ (Nurse 9)

Several nurses wondered if parents were able to be realistic about how their lives and the lives of siblings could be affected. One commented:

I feel for the parents because they desperately want this child to survive. They have no idea what’s ahead of them and how it’s going to disrupt not just their lives, but their family’s lives and everybody around them. It’s like a whirlpool, and it just keeps going out and drawing in concentric circles, affecting everybody around them. They have no idea...They just see this baby and it looks perfect and they want everything done. (Nurse 21)

The nurses all emphasised this was not an issue about saving, or not saving disabled babies. For them it was an issue of choice and that parents should know how their decisions could affect their future lives. The nurses were troubled because they believed parents were abandoned as they left through the door of the NICU. They all maintained there were not enough services in the community and their experience led them to believe parents with disabled children had to fight to get much needed services.

7.2.11 Summary

The birth of an extremely premature baby is an emotional event for the parents and family. Decisions to resuscitate, maintain or withdraw treatment often have to be made at a time when the parents are not emotionally prepared to make these decisions. Being emotionally unprepared does not in itself disqualify the parents as decision makers. Parents need, however, sufficient information and support to make difficult decisions. This would mean medical staff would facilitate rather than direct parental decision making (Kon 2006a, p. 396).

7.3 A legal and ethical voice

There was confusion and uncertainty for all the nurses about legal and ethical issues and the role of ethics committees. They were all convinced the law should not direct decisions to resuscitate extremely premature babies. For example, they had a concern that the law might influence neonatologists to treat 20-week babies, because viability is legally defined as 20 weeks gestation. None of the nurses understood why viability would be set at this level. They believed that 25 weeks would be more accurate level because the outcomes had improved for babies of this gestation.

7.3.1 A legal voice

The nurses all held that obstetricians and neonatologists were given much scope in the resuscitation and treatment of extremely premature infants. They emphasised that babies should be treated individually, one nurse stating, *'I don't think the law should make a blanket statement. Every case is different'* (Nurse 11). An extremely premature baby who breathed at birth might not be able to sustain this breathing effort. One nurse said about the involvement of the law in such an issue:

What would they [law] say? 'Oh, if they're breathing below 24 weeks, you've got to do something.' I mean lots of babies [24 weeks and less] breathe, but they're rarely functional. (Nurse 18)

This nurse was concerned that if a law was applied, immature babies could be treated from 20 weeks gestation and doctors and parents would not have a voice. Most nurses spoke of neonatal staff arriving at a delivery to resuscitate an extremely premature baby. Their knowledge and extensive clinical experience enabled them to differentiate between terminal gasps and the breaths that indicated the baby might live. Parents did not have this knowledge and clinical judgement and were unable to recognise the difference. It was the understanding of most nurses that parents might be under the misapprehension that because their baby was born alive, it could survive. The public have become used to

seeing medical triumphs. One nurse stated, '*...people come to expect it and I think that's what worries them [neonatologists], to some degree*' (Nurse 17).

One nurse opened up the discussion in relation to a definitive criteria that was more in keeping with what was known about the outcome for extremely premature infants.

Perhaps the phrasing should be that those fetuses born displaying the gestational characteristics of a 24 or less weeker, combined with a five minute Apgar score of less than 5 at one minute, unassisted by other than suction and blow over oxygen, should be allowed to expire... Why can we not have a set of agreed conditions for infants that are offered life support? (Nurse 6)

This nurse proposed that the law should protect decisions not to treat if a baby did not meet the criteria for intervention. This position would mean health professionals and parents would not be at risk for prosecution.

It is difficult to know if the law should have a voice in deciding which babies should be resuscitated. The nurses were all convinced the legal system should not be involved in situations involving babies less than 24 weeks gestation. Several nurses made it clear that the law in Australia defines viability at 20 weeks and 400grams, however this does not mean babies at 20 weeks should be resuscitated. These arbitrary figures should not be applied when it comes to decision making. There is no provision in Australian law stating that treatment where the benefits are uncertain must be provided. Clearly, the nurses all agreed that providing intensive care to 20-week babies was futile in the extreme. They expressed concern that the involvement of the law could lead to all babies of a certain gestation to be resuscitated, therefore parents could and would demand resuscitation. They were all worried they would be expected to be involved in the resuscitation of babies who were clearly not viable. One nurse explained:

And 400 [grams], no we don't try. If they really insisted that we would have to go along to a delivery and do everything that's a bit of a worry. Very few babies would be capable of survival. It would be heroic measures. I think you're taking the decision away from the

doctors totally, aren't you? Parents will expect that if they're saying that you legally have to and they see that it's the law, then it's their right that you do that. That's a bit of a quandary. I would be horrified to go down to Labour Ward and be expected to help with the intubation of a 20-week baby. (Nurse 17)

The nurses were all troubled if they thought Australian laws related to viability would be applied. Parents might threaten litigation when medical staff refused to resuscitate their baby. One nurse talked about parents who were determined to have their 23 week gestation baby resuscitated. It was the belief of this nurse that if the neonatologist refused, the parents would have pursued legal action. Waltman and Schenk (1999, p. 27) believe the fear of litigation has prompted some medical staff to change their practice. The nurses worried that litigation fear would lead to over-treatment. Many nurses thought neonatologists were afraid of being sued by parents. One nurse recalled:

The problem was the parents. While they didn't actually mention the word 'sue', but the litigious kind of inference was there. If we did anything to stop them having this time with their child...they may in fact get very angry with that and pursue the matter further. And so when that's actually placed in front of you as a bit of a barrier, you naturally all get a bit scared. (Nurse 10)

There was anxiety for several nurses as they questioned parental motives for keeping their baby alive. They further believed the law would not authorise the termination of treatment even if the motivation was to prevent pain and suffering (Peterson 1994, p. 378). It is understandable that neonatologists in Australia might be afraid of litigation given the cases in the USA (Lantos, 2001; Paris et al 1998). When parents have threatened to sue the staff the nurses found themselves in a quandary. They knew a 20-week baby deemed legally viable could not be saved with current technology and found it difficult to understand why parents would sue them, when they believed they had the baby's best interest at heart. Rightly or wrongly, parents also believe they have their child's best interest at heart.

7.3.2 An ethical voice

The nurses were all convinced that ethical guidelines, not policies, were essential when confronted with the birth of a baby at the edge of viability. To the nurses, policies were not considered in keeping with treating babies as individuals. One nurse explained:

Some places have tried to make policies available on how you should treat a 24 weeker or less. I don't think you can actually do a policy. Every baby is an individual. Every baby has different needs and every baby is treated upon their results [diagnostic tests and how they cope with treatment]. I don't think a policy can determine whether or not you treat and how you treat a baby, 24 weeks or less. (Nurse 2)

The majority of nurses who answered the questionnaire believed ethics committees might be useful when confronted with an ethical dilemma. It seems however, that these nurses were not aware that in Australia, ethics committees were mainly concerned with research ethics and whether or not a specific research proposal should be given clearance. The Australian Health Ethics Committee as part of the National Health and Medical Research Council (NH&MRC) has the brief to advise the council on ethical issues relating to health, and to develop the NH&MRC (2004a) guidelines for the conduct of medical research involving humans. Their website <http://www.nhmrc.gov.au/ethics/ahec.htm>, lists numerous publications about the conduct and functioning of research ethic committees, but nothing specifically related to ethical dilemmas. In practice, the primary function of an ethics committee is to protect researchers, their institution and human participants (Annas 1991, p. 36).

There are very few ethics committees in Australia who deal with ethical dilemmas. When neonatal nurses were experiencing ethical dilemmas about the babies in their care it seemed there was no forum for them to discuss these dilemmas. Most nurses considered an ethics consultation could be useful, however they did not believe an ethics committee should make treatment decisions. One nurse explained:

I don't think an Ethics Committee can say that it is right or wrong that you treat this child. They don't understand. (Nurse 2)

Patient care committees in the USA are utilised as ethics committees, however their medico-legal constraints differ from those in Australia. Ethics committees in the USA provide forums where conflicts in personal and professional values can be raised, issues debated and professionals discuss the ethical issues they face (Levine-Aruff 1989, p. 447).

The nurses could not imagine that ethics committees would be helpful for the resolution of ethical dilemmas. They noted that ethics committees could not convene at a moment's notice. It was usually after hours that clinicians faced their ethical dilemmas regarding treatment issues. As summed up by one nurse:

My problem with Ethics Committees is they function 9 to 5 Monday to Friday and that's not life. They cannot convene in an hour's notice. They cannot have all the case reduced in an hour's notice. They cannot make decisions in an hour's notice. Sometimes you may only have an hour to make that decision...They may be knowledgeable, they may have all the evidence, they may have all the background, but when the crisis comes, the five or six members of an Ethics Committee that can make a quorum are scattered across the city's residential areas, and just can't be there when you need them. (Nurse 1)

The nurses were all convinced there were more negatives than positives associated with ethics consultations. One nurse described a situation where two different issues were referred to an ethics committee. It was her belief that all that occurred was that there were '*...just more fingers in the pie. It's taken far longer for things to resolve and it's definitely muddied the waters, rather than clearing anything*' (Nurse 6). This nurse believed a baby suffered because the ethics committee could not reach consensus. Some have thought that the detached position of ethics committees might make them ponderous, insensitive, erring on the side of caution and continuing life support (Dunn 1993, p. 82). There was a suggestion by three nurses in a focus group that an ethics committee might arrive with its own agenda precluding objective decision making.

7.3.3 Summary

The law presented yet more confusion in an area that was for the nurses already fraught with confusion. The nurses all held firm to their conviction that the law should not have a place in determinations of whether an extremely premature baby should be treated. The law was seen as inflexible, and it was this inflexibility, which may have prompted neonatologists to fear litigation. The nurses all emphasised that decisions to treat or not treat should be based on clinical evidence and the baby's response to treatment. The law and ethics committees represented a '*Big Brother*' (Orwell 1949) mentality (Nurse 10) where decisions were scrutinised by an external body that did not appreciate the intricacies involved.

7.4 A medical voice

Neonatologists are responsible for treatment decisions. Decisions about treatment were known by the nurses to be fraught with difficulty and they did not understand how such decisions were made. Rhoden (1986, p. 34) described three different types of decision making practised by neonatologists in neonatal units. In the 'statistical prognostic strategy', intensive care would be provided only for babies who have acceptable survival statistics. A trial of intensive care is given in the 'individualised prognostic strategy', giving all infants a trial of intensive care, with care withdrawn when the infant's prognosis was poor. The 'wait until certain' strategy is where all infants receive intensive care until death becomes apparent. The nurses in the study had seen and discussed these decision making strategies, although in keeping with Rhoden (1986) it was the 'wait until certain strategy' that was likely to carry the greatest risk for futile treatment.

It was the understanding of all the nurses that neonatologists with many years of experience were comfortable making treatment decisions. It was the experience of these nurses that neonatologists and families can work together to make timely compassionate decisions about treatment (Pearson et al. 1995, p. 462).

7.4.1 Life and death decisions

It was the understanding of all the nurses that neonatologists had the extensive knowledge about outcomes of extremely premature infants the parents needed to help them make decisions. Such decisions, should be made using scientific evidence and clinical experience. The nurses were all convinced that information provided by the neonatologist was extremely valuable to parents. One nurse explained:

It's like any other decision you make in life. You ask the most experienced, knowledgeable person. If that's the expert who looks after those babies, the neonatologist,... that's his area of expertise. He will be able to tell you what the outcomes are and what the costs are to the baby and to you are; not just financial but emotional in terms of suffering, so you need that kind of input to make that decision. (Nurse 6)

Several nurses explained that neonatologists presented the facts about the baby to the parents, allowing them to make the decision about withdrawing treatment. One nurse explained how the consultants in the NICU where she worked approached the situation:

They [neonatologists] don't necessarily say 'We would advise you to do this or we would advise you to withdraw treatment.' What they actually say to the parents is, 'This is what is happening with your infant. It has a Grade 4 IVH. We are not able to maintain its blood pressure properly. Your baby hasn't passed any urine and you know how important that is.' Then they often say to the parents 'And we believe, based on all of this, that this cannot be reversed and that what we are doing here is putting your infant through an enormous amount of pain and suffering'. (Nurse 10)

It was the understanding of the majority of nurses that some neonatologists experienced difficulty with decisions not to resuscitate a baby at birth, because of their presumption in favour of life. The nurses all accepted that the aims of medicine were to treat and cure disease, preserve life, causing the least amount of harm to the patient. One nurse summed up, '*I think they [doctors] would probably be itching to try [to save the baby]. They probably have a very difficult time*' (Nurse 24). The nurses were all aware that

experienced neonatologists were less inclined to use extreme measures with extremely premature babies. Candee, Sheehan, Cook, Husted and Bargen (1982, p. 846) proposed that experience generally implies higher reasoning ability, with an emphasis on personal dignity and individual or parental rights. The nurses all acknowledged that medical staff could be affected by decision making. Neonatologists in a study by Catlin (1999, p. 9) believed themselves to be burdened by resuscitating extremely premature babies whose outcome was uncertain. One doctor stated, “I just agonise over some of them all the time. You are sorry for what you did. But you don’t know what you would have changed or how you would have decided differently....” (p.9). Another doctor who looked at the ramifications of treatment stated, “I rarely feel like a hero now” (Catlin 1999, p.9).

Parents of extremely premature babies rely on the medical staff to help them make decisions. The nurses all held that most parents did not want to make these difficult decisions.

Very few parents that I’ve seen have been I think brave enough to say ‘We want you to stop.’ I think the majority of parents rely on what’s said to them by the doctor to make that decision, and leave it at that. (Nurse 17)

Contextual influences have been identified in decision making. Pearson, Bose and Kraybill (1995, p. 462) suggest guided decision making has the potential to impose the values of the neonatologists on the family. Skene (1993, p. 299) too, suggested that parents might be unduly influenced by the medical staff’s advice.

7.4.2 A team voice

The nurses wished that decisions to withdraw treatment could be, ‘...*a team approach*’ (Nurse 10) involving doctors, neonatal nurses and parents.

Collaborative decision making is important. Doctors have medical knowledge and experience. Nurses certainly can be asked to contribute to this knowledge and experience.

Ultimately, the family's decision needs to be respected. It is their child after all. (Nurse 5).

Team involvement was highly valued with an emphasis on parental decision making with input from professionals. Most nurses were convinced that social workers should not be included in decisions to withdraw treatment as they might not be able to offer anything to the discussions. One nurse explained, *'I don't think we've ever had a case where we're withdrawing a baby that we think this is not the right thing to do'* (Nurse 15). The nurses who considered social workers to be helpful held that, *'...social workers can tend to know more about the parents'* (Nurse 8). Neonatal nurses in a study by McHaffie and Fowlie (1996, p. 144) did not consider social workers had a role in life support discussions and decisions. A nurse in the current study thought that social workers were:

Probably good for trying to hold their hand. I don't think they can talk about the outcomes and the treatments that a baby will go through. I don't see them... contributing to that decision of withdrawing and holding treatment. I see them... supports for parents, but not part of the decision making team. (Nurse 17)

The nurses placed importance on case conferences. Case conferences could address treatment issues where all team members voice their concerns. One nurse summed it up:

I think talking is a process where we don't do very well. We can't seem to manage to get people together. If you get a really small baby...you should be having case meetings involving all the relevant parties, and should be involved right from the start with the parents. (Nurse 7)

Most nurses spoke of neonatologists who were content to make decisions without input from others. McNeill, Walters and Webster (1994, p. 487) found that 44% of medical staff resolved ethical issues without consulting others. Pearson et al (1995, p. 462) found the neonatologists' perception of viability was the basis of providing intensive care, and those decisions were often made solely by doctors. A nurse in the current study spoke

about working with a neonatologist who excluded parents and nurses from decision making,

The babies that were part of her unit would then be part of that treatment, and once they were under her roof and having her treatment then outcome was her responsibility.
(Nurse 6)

Although all the nurses were committed to their belief that they should be part of the team there were times when they were reminded of their place within the hierarchy. One nurse recalled having been told, '*...that they are the neonatologists and we are the nurses*' (Nurse 18). The nurses all wanted to understand the decisions made by the medical staff but believed themselves to be in a bind because, '*...the doctors you can't challenge and say 'Why?', otherwise you're picking on them*' (Nurse 18). There were medical staff who responded well to questions but, '*...others they think we're challenging them. And it's not a challenge, we're just trying to work out why*' (Nurse 18).

When the nurses worked with neonatologists who excluded all others from decision making they were influenced in the way they perceived themselves as professionals. In these situations they could either continue to work in an oppressive environment, or they could leave and find a neonatal unit more keeping with their own philosophy. One nurse spoke of such an experience.

They [parents] had talked amongst themselves and they had said, 'if there is a chance that we have a severely handicapped child, and there is the chance to withdraw treatment we are adamant that we will withdraw treatment'. When they discussed this with the neonatologist...the child had a grade 4 IVH. The neonatologist said they had no right to withdraw treatment. I felt that I could not work in that unit. (Nurse 6)

7.4.3 Stuck in the middle

The nurses were all concerned when they believed necessary decisions were not made. They spoke of the difficulty when medical staff would not approach withdrawal of

treatment with parents, or the parents would not allow withdrawal of treatment. They thought some medical staff were unable to deal with crises. This was a dilemma for the nursing staff:

Whether it's because individual consultants either can't deal with what's happening or don't want to. It could be for a variety of reasons. You can't really ask them what their reasons were, or whether they just want to leave it for the next person to handle. (Nurse 15)

One nurse spoke of an experience with an extremely premature baby.

I rang the consultant at home at 3am and said 'Something is going wrong. What's this baby doing?' I said, 'Do you think she's had a bleed in the head. I know they can have it from hypertensive episodes. He said, 'Oh we won't talk about that now.' We just discussed ventilation. I thought 'well something has gone on'. (Nurse 15)

The baby improved, but developed symptoms of a grade IV IVH. The nurse stated withdrawal of treatment was not discussed following the diagnosis of the intraventricular bleed. The nurse explained:

The first consultant had gone off duty, the second one come on and discussed it with a third one... The baby was sent elsewhere [surgical centre] for a shunt [ventriculoperitoneal shunt] to be put in. (Nurse 15)

At no stage was withdrawal of treatment offered to the parents. This nurse became frustrated when medical staff did not respond to a crisis, but she could only do so much. She could not force a consultant to take action, she could only give him information. Nurse 15 felt a sense of responsibility, and questioned whether she could have managed the situation differently. The baby was transferred to the nearby surgical centre for management. The nurse stated it was embarrassing and yet a relief, for her and her colleagues when withdrawal of treatment was offered at the surgical centre.

The nurses all believed themselves to often be stuck between the parents and neonatologists. One nurse referred to herself as, ‘...*being the meat in the sandwich*’ (Nurse 18), and another nurse stated, ‘*It’s really hard for us because we’re always left in the middle*’ (Nurse 12). It was as if the nurses were caught with nowhere to move. McHaffie and Fowlie (1996, p. 9) too describe, “...the nurse in the middle”, as nurses having few decision making powers.

Several nurses reflected on the difficult situation when consultants changed rotations, resulting in a new barrage of tests to ensure the oncoming neonatologist was satisfied with the decision to withdraw treatment. The nurses’ experience led them all to believe there were neonatologists who were unable to make difficult decisions. One nurse explained:

That really puts you in a bad situation because you know that baby really does need to just die, and no one will make a decision. You’ll find that when the neonatologist changes their week’s term that something may well be fixed at that time, but you have to hang on till then. (Nurse 11)

When a new neonatologist arrived on service and was able to make difficult decisions, they were almost welcomed with open arms by the nurses. Living with the indecision of some was frustrating and demoralising. One nurse explained:

I think parents need all the guidance they get and sometimes they’re just saying... ‘Look we need to stop’ and they will be happy if the doctor said that. They would say, ‘Yes we’ll stop.’ If the doctor...beats around the bush and doesn’t come straight out and say it, like, ‘Well he’s definitely going to die anyway’ Sometimes they [parents] just need the doctor to say, ‘We can’t go on’ and just leave it at that. (Nurse 17)

It was the understanding of the nurses that the medical staff’s, ‘...*beating around the bush*’ (Nurse 7) was confusing for the parents, leaving them not knowing in which direction to proceed. One nurse stated, ‘...*you’re dragging out the inevitable and I find that frustrating. It’s going to be dreadful, so let’s get it over and done with*’ (Nurse 23).

The nurses wanted the inevitable to be over for a baby, finding it intolerable when a baby was not allowed to die.

7.4.4 Summary

The decision to resuscitate and treat extremely premature babies is not easy, and decisions are made more difficult when the stakeholders cannot agree about the baby's future. At times the nurses seemed caught between the parents and the medical staff, trying to be supportive yet trying to understand how decisions were made. The nurses all appreciated working with consultants who were able to make hard and difficult decisions about withdrawal of treatment. The nurses were all convinced a collaborative approach to decision making was essential to ensure all voices were heard.

7.5 A nursing voice

Neonatal nurses provide around the clock care to the extremely premature baby and its family. Providing care sometimes contained ethical challenges for the nurses and at times they seemed consumed with concern about the outcome. When the nurses wrestled with ethical questions they attempted to determine what was good and do no harm.

Most nurses sought involvement in decision making about extremely premature babies. They acknowledged it was traumatic for parents to make decisions, however, in the words of one nurse, '*...it's traumatic for everybody, us included*' (Nurse 21). The death of a baby elicits emotions in the nurse, mostly sadness, but just as often there was a sense of relief. The emotions of the nurse might disrupt the process of ethical decision making, however emotions could also energise the ethical quest. Involvement means the nurse must be emotionally interested and care enough to persevere with his/her quest (Callahan 1988, p. 10).

7.5.1 Seeking a voice

There was overwhelming support, in the initial questionnaire, for neonatal nurses to be involved in decisions about the life support for babies of 24 weeks gestation and less. The nurses interviewed were all aware they did not carry the responsibility for treatment decisions, however, they fervently believed they could contribute to the discussions. Involvement was important for the nurses even though they were aware the neonatologists bore ultimate responsibility. One nurse suggested:

I don't go into resuscitation and say, 'Yes, we've got to resuscitate this baby, or we should keep on going', despite resuscitating the baby for 10 minutes. I think that they [neonatologist] think it's just ultimately their decision and their decision alone. (Nurse 17)

The nurses understood the difficulty associated with decisions, and one nurse stated, *'I'm glad I don't have to do it'* (Nurse 23).

The nurses considered what it was that they could bring to the discussions about treatment withdrawal? It was suggested that they bring, *'...a human side to the decision'* (Nurse 5). They knew that parents often discussed their apprehensions with the nurse but were reluctant to voice concerns with medical staff. They believed nurses could act as go-betweens to help parents voice their concerns. During meetings, parents often talked about their wishes for the future. If a nurse was present during these discussions, he/she assisted the family in achieving their wishes. The word, *'facilitate'* (Nurse 6) was offered as a description of what the nurses do best. The nurses all perceived their role as allowing the parents greater understanding of their baby's condition and assisting medical staff to understand the parents' concerns.

The nurses all held they brought their intimate knowledge of the baby and family to discussions. It was their understanding that they spent more time with the baby and family than other health professionals. Interestingly, several nurses believed the type of

qualitative information they possessed was generally not considered important because it was based on observation, not quantitative or hard data. One nurse thought medical staff might not include nurses in decision making team because, '*...they think they can't be objective*' (Nurse 16). In order to be part of the discussions, nurses needed to be articulate, and base their information on objectivity rather than subjectivity and '*gut feelings*' (Nurse 10). This is not to belittle such feelings or intuition, however, when discussing issues related to treatment withdrawal the value of subjective opinion is limited. There is a case for nurses becoming familiar with the language of ethics, so they can participate in discussions. The language of ethics is both inclusive and exclusive. If nurses are to participate fully in discussions a knowledge of ethical language is essential. The nurses all considered themselves able to be objective.

I'd like to think...I do take stock and look at both sides of the fence. I think that probably still it's weighted towards we need to be very careful with these babies in what we do with them, but I'm prepared to listen to all sides. (Nurse 10)

The nurses might have believed themselves able to be objective, however, historically nurses have neither been involved in ethical decision making, nor received ethics education (Johnstone 1999, p. 11). The questionnaire results showed over 85% of nurses had not received ethics education. This finding is somewhat disturbing, as the NIC is one of the most ethically charged areas in health care, yet the majority of nurses had not been offered the opportunity to gain the formal skills to help them deal with the ethically difficult situations they encountered.

The nurses all recognised the problems involved in decision making. One nurse believed that:

I think it doesn't matter how long you've been working with them [sick babies] and your experience working with them. I think every single one is as hard as the first one, the first involvement. You get more involved as your experience increases, but my experience is that every decision like this is as hard as the first one, because every parent is totally different. And their reactions are totally different. (Nurse 2)

Perhaps a good way of utilising the skills of neonatal nurses was helping parents understand the reality of extreme prematurity. One nurse stated '*we see what happens when they [babies] don't do well and they go home and they have all the problems, so we can actually tell them about that. We can actually give them reality*' (Nurse 13). The nurses were convinced they possessed a realistic understanding of the possible short and long term outcome. The realism nurses could bring might, according to one nurse, '*...help the parents to see the way things are going in the early days*' (Nurse 14). Experienced nurses could also convey what might lie ahead for the family. Neonatal nurses:

Could probably tell them [parents] straight out what a long haul it's going to be....some of the specific problems they're going to face along the way, and how hard it will be and how this will be one crisis, but there will be so many along the way. (Nurse 17)

The nurses all considered their involvement essential to ensure all participants knew what was happening with the baby and family. One nurse emphasised, '*...everybody in that unit needs to know what was said, so we can be consistent with those parents*' (Nurse 8). One nurse explained:

You can hand over information to your colleagues that are coming along behind. The information from the case conferences are recorded in the continuation notes so that people know that they [discussions] have happened. (Nurse 10)

Not all the nurses wanted to be involved in decision making. One nurse had a pragmatic approach to ethical decision making when she stated, '*I have no idea why nurses wish to be part of this can of worms. Nurses open the door to litigation if they wish to have a greater role*' (Nurse 6). The other nurses emphasised they did not want to make the decisions but they wanted to be consulted as a professional with expertise. They were acutely aware they were not responsible for decisions and did not wish to be.

7.5.2 Knowing the unique needs of the baby and family

Most nurses were convinced that they should be involved in the decision making process. *'I personally think it's imperative that they are involved in the decision making'* (Nurse 2). This imperative was related to the nurses' recognition of their unique knowledge of the baby and family. By unique, the nurses meant a specific knowledge of the baby and family that differed from other health professionals. Neonatal nurses in a study by McHaffie and Fowlie (1996, p. 124) were dissatisfied with their level of input into decision making. They, too, perceived themselves as having unique insights into the lives of the baby and family. The nurses in the current study believed their desire for involvement in decision making increased as they gained experience. With experience, the nurses held they had something to offer discussions and decisions. One nurse stated:

As you become more experienced you gravitate towards more involvement. When you're new to the NICU and you are feeling very unsure, you're more likely to avoid that situation. (Nurse 4)

The nurses spent extended time with the baby and family. They understood the parent's hopes and dreams for their baby, the baby's likes and dislikes and the baby's response to handling. One nurse stated, *'...We end up knowing a bit more about the family than the doctors'* (Nurse 11). Another nurse emphasised:

We're there at least for an 8 hour shift. Sometimes with continuity you could do your whole week. You could look after the same baby, go on days off and then still look after the same baby. You're there most of the time, so you've got much more information than even the doctors who just look once in a shift, or once in a while, or the parents who come in for a couple of hours here and a couple of hours there. (Nurse 12)

The special knowing the nurses claimed to possess could be related to the visual, auditory sensory and tactile interactive cues between the nurse and baby. One nurse suggested:

Sometimes you can just see that that baby is OK. You want to strive on and keep going and you just have that feeling...that neonatal feeling. I think that's one thing that we can bring to it. We can often have that feeling that this baby doesn't do anything [does not interact at all]. (Nurse11)

The nurses in providing such close care to the baby and emotional support to the parents held it to be important to be involved in the discussions. There were several reasons for their involvement. Firstly, the nurses deciphered and reinforced the information given by the medical staff (Kavanaugh et al. 2005, p. 353). The nurses wondered how they could provide support if they were not present for crucial case conferences. One nurse emphasised:

I don't believe it's possible to give the support that you need, if you're not apprised of all the facts yourself. It's very important. As a neonatal nurse...to have all the facts yourself, so that you can then tailor what you tell the parents during your day to day care. (Nurse 10)

The nurses spoke of their frustration when parents returned from discussions with medical staff and asked them questions. One stated, *'...so it's often maybe half an hour, an hour or so after the meeting, that they [parents] are then asking you to clarify what it was that the doctor has said'* (Nurse 10.) This situation could create difficulties for the nurses and they worried they would inadvertently leak information. One nurse suggested:

You get a bit cross, because the parents will come back and ask you things and you'll have to say, 'What did the doctor say?', because suddenly you might blurt out something that the doctors haven't discussed yet,...they haven't come up with the final conclusion and you've put your foot right in it. (Nurse 18)

Secondly, the nurses understood they had built rapport with the family. They did not develop the same rapport with all families, yet they developed rapport with many parents. Rapport for the nurses meant a trusting relationship had developed. One nurse stated, *'...if*

you're going to have a relationship with somebody, you should at least have an input, even if it's just to reassure them that they're making the right decision' (Nurse 21).

It was the understanding of most of the nurses that parents valued their input because of their constant presence at the baby's bedside. One nurse suggested:

I think as nurses we see more, because we're actually looking after the babies for a shift and then maybe the next day. The doctors will just say something and then walk out...I'm sure the parents would like the nurses sometimes to say a bit more of what they think would happen. (Nurse 17)

One nurse was asked her opinion by the parents and she replied, *'...well it's too early yet to pull out'* (Nurse 17). Following the nurse's comments the parents decided to continue treatment. This nurse appreciated the involvement and stated:

I think that was good that they asked, because it is more realistic sometimes to ask what the nurses do think. Sometimes the nurses have the experience to say. (Nurse 17)

There were times the parents wanted to speak to the nurses for reassurance that they had made the right decision. It has been suggested that nursing involvement can reassure the parents that withdrawal of life support "was all above board" (McHaffie & Fowlie 1996, p. 115). One nurse in the current study stated:

After they've got all the information from the doctor...sometimes they just want to talk about their baby, and you're the one that's been there for them and their baby. It's like a comfort thing for them that you know their baby, and they just want to talk and say 'Do you think I'm making the right decision or do you think we should try a little bit longer?' (Nurse 21)

Thirdly, the nurses were emphatic they were the ones who comforted and supported parents when they had been given bad news. One nurse talked about her involvement in case conferences as the nursing representative and what it involved:

...either with my holding and supporting the parents physically, while they may even be crying. Just simply being there, you can simply empathise with the way they are feeling at the time. (Nurse 10)

Most nurses were not involved in the decisions to withdraw treatment, however, they overwhelmingly supported their involvement. Nurses who had been involved believed they benefited personally and professionally from involvement. They were certain parents benefited from their presence. It was difficult for the nurses to be involved when discussions occurred outside the NICU. One nurse stated:

A lot of those discussions are actually taken out of the unit. Some of those parents are spoken in a room away from us and the nursery [staff] isn't always invited unless they make a specific request. In most cases, the decision has been made without sometimes even consulting the nurse or asking the nurse what they think. (Nurse 17)

McHaffie and Fowlie (1996, p. 263) suggest it is difficult for nurses to feel confident that decision making is a group effort when the medical staff secret the parents out of the NICU for a meeting that no one else attends. Not being involved came at a price for the nurses, personally and professionally. It was as if involvement elevated their expertise to another level. As the nurses became more experienced, job satisfaction for these nurses depended on their involvement in difficult issues.

7.5.3 Silencing and excluding the voice

It was hard for the nurses to accept they were not asked to participate in decision making, and that at times they were excluded. All the nurses were knowledgeable about extreme prematurity, the conditions, treatments and long term prognosis. Knowledge of the condition of the baby and treatment were seen by the nurses as pre-requisites for parental decision making. Pinch and Spielman (1990, p. 712) found nurses were frequently mentioned as sources of information for parents.

Most nurses declared they were not involved in either treatment decisions or ethical decision making. Involvement depended on their place of employment and how they were viewed as professionals by themselves and others. Two nurses from a focus group stated:

Nurses are rarely involved in these decisions. There aren't too many neonatologists who actually ask our opinion. There are some. (Nurse 4)

I think that's dependent on where you're working. (Nurse 1)

Hinson Penticuff and Walden (2000, p. 64) found neonatal nurses perceived themselves as having limited ability to influence patient care. The nurses did not carry a sense of being valued by their institutions, therefore, their willingness to take action to resolve ethical dilemmas was often limited. There were both positive and negative accounts of experience from the nurses in the current study in relation to involvement in decision making, although the majority are negative. They spoke about having little or no involvement and one nurse emphasised, '*...I quite often feel though, the nurses are the ones that get left out of the whole discussion*' (Nurse 11).

The nurses lamented a lack of involvement in decision making. Medical staff in a study by Benbenishty, Ganz, Lippert, Bulow, Wennberg, Henderson, Svantesson, Baras, Phelan, Maia and Sprung (2006, p. 130) perceived nurses were involved in end of life discussions to a larger extent than that perceived by the nurses. Medical staff have been found to consistently report a greater level of collaboration than do nurses (Copnall, Johnston, Harrison, Wilson, Robson, Mulcahy, Ramadu, McDonnell & Best 2004, p. 111). The nurses in the current study were disappointed at not being involved in decision making. Several nurses noted the acceptance of allied health professionals, yet they still strove for this recognition. The nurses experienced a range of feelings about being disregarded, which included feeling hurt, betrayed and feeling devalued as a professional. One focus group explained:

To then be cut out of the decision making process altogether, it hurts to be honest at times, because there's no easier way to put it than that. You're cut out. (Nurse 4)

Are you hurt or betrayed? (Nurse 1)

Hurt, I think. Your professional expertise is not valued. (Nurse 4)

Do you feel, 'why am I here, if you're not going to listen to what I have to say?' (Nurse 2)

Yeah. That's what it is. (Nurse 4)

Several nurses believed their input was not sought because they were not respected by the medical staff.

The doctors are frustrating, because they do listen to the nurses up to a point, but feel that it's their decision, not the nursing staff. I don't think they respect the nurses. (Nurse 16)

When the nurses were asked for their opinions they could feel bitter if they perceived it to be tokenism. One nurse stated, *'I think sometimes they do ask you, but I think it's a token gesture. I don't think they really care what you think'* (Nurse 19). Another nurse suggested that, *'...they probably just get a consensus just to make themselves feel better'* (Nurse 20). The nurses had to be sure that their input was welcomed and valued, and then participation equated with being valued as a professional. One nurse spoke of her shock when her opinion was asked and stated, *'I think I've been asked twice what I thought. Once I nearly fainted because they actually asked me'* (Nurse 19). McHaffie and Fowlie (1996, p. 168) found that "other people's opinions, even if heard, would not really influence the final choices".

Many nurses became bitter at being excluded from discussions and decision making. One nurse stated, *'...now I think we all know that often decisions are made away from the bedside and the nurse is not invited to comment'* (Nurse 15). Even when the nurses were not invited to comment they used "backstage speech" (Schlomann 1996, p. 45) in an attempt to vent their frustrations and influence outcomes. It became obvious very early that the nurses carried bitterness and resentment about their exclusion. One focus group suggested the nurses became bitter because they could not understand how their expertise could be so undervalued:

The fact that nursing staff are left out. To me it's so typical of what you see happening all the time. (Nurse 9)

Part of the furniture. (Nurse 7)

So totally overlooked and you're just taken for granted. (Nurse 9)

Taken for granted and so very little time ever given to the fact that the nurse is there by the bed and might see more than what anyone else does when they [doctors] just flip in and see five minutes...You've been talking in depth to parents and someone can come along and just wipe it all off as if what you've said was nothing. (Nurse 9)

Another nurse described the situation as:

Being the meat in the sandwich, we don't have much of a say. Often in this unit the doctors go away with the parents. We don't hear what goes on and we don't have much feedback from that meeting and we don't give anything to the meeting. (Nurse 18)

In addition the nurses experienced anger in being left out of the discussions. In a focus group they told a story about being the primary carers to an extremely premature baby. A case conference was about to start. The neonatologist, parents, relatives and social worker were assembled and the nurses were excluded from the discussion. To be excluded was experienced as if they did not exist in the eyes of the medical staff. They became invisible. To be thought in this way was disturbing. When they became bitter and angry about being overlooked or having their expertise devalued, the nurses would seek out another NICU for employment, one in which nurse involvement in decision making was encouraged. Secondly, they could continue but were never given professional status or achieve professional satisfaction. Thirdly, they could remain bitter and make comments when their suggestions were not heeded. The nurses had options, but many found other ways to deal with being excluded.

7.5.4 Not subjecting their own baby to treatment

Knowledge about the outcomes of tiny babies was considered powerful knowledge by the nurses. They claimed they would not consent to treatment for their own baby if they were

to deliver an extremely premature baby. There are difficulties in talking about hypothetical situations. The nurses spoke as if they knew what they would do. They made it clear that if they started to labour, they would avoid any centre capable of providing treatment for an extremely premature baby. They feared having the decision to treat taken out of their hands. Most nurses said they would present to a tertiary care facility only if they feared for their life. Two nurses in a focus group stated:

Unless I was bleeding and feared for my own life, I would sit at home. I would labour at home, deliver at home and then wrap it and just cover it until it died. Then present [to hospital] with the dead baby. I would not present in with something you could ventilate. (Nurse 19)

You could still present, it doesn't mean they have to do anything. (Nurse 20)

That would be my fear that it came out and it cried, and they did something and then there was no pulling out. And if it cried they would take it off me and they would bring it here [a NICU]. That would be my fear. (Nurse 19)

The nurses were convinced they had a realistic perception of extreme prematurity because of their experience in working with these babies every day. When speaking of her hypothetical reluctance to have a baby of 24 weeks or less resuscitated, one nurse stated in a matter of fact way,

I wouldn't leave it for dead or anything, but the baby wouldn't survive. I'm afraid I'm not one of those courageous people who can see it as God's plan or anything else. (Nurse 14)

Caring for other people's extremely premature babies, but not wanting their own treated represented a contradiction and a possible conflict for the nurses. One nurse explained she would not present to hospital because of her belief that presentation implied she was seeking treatment. She stated, '*...if I do present at the hospital 24 weeks pregnant. I'm asking for help. Usually the patient, they do want something done*' (Nurse 11). In this situation informed consent was needed. Initial and ongoing consent is required for all treatment (Johnstone 1999, p.211). It is possible that the nurses were alluding to the emotional aspects of seeking help for an extremely premature baby. Many nurses held

they would stay away so they could not be persuaded to have their baby treated, or have the staff treat the baby without consent. Fear was a powerful motivator for these nurses. Fear of the technological imperative would keep them away from any centre capable of resuscitating and treating tiny babies. It was not the fear of resuscitation that drove these nurses to despair, it was their fear that treatment would not be withdrawn when a baby was damaged. Technology appeared to take on a power of its own, and once instituted it is harder to withdraw. The nurses understood it was the medical human hand that would not, ‘...*pull the plug*’ (Nurse 16). The nurses were not prepared to take the risk.

When the nurses considered what was required to keep an extremely premature baby alive, they were not surprised when some educated parents chose not to have their baby resuscitated. When asked if she would have her own baby resuscitated, one nurse replied:

I come back to the amount of intervention at a very basic sense of the word, and I intervene with my large plastic tube [ETT] to keep this child alive. I invade its body, I create holes in it to make this child live. And if I can give out the relationship on that small baby to the size of the plastic and try to say ‘how big would that bit of plastic be in relation to me’. I find it completely unacceptable if I had to accept a UAC [umbilical artery catheter], a UVC, [umbilical vein catheter] a peripheral cannula, the size of the endotracheal tube, even a chest drain. All of these things in my baby. I know if I had the decision I would say definitely not. (Nurse 6)

7.5.5 Concern about approaches in other states

The nurses expressed concern about what happened in other NICUs around Australia. They wondered how their colleagues could work in NICUs that resuscitated in a manner they considered indiscriminate. One nurse told of a conference she and her colleagues attended on the care of the extremely low birthweight infant. The NICU this nurse worked in was considered relatively conservative. There was reluctance to initiate resuscitation on 23/24 week infants because of the poor outcomes. They chose to counsel parents and inform them of the poor outcomes, and emphasised they were unable to

guarantee the baby would not be damaged. This nurse spoke of her concern about a case that was presented.

I was shocked and horrified that they actually presented a case history of an infant that was at 22 [weeks] plus 6 days. I think it was 350 odd grams [at birth] because when the baby was weighed some many weeks down the track, it had lost weight to 295 grams.
(Nurse 10)

This nurse spoke of her shock and distress as, '*...they spoke about how many times the baby had needed active resuscitation with IV [intravenous] adrenalin, ET [endotracheal tube] adrenalin and, there were numerous episodes where the baby I believe had tried to die. But they had kept on resuscitating the infant*' (Nurse 10). At the end of the session the infant was brought into the auditorium to be displayed for the conference delegates. This concerned the nurse, '*...it was now 12 months down the track. The infant was 3 kilos, it was 12 months old. It was still on oxygen*' (Nurse 10). This infant was severely growth restricted. Premature infants on reaching term have a different body composition than infants born at term. They have a lower weight, lean tissue and bone mineral content and a higher percent of body fat. On average, preterm infants are growth restricted with respect to weight and length while their head size has caught up to birth percentile (Fenton 2003, p. 1). Cronin (2000, p. 1) states that infants of 28 weeks gestation (this is the lowest gestation that he speaks about) should gain 16.8g/day. Over one year this would equate to the child weighing 6.1kg. The child described by the nurse who was 3.0 kg, was significantly underweight for age.

The nurse who gave the account was troubled that the neonatologist could be excited at the survival of this baby. It was clear to this nurse that the child had other problems.

Just looking at the infant, you could see that there were enormous problems with this infant, developmentally. They glazed over the fact that the infant was considerably developmentally delayed. They didn't really get into what was going to happen to this infant, just that it was a miracle that this baby had survived and was now 12 months old. The human cost I'm sure would be great for that family. And myself and my

colleagues...were shocked and horrified at seeing this child at 12 months of age, only three kilos and still on oxygen and all the rest of it. We just thought that, 'Oh my God, what hope does this poor little thing have'?' (Nurse 10)

Following the conference the nurse visited to the NICU in which this baby had been treated. '*Our eyes were well and truly opened to just how small that the infants were that they were resuscitating*' (Nurse 10). This nurse spoke candidly about looking at a baby of 23 weeks gestation on high frequency ventilation. This moment is still clearly etched in her memory:

I can remember looking at this little infant and thinking, 'What are they doing here?' What I was seeing was an infant whose skin was dropping off, whose skin just looked like tissue paper essentially. You could see everything through the infant's skin, but had every imaginable and conceivable line running into this infant. Here was a baby that was of course just laying there with every single vein that you could possibly have cannulated, including its central veins. It looked so sick and so much in pain, certainly had no developmental considerations. It was just lying there, flat on its back in the crucifix position. (Nurse 10)

This nurse was shocked and could not fathom how the medical staff celebrated this baby as a medical triumph. It was as if the nurses could look beyond the baby in the NICU to the ramifications of the baby's survival on the family and society. This type of projection was not uncommon with the nurses. They insisted that all who work in NICUs needed to be accountable for their decisions.

7.5.6 Summary

It is clear the nurses wanted to be involved in the decision making process, but they also knew they did not bear the responsibility for the decisions. This stance is similar to the nurses in a study by McHaffie and Fowlie (1996, p. 169) who believed the neonatal consultant bore the final responsibility for all decisions. Nevertheless, the more senior nurses sought involvement believing they could offer something to the discussion and

support the family during the difficult times. The nurses made it clear that they would not want their own extremely premature baby treated. This represents a double standard, however, they feared losing the right to make decisions on behalf of their baby.

7.6 Conclusion

In this chapter, *Having a voice*, the role of parents and nurses in decision making has been shown to be important by the nurses. The decisions related to the care and management of babies less than 24 weeks gestation were a cause of anxiety for neonatal nurses. The nurses made it clear that the parents should take a principal role in decision making. The parents should have a voice. Neonatal nurses should be involved in the decision making related to extremely premature babies, because they could offer their unique knowledge and expertise. The majority of nurses wanted to be involved. They too wanted a voice. They believed parents benefited from their presence, and they benefited from involvement. The nurses sought involvement though it was clear that the majority of them were not involved. Many had been excluded from discussions. For these nurses this exclusion could bring detrimental effects on them as professionals. They could not understand why their professional expertise was not valued by the medical staff.

The following chapter ‘dealing with awfulness’ considers the care giving dilemmas associated with caring for extremely premature babies, and the experiences of conflict, anger and frustration that such caring brings to the nurses.