

CHAPTER 8 DEALING WITH “AWFULNESS”

8.0 Introduction

Dealing with awfulness has been revealed as the largest theme in the description of the ethical issues faced by neonatal nurses in the care of babies 24 weeks gestation and less. It describes the nurses' responses to dilemmas associated with caring for the extremely premature baby, and the conflict, anger and frustration they provoke. In an investigation into ethical issues it is perhaps no surprise that it is the largest theme. Awfulness is related to extreme unpleasantness and describes human experience that is awful and appalling. In the words of one of the nurses there are situations associated with caregiving that are “*just awful, absolutely awful*” (Nurse 7).

The neonatal nurses experienced conflict in many aspects of their care of babies 24 weeks gestation and less. To be in conflict meant the nurses had to fight and struggle. Inner conflict was experienced by the nurses as anxiety or the state of uneasiness and apprehension, about future uncertainties for the baby. The nurses all experienced frustration. They felt disappointed, defeated and let down. They became frustrated when they were thwarted in achieving goals. For the nurses, frustration resulted when their actions to provide care for the baby were thwarted. Frustration is part of their dialectic tension about being and not being a good nurse (Fagerstrom 2006, p. 622).

Anger is the emotional response to stress. It involves antagonism, but there is an element of annoyance as a result of a real or supposed grievance. Anger was kindled in situations that were incongruent with the nurse's values as professionals (Thomas 2004, p. 6), and when they experienced moral distress (Hylton Rushton 2006, p. 162). Being angry and in conflict could be detrimental to the nurses. It would be naive to think that anger in nurses is a new phenomenon, or that anger is unique to neonatal nurses. Even Florence Nightingale was known to vent her anger and she stated, “I do well to be angry”.

(Thomas 2004, p. viii). Nightingale's angry tirades had the effect of mobilising herself and others towards a common goal of improved patient care.

In this chapter the relevant dimensions of the theme dealing with awfulness is explored. Dealing with awfulness will offer an understanding of what it is like for the nurses to be in conflict and experience anger and frustration when caring for extremely premature babies and their families. For the nurses, the amalgamated experience is best described as awful. Awfulness describes the full experience of caring for the extremely premature baby, the parents, managing professional relationships and dealing with the ethical issues that caregiving provokes. Awfulness refers to the most distressing, shocking and disturbing aspects of providing care. It is about how the nurses distance themselves from ethically troubling situations, and derive support from their colleagues. Dealing with awfulness is about enduring and how the nurses somehow found a pathway through what they had to do to a baby to save its life. It is about the nurses being distressed and traumatised, yet resilient and determined. It is this resilience and determination that has allowed the nurses to endure and deal with awfulness.

8.1 Enduring awfulness

Caring for the extremely premature baby meant that, at times, endurance was required of the nurses. They carried on despite experiencing hardships and unpleasantness. They disliked situations they found themselves in but tolerated them, and developed ways to help them cope with extraordinarily difficult situations.

Enduring can be defined as an, "...emotionless state that focuses on the present" (Morse & Penrod 1999, p. 146). The nurses were "enduring to live" (Morse & Penrod 1999, p. 146). Meaning there were times when the nurses experienced emotional and psychological shutdown in response to a significant psychological threat. The significant psychological threat was caring for the extremely premature baby who made them experience profound moral distress. Moral distress occurred when the nurses were unable

to translate their ethical and moral choices into moral action (Hylton Ruston 2006, p. 161).

There was conflict for the nurses in caring for an extremely premature baby, and they endured during the conflict. Conflicts were not ordinary disagreements. They were common and flared up when someone responded in a hostile manner. Anger and resentment were common. There was conflict with medical staff, the baby's parents, their own nursing colleagues, the media and general public. There was anger with the media for fostering unrealistic expectations about extremely premature babies. There were conflicting emotions when questioning whether they should be saving tiny babies. Nurses welcomed seeing satisfying results of hard work, however, with tiny babies this was not always possible. Recurring inner conflict was confronting and distressing. The nurses' professional esteem was often challenged making them wonder, '*...what are we doing here?*' (Nurse 15). Such statements are also indicative of moral distress where the nurse laments feelings of powerlessness to change the situation (Hylton Rushton 2006, p. 162).

8.1.1 Protecting themselves

The nurses attempted to cope with the difficulties of caregiving by protecting themselves psychologically. In this regard they all made jokes, though they recognised the fine line between humour and offense. One nurse explained the joking:

We joke around and make really, really bad jokes of the situation. I know that a lot of people who aren't in the know are very horrified at what we laugh at. But it's a protective thing. (Nurse 12)

Humour is a way of managing overwhelming situations, it is not uncommon to find humour in stressful situations (Eisendrath & Dunkel 1979, p. 756; Mandel 1981, p. 1196; DeSpelder & Strickland 1992, p. 26). The nurses tried to defend themselves from the sadness by laughing and joking. If other people heard these jokes and misinterpreted their context they might be offended. For all the nurses, humour was a way of coping with the

darker aspects of nursing. It was not their intention to demean the baby or the situation. Maeve (1998, p. 1139) found that, "...the reality of nursing is that some things are awful to behold. Making jokes appeared to bolster courage, made the 'awful' merely silly, less real". Lawler (1991, p. 191) noted that uncontrollable laughter in these stressful situations is common. The laughter is different from everyday laughter, because it is unintended.

The nurses all seemed to understand the fine line between amusement and stress relief, and jokes which were insulting. Tendentious jokes of the type used by the nurses often contained the topic of fetal infants. One nurse stated '*I think we all joke about the fetuses*' (Nurse 16). Freud saw this type of humour as liberating as it corresponded to a momentary freeing up of energy (Erdelyi 1985, p. 174).

The nurses all spoke of the importance of finding ways to cope with the nature of NICU work. One nurse explained:

I don't take work home or I try to not to. There's some times that you do, especially if you get involved with a family. But I think you've just got to go home and say, 'Well you've done the best you can'. I think otherwise I would have been out of this unit a long time ago. (Nurse 18)

The nurses were all convinced that only those who worked with tiny babies would understand their dilemmas. They were reluctant to speak to their family about the NICU. They could not talk to friends and family, because they considered the content of the conversation might cause them distress. One nurse spoke of not being able to talk about stressful episodes:

It's such a state that you can't even talk to people at home, because they just bomb out. They can't cope with what you're coping with. (Nurse 9)

Several nurses spoke of informing partners, friends and family about the difficult work situations they faced, however, the responses were often trite and not what the nurses wanted to hear. One nurse stated:

And all they'll say at the end of the day is, 'I don't know how you can stand that? Why do you go back?' So you can't talk to them. (Nurse 9)

The nurses all welcomed the understanding that they had a difficult job. They argued with their external support people when that understanding was not forthcoming. To the nurses finding another job was not a solution. They found it easier not to disclose their difficulties to external people. Nurses with difficult jobs tend not talk to their families about these difficulties (Hainsworth 1998, p. 48). Confidentiality further required that nurses would not speak of problems at home.

Caring for an extremely premature baby was physically and mentally exhausting. One nurse spoke of her exhaustion:

You'd go in and look after these small babies particularly in the first few weeks. They were just so unstable. By the end of the shift you were so exhausted, mentally exhausted that you just want to get out of there. (Nurse 5)

The nurses all understood their role was to help the parents, '*...you're just there to look after the baby and probably pick up the pieces when they [the parents] all fall apart*' (Nurse 17). There were times when they struggled to summon the energy to care for the baby and parents. The most common way the nurses coped with such difficulties was to avoid the situation and the parents. One nurse talked about her avoidance:

The whole thing makes you really down. I got to the point that... unconsciously, I was avoiding looking after the baby. Not because I didn't want to look after the baby, but because I couldn't stand to have to confront the mother. (Nurse 7)

In this situation having to confront the mother was beyond this nurse. Confront in this situation was probably about the nurse being physically and emotionally exhausted and unable to interact with the mother. She was unable to be emotionally available for the mother. In her exhaustion she was afraid of saying something to the mother she might later regret.

There were times where the nurses chose not to care for a particular baby, because they needed a break. In this situation it seemed that caring for the baby was easier than caring for the parents. One nurse explained:

It wears you down after a while. Because sometimes you're like, 'Well I really don't want to look after that baby today'. It's not so much the baby that you can't look after, it's coping with the parents. (Nurse 16)

To prevent the nurses from becoming exhausted the nursing manager would rotate the nurses in the NICU to care for different babies.

You might just move people around every two shifts. Instead just two shifts with that baby, rather than making them stick it out. At the end of six days you can be a write off. (Nurse 14)

For this strategy to be effective the nurse must desire to take a break from the situation. It was unacceptable for the nurses if others implemented this action on their behalf. Moving nurses around has been found to exacerbate rather than decrease a problem (Williams 2001, p. 660). When the nurses desired a break it was often because they knew they had a responsibility to support the parents. One nurse explained:

They [the nurse] think, 'Well this person [parent] really knows me very well and we've really only got three people looking after this baby and if we introduce a new person now'. And you're waiting for the baby to die and it doesn't. It goes on and on and then people can get stuck with that baby and they can't get out of it. (Nurse 14)

This nurse experienced a dilemma. She did not want to care for the baby, but she wanted to provide the best care for the baby while it was alive. The needs of the parents to have familiar staff caring for the baby was understood. Parents in a study by McHaffie and Fowlie (2001, p. 215) were saddened when surrounded by new faces on the day of their baby's death.

It seemed the nurses were often just managing to hold themselves together. Constant exposure to overwrought parents, however, might just unbalance their coping mechanisms.

You're only coping from shift to shift. You're trying to get through your shift and trying to make the parents feel as comfortable as possible and obviously the baby. It is hard to cope. (Nurse 15)

In addition, the nurses experienced vicarious traumatisation and compassion fatigue, both of which can be precipitated by caring for and helping traumatised parents. The nurses all knew that constantly working with parents in situations charged with grief and guilt could be difficult for them. They told incredibly sad stories about parents and babies and, at times, seemed to be caught up in the personal tragedy of the parents' situation. They spoke as if they had absorbed the intensity of the parents' feelings and shut down their emotions in an effort to prevent the situation from overwhelming them. The nurses all talked about their fatigue and exhaustion, both of which are key indicators of compassion fatigue (Maytum, Heiman & Garwick 2004, p. 174).

There were strategies that several nurses developed to prevent themselves from becoming overly attached to the baby, such as not thinking about what the baby was experiencing. One nurse explained:

These people [nurses] are saying, 'Oh...what are we doing here?'...They obviously can close their mind at an earlier point. (Nurse 15)

When the nurse's mind closed off they were still able to provide care for the baby, by not dwelling on what was happening to the baby, or what the future held. They developed skills in switching off their emotions. They sometimes said thoughtless and pessimistic things about the baby, helping themselves from becoming attached. One nurse stated:

I have a great affection for the tiny babies, whereas some people might be very pessimistic and say, 'Oh you know it looks like a skinned rabbit', which is a word I hate

using. So they will refer to these babies like that, or say very pessimistic things. (Nurse 15)

The nurses all spoke about the experience of providing care to babies who resembled fetuses more than babies. Many nurses stated they did not enjoy caring for these babies, thereby bringing them into direct conflict with their colleagues. One optimistic nurse stated, *'I get a bit angry when people are a little bit negative towards looking after them'* (Nurse 7). The nurses did not like caring for these tiny infants because of their fetal appearance. One nurse explained how different they looked:

We call them fetuses because they have such a fetally appearance. A larger baby, they look like a baby should look. You very rarely see a 23/24 weeker that really does look like a baby to begin with...They may grow into looking like a proper baby. (Nurse 16)

It seemed important that the baby should possess the physical characteristics of what the nurses perceived to be a baby. One nurse stated, *'...people are shocked when they first see a baby that size, because they don't look like a baby...the fetuses'* (Nurse 16). Such terms could be in keeping with Preston's (1979) and Schlomann's (1999) notion of ambiguity, where nurses experienced difficulties caring for babies whose appearance markedly differed from what was considered ideal. Using the term fetus could be a protective mechanism that shielded the nurses from the realities of awfulness. Bogdan, Brown and Bannerman Foster (1982, p. 8) have shown that extremely premature babies are referred to as fetuses. The nurses preferred to work with a baby greater than 28 weeks gestation because they looked like *'a proper baby'* (Nurse 16), and not a *'skinned rabbit'* (Nurse 15). Greenall (2001, p. 112) considered the use of the word 'proper' and wondered if nurses thought "there is something improper about the preterm infant".

Dehumanising the infant by making negative remarks seemed to protect the nurses because being pessimistic might prevent attachment. One nurse stated:

I don't think it's that they [nurses] don't like them. They may give that outward appearance, but I think it might be sealing in their minds that, 'I don't know why we're doing this and we shouldn't be doing this'. (Nurse 15)

Dehumanising however, denies a baby's humanity. Depersonalisation of a baby could be a response to an ethical dilemma in which a negative coping style is adopted (Raines 2000, p. 31). It is this coping style that allows nurses to distance themselves from the baby and family. Dehumanising helps the nurses diminish the dilemma of caring for the baby that does not resemble the ideal baby, thus reducing its intensity. One nurse described this phenomenon:

It's a survival technique; you learn to dehumanise these babies. These babies are part of the process line. These are the product. They are not anything to do with you as a human being and your own humanity. If you say here is a bit of work and this is the outcome of the work, rather than identifying with that as a human being and putting yourself in the isolette, then it's a survival technique. (Nurse 6)

The technique of dehumanising extremely premature babies was how this nurse made sense of keeping them alive. Imagining the baby as part of a production line allowed her to distance herself during those difficult times. The baby is considered the product of the commodification of health care; treated as if it were on a production line. This nurse emphasised that neonatal nurses needed to develop techniques to help endure and survive the NICU. These techniques include distancing (Nagy 1999, p. 1433) and disembodiment (Schroeder 1992, p. 217). Kraemer (2006, p. 152) has suggested that neonatal nurses rely on "detachment, denial and depersonalization". Perhaps this is true, because denying their emotions might be easier than confronting them.

I think each nurse learns their own survival technique for what is a very confronting area. You can either approach it with a certain degree of honesty, or you can learn techniques for putting it on the shelf, and leave it from being too confronting for your own emotions. If you approach it with a degree of honesty then you've got no option but to lay it all....till you feel far more comfortable with what happens. (Nurse 6)

Parental emotions could be problematic for the nurses. As the primary caregivers to the baby and family the nurses were subjected to parental outbursts associated with their grief. One nurse explained:

So their anger, guilt and whatever other emotion that they have at that time, is quite a challenge to deal with for a neonatal nurse. (Nurse 10)

The nurses understood that anger was a common response to grief and frustration. They understood this anger was not directed at them. There were difficulties in dealing with the parent's anger when they perceived themselves helping the baby and family. Nurses can feel inadequate when dealing with parental anger. They may personalise the anger and become distressed. They can feel shocked, attacked, blamed, powerless, angry (Griffin 2001, p. 59), undervalued and unappreciated (Griffin 2003, p. 212). When parents raise their voices the nurses might believe the anger could escalate to physical aggression (Griffin 2003, p. 212). The recommended response in this situation is to acknowledge the parents anger and express a desire to help (Griffin 2003, p.214). Several nurses suggested that the triggers for parental anger included unexpected changes in the baby's condition and confusion related to conflicting or insufficient information (see footnote).

Perhaps the anger was directed at the staff, as Hainsworth (1998, p. 41) suggests that families perceive a loss, and that anger is frequently directed at anyone believed to be associated with that loss. It is possible that nurses might inadvertently trigger the parental anger. The nurses wanted the parents to know the realities of extremely premature babies, however Hainsworth (1998, p. 47) suggests this reality orientation is unwelcome for many families, making the nurses targets for parental anger and frustration.

8.1.2 Responding to the immediate

The time around the birth of an extremely premature baby was considered by all the

nurses to be chaotic. The nurses did not have time to reflect on their actions. Following delivery they were responding to the immediate, stabilising the baby and attending to its physiological needs. It was not until they had time to reflect on the situation they realised their dilemma. One focus group commented:

Initially just through the ropes. (Nurse 23)

Initially you don't feel anything, you go through the ropes. You know what you've got to do, so you go ahead and do it. It's later when you stop and reflect. (Nurse 21)

It's two weeks down the track when you're hitting all the problems and you think 'Oh why, why did we do it? Can't get out of it now'. (Nurse 23)

The nurses all regretted they had little opportunity to discuss their ethical dilemmas. One nurse stated:

I think a lot of neonatal nurses become frustrated and quite distressed at the fact that we aren't able to talk about it. We aren't able to discuss all the issues and the pros and cons of why this decision was made... I think we need an opportunity where we can get together in a forum perhaps an informal way and talk about how we felt about it. (Nurse 4)

Formal case discussions often became emotionally charged as they attempted to air their grievances. Case conferences similarly did not always alleviate the nurses' distress.

All you get to do is air your grievances or say what you're not happy about. As I say, it's a token gesture. It will make absolutely no difference, one way or the other. (Nurse 19)

During the discussions the nurses voiced their preferred ethical options, but decisions were often taken without any input from them. Raines (2000, p. 31) suggests the stressful effects of the inconsistencies in the real and ideal ethical behaviour could make nurses avoid the situations that involve ethical conflict. The nurses all wanted to discuss their ethical concerns, rather than avoid them.

When nurses consider their opinions are not valued, several possibilities could result. Firstly, nurses could become passive, provide care to the baby, and not become involved. Passivity would be detrimental to the baby and parents. Nurses who are not provided with opportunities and challenges may experience burnout, which is where the individual nurse loses motivation for creative involvement in the NICU (Marshall & Kasman 1980, p. 1160). When burnout occurs the commitment of the nurse to the unit will decline, the nurse will do his/her job, but little else. Burnout is the cause of significant staff turnover (Gribbens & Marshall 1982a, p. 137). The state of burnout is illustrated by Gribbens and Marshall (1982a, p. 131).

As I look around the neonatal intensive care unit and see the suffering endured by the babies and their parents and the dedication of many caregivers in this unit, the fact that makes me feel most guilty is that I no longer care.

Secondly, the nurse could find another position within the organisation where he/she did not have to confront ethical dilemmas. The position would be away from direct patient care involvement, for example a nurse unit manager, educator, clinical nurse consultant, or research nurse. Thirdly, the nurse could resign from the NICU, work in another NICU, leave nursing, or find a position in a related field. Experienced neonatal nurses are difficult to obtain. To lose them because they were unable to discuss their issues of concern would seem unforgivable. Giving them the opportunity to air issues of concern might help them remain productive.

8.1.3 Doing a job

The majority of nurses did not enjoy providing care to extremely premature babies. They might enjoy the challenge of caring for such a sick baby, but their negativity prevented them from enjoying the caregiving experience. The nurses recognised that '*not everyone actually wants to look after an infant that's going to challenge them every minute of the shift that they're there*' (Nurse 10). Caring for tiny babies was '*hard work and it can be emotionally draining, physically draining looking after them*' (Nurse 17). It was difficult

for the nurses to watch the same scenario unfold time and again. For the nurses it was a case of, '*...here we go again*' (Nurse 8).

When the nurses embarked on their neonatal nursing careers they perceived tiny babies as a clinical challenge. These nurses now thought deeply about the care of tiny babies, where previously the clinical challenge was exciting. One nurse discussed her anxiety:

If they do survive, they've got such a long road ahead of them. You're going to have so many problems. If they do survive, it's not something you'd really wish on anybody.
(Nurse 17)

The unrealistic expectations of parents could foster negativity within the nurses. They understood that because parents had seen their baby cry at birth, they might believe '*medicine can fix everything*' (Nurse 2). This negativity was explained by one nurse:

There's a lot of negativity within the nursing staff because they can see that really what the parents are expecting to be the outcome of this child is not going to be there. I think that's where they [nurses] don't want to commit totally and have this negative view. Because they think 'Why am I doing this?',...not 'I'd like to do this.' (Nurse 2)

Caring for extremely premature babies could influence the nurse's mood. This experience could influence which babies they chose to care for. One nurse believed she felt,

Depressed about caring for these infants. Particularly if you are in a position where you are caring for sick, tiny infants day after day,...and you are seeing a lot of infants die and or have significant clinical sequelae. It can get very depressing looking after those sort of infants. (Nurse 10)

Another nurse had a similar reaction:

I feel very depressed...you're looking after a child who's coming out with that sort of outcome. (Nurse 9)

The nurses' experience led them to believe treatment could harm the baby. They all attempted to balance how treatment could help and harm,

What we do to screw it [baby] up inside that makes the difference. And we do. It's iatrogenic, a lot of their problems. We do it to all in an effort to make them well, I realise that. I'll continue doing it. But we do some terrible things to them. (Nurse 21)

The nurses spoke about what happened to the babies during the course of their treatment. The babies, '*...have such a battle on their hands to stay alive*' (Nurse 18). The babies demonstrated oedema, blood dyscrasias, sepsis and skin loss in response to their treatment. The nurses were distressed and powerless and one nurse emphasised '*it's very sad to watch. I just think it's awful at the beginning, what we do to them to keep them alive*' (Nurse 18). Clearly, the appearance of the baby was a source of concern for the nurses, and they spoke of the difficulty of '*just trying to keep them normal looking babies*' (Nurse 18). It seems that when the baby's appearance changed so dramatically the nurses could experience difficulties relating to the baby as a human being, or the image of baby as human could be supplanted with the image of baby as object (Schlomann 1999, p. 168).

The nurses were not able to articulate why they cared for extremely premature babies when they did not enjoy the experience. It could be that it was their job, and they chose that job. One nurse spoke in a pragmatic way in attempting to explain:

I do it. There's not much else you can do in the world. You've got to live with yourself. You still have to pay the bills, which may not be ethical, may not be moral, but you still have to pay the bills, and you still have to get on with life. (Nurse 5)

Extremely premature babies are usually delivered and nursed in perinatal centres. Nurses employed in perinatal units are exposed to more tiny babies than nurses from surgical centres. The issue might be about the number of premature babies of varying gestations in perinatal centres, and one nurse stated '*you don't have any choice. If the baby is put in*

front of you, you've got no choice' (Nurse 23). All the nurses knew the demands of their job. One nurse explained:

It's part of their job. If you're in this job, you know what it entails. If you've been in it for a number of years you know it entails looking after that [extremely premature babies].
(Nurse 20)

The nurses all emphasised the number of extremely premature babies in the NICU was very small, yet the babies made an impact on the NICU, staff and morale. One focus group explained:

I don't know how many 23 weekers we get a year. (Nurse 20)

Not a lot. (Nurse 19)

It's a little part of the job. (Nurse 20)

It makes a big impact when it happens. (Nurse 20)

If it was a big part of the job, I couldn't do it. It'd drive me up the wall. (Nurse 19)

The nurses continued to work in the NICU because extremely premature babies were not the only babies in the NICU. The negative feelings of the nurses were often balanced with positive ones. One nurse emphasised:

They're not all 23 weeks, right. You have your 23 weekers. You might have one or two in the unit. The other 20 or 30 are your 28 and 29 weekers who do well, so that sort of balances it. (Nurse 19)

One nurse expressed surprise that her colleagues could display such negativity, yet continue working in the NICU. She stated, '*...it's surprising that they would have all those really bad thoughts, but they're still doing it. They're still in the job and they're still doing it*' (Nurse 20).

The nurses all struggled with conflicting emotions, wanting to save the baby, yet weighing up the realities of care. One nurse stated, '*I think...we should do everything we*

can, because we do have some positive results. But I think the negative ones on these tiny prems outweigh it' (Nurse 11). Sometimes they wanted the awfulness to be over, and this is reflected in a statement by one nurse:

I've found that some people [nurses] want to look after them, but at the same time they wish that the babies would just hurry up and die, because they know they're not going to survive. (Nurse 7)

The nurses all experienced difficulty when exposed to babies whose outcome was not considered optimal. As professionals, the nurses desperately wanted to believe the product of their work would not be significantly impaired. They found it difficult to confront this ideal, *'...not every neonatal nurse actually likes to care for an infant whose outcome may in fact be significantly impaired'* (Nurse 10). The nurses' professional esteem was enmeshed in the outcomes but, as one nurse stated, *'...no one pats us on the back when we save these babies'* (Nurse 15). The ongoing struggle was often overwhelming for the nurses. There were times when they could no longer cope, and decide to seek other employment. One nurse who did this explained,

That is why I left perinatal care, because I didn't have the optimism anymore. My feeling was 'why bother'. We are putting this family through a whole lot of pain. At the end there's not a lot of good things there that I was contributing to. (Nurse 5)

8.1.4 Learning on the job

The level of expertise of nursing staff caring for tiny babies could cause concern for the nurses. Although the nurses understood the outcome was likely to be poor they believed the babies deserved the best care in the NICU. One nurse explained staffing difficulties:

With our current NICU population of very poor staffing mix between junior and senior nurses, it often presents a huge challenge to find appropriate staff to look after these infants whose acuity is quite drastic in terms of their specific needs. (Nurse 10)

The nurses all held that experienced staff should care for extremely premature babies. One nurse stated, '*I reckon you should only have people who know what they're doing looking after them*' (Nurse 14). The nurses with the experience and knowledge, however, were often discouraged by the outcomes. One nurse explained:

You're often quite discouraged. It's almost like a double edged sword. You want to do the very best for that infant that's in front of you. You know that the infant has a very immature system and you know that no matter how much labour, toil, blood, sweat and tears, that you put into caring for that infant and family, you're also discouraged because you know that the statistics are there telling you that the outcome for these very tiny babies is poor. (Nurse 10)

The nurses spoke about lacking knowledge and skills when they commenced neonatal nursing. One nurse said she, '*...didn't have a clue at the beginning. I had pretty much no orientation*' (Nurse 14). This nurse was full of regret as she explained:

I just have nightmares about what I must have done to babies during that period. At the time I was stressed and feeling shocking about it anyway, because I knew that I didn't know. (Nurse 14)

The condition of extremely premature babies can change on a minute-by-minute basis. The nurses were distressed when a baby died suddenly after their shift had finished. As an example they all spoke of the baby who developed NEC with perforation and died rapidly. This could happen in a very short time. In such a situation a nurse questioned her own and her colleagues care,

You think 'Oh it did so well on me.' You feel 'Could I have done anything better. Could I have changed the outcome'?...The shift before when you had the baby was really good. 'Oh did I miss something? What time did it happen'? ...To see it wasn't anything to do with your shift, ...even though you know that baby's chance of developing anything has to happen some time. (Nurse 11)

The nurses all worried about the care the baby would receive when they handed over to inexperienced staff. One nurse explained the difficulties arising at the change of shift.

You feel that you shouldn't go home half the time. Wondering who's going to take over from you. I really think that these little babies should be only looked after by the people who know what they're doing. Not let every man and his dog look after little babies.

(Nurse 14)

8.1.5 Neophyte optimism

Several nurses experienced difficulties with junior nursing and medical colleagues. Junior staff might not have considered the ramifications of treating tiny babies, nor experienced first hand the outcomes of extreme prematurity. It was often inexperienced nurses who believed technology could save every baby. One nurse stated, *'I find the younger ones... a little bit more optimistic to begin with when they first start'* (Nurse 16). The inexperienced nurses were described as *'gung-ho'* (Nurse 16). One such nurse was described as being, *'very conscientious and I think she just wants to do the right thing more than anything else'* (Nurse 16). This was not experienced nurses dismissing the opinion of their neophyte colleagues. Neophyte nurses initially try to master the technology, develop some clinical expertise, and care for the baby and family. It took several years before a nurse could step back and objectively consider the results produced by the NICU.

It was the experience of the majority of nurses that junior medical staff would have difficulty letting nature take its course. One nurse stated:

They are battling with their own sense of becoming a registrar [senior medical officer]. They're also battling with the politics of being responsible to several consultants..., and it's a very hard call. If an infant at 24 weeks comes out and perhaps makes a weak cry, then their instinct is to put a tube [endotracheal tube] in. (Nurse 10)

One nurse related an experience about a nurse, a registrar and a couple with 22-week twins in labour. It had been decided in consultation with the parents that nothing could, or would be done when they were born. When the babies were about to deliver the neonatologist was called to reaffirm the babies were not to be treated. The registrar intubated one of the babies, and when the nurse explained to him what the consultant had said, the registrar said:

‘Oh well, I’ll have to hear that from him.’ And I said ‘Well you’ll have to go out and talk to him on the phone, because he’s not coming in and he doesn’t want you to do anything.’ (Nurse 16)

The nurse intervened and described her actions:

I took the baby, wrapped it up and took it over to the parents. They were happy enough with it. Then the next one [twin] delivered. ‘No don’t do anything’! The registrar wasn’t too thrilled about it either. I think he wanted to get in there. I think they found it awkward. (Nurse 16)

The babies lived for approximately two to three hours. The delivery suite midwife went to the NICU to discuss another baby, and mentioned the babies were still alive. The junior nurse stated, ‘*Do you want us to come around, do you want us to come around?*’ (Nurse 16) The senior nurse explained the parents’ wishes for non-treatment. For this nurse it was concerning that her colleagues would treat the baby without fully understanding the ramifications of treatment. She understood that her nursing colleague and the registrar needed time and experience. Resident medical staff are still constructing their moral philosophies. As their moral reasoning develops, they might be less aggressive in their management, especially when the family request no treatment (Candee et al 1982, p. 850).

8.1.6 Summary

Enduring was an everyday occurrence for the nurses when they cared for an extremely premature baby. The NICU arouses strong and mixed feelings in the nurse including pity, compassion, guilt and anxiety. Menzies (1960, p. 98) has suggested that nurses can feel resentment for patients (or in this research babies and parents) who arouse these strong feelings. The nurses had all developed protective mechanisms that helped them cope. There were times when the nurses could endure no longer and they left the NICU and sought alternative employment. Accepting they could no longer work in the NICU was important. Here the nurses realised their health and well-being would be jeopardised. Clinical supervision offers help as nurses endure. Clinical supervision is the “provision of monitoring, guidance and feedback on matters of personal, professional and educational development” (Kilminster & Jolly 2000, p. 828) as it relates to the nurses practice. It is the exchange between practising professionals to assist the development of professional skills (Lyth 2000, p. 722). Currently clinical supervision has not been easily embraced by clinical nurses as it is seen as a form of surveillance (Clouder & Sellars 2004, p. 262), and considered part of the “confessional” (Gilbert 2001, p. 199).

There are three main functions of clinical supervision that have been proposed. These are normative, formative and restorative (Proctor 1991, cited in Teasdale, Brockelhurst & Thom 2001, p. 217). Normative supervision entails advice on the provision of high quality care, while formative supervision would help the nurses develop their knowledge and skills (Teasdale et al. 2001, p. 217). The nurses in this study could derive more benefit from restorative supervision as it is designed to help nurses cope with work related pressures and stress.

Enduring is about dealing with the realities of nursing practice. For the nurses it was a difficult, painful part of their practice. They did not like this part of the work but they endured because they are pragmatists. It would be a mistake to think that nurses can give physically and emotionally without it having detrimental effects on them, hence the terms vicarious traumatisation, compassion fatigue and burnout. Nurses may not deal with

awfulness easily but they deal with it, staying productive in the NICU. It could be argued that during these times the nurses were not fully productive because they provided physical care only. While it is the ethical ideal, it would be unreasonable to suggest that every nurse was fully emotionally available to patients and families throughout every shift.

It can be hypothesised that nursing theorists have inadvertently set contemporary nurses up for failure. The literature on caring can be said to avoid current nursing reality in which ethical dilemmas are commonplace. Romanticised notions of nursing in the caring literature are likely to be out of touch with the ethical complexities of the NICU. The nurses in the current study showed signs of internalising the caring ideal, without fully understanding the dichotomy between ideal care and realistic care (Flaskerud, Halloran, Janken, Lund and Zetterland 1999, p. 33). The literature on caring seems to forget the dark parts of nursing. Menzies (1962, p. 98) suggests that nurses carry, "...out tasks which, by ordinary standards are distasteful, disgusting and frightening". Publication of the dark aspects of nursing is essential. The not-so-nice realities and complexities of current nursing practice need to be revealed. Ethical dilemmas continue, but with burgeoning technology, their effect on the nurse is extensive.

8.2 Conflict with the medical staff

In the main, the relationship between the neonatologists and neonatal nurses was seen as a symbiotic one, where both health professionals believed they worked together for the common good, the best possible outcome for the baby and family. The nurses referred often to this good relationship, however, the negative aspects of the relationship presented the nurses with a number of dilemmas.

The nurses experienced conflict with the consultants in certain situations. Firstly, conflict occurred if the nurses believed the best interests of the baby were not being served. Secondly, if the nurses did not feel appreciated or welcomed as professionals they

perceived themselves to be in conflict with the consultants. Thirdly, when consultants could not agree about a course of action the nurses become involved in conflicting positions and tried to expediate decisions, thus taking sides.

8.2.1 Banging our head against a brick wall

In NICUs there are several neonatologists, however, only one is on service at any time. Some NICUs change consultants weekly, fortnightly or monthly. All the nurses spoke about the difficulties associated with change of service, and the invariable change of management. Several nurses spoke of consultants coming on service, changing the management regardless of how the previous management was working. Other nurses explained their consultants changed management that did not appear to be working. One nurse discussed the difficulty associated with the change of consultants:

I think when there's more than one consultant on and they change, and you have different opinions from different consultants...Come to some sort of a mutual agreement that is what is going to happen. Otherwise you get this ongoing friction that's...more stressful.
(Nurse 3)

The situation that caused the most difficulty for the nurses occurred when consultants could not agree on management. The frustration was expressed by one nurse:

In that situation, you as a nurse, you become very angry because you just want to get all the consultants into a room and say 'For God's sake you guys,...can't you come together?'
(Nurse 3).

One nurse waited for the consultants to, '*...come to some sort of a mutual agreement, that is what is going to happen*' (Nurse 3). It was difficult for this nurse because, '*...the ongoing friction is stressful because we're at loggerheads, banging our heads against a brick wall*' (Nurse 3). The same nurse spoke of her frustration when '*they're [consultant] on a power play because they have animosity between their medical colleagues and it's very frustrating*' (Nurse 3).

8.2.2 Forced to care

The nurses at times gave the impression they were forced to provide care. They experienced distress when a baby was kept alive when they had come to believe the baby was dying. One nurse agonised:

They're wanting to die and we won't let them...you could see they were dying. (Nurse 18)

Further distress was experienced when the nurses perceived the medical staff tried to resuscitate every baby. One nurse explained her dilemma:

Some doctors can't bear not to [resuscitate]. It's...a failure, so they have to resuscitate everything. They can't keep their hands off. You...look back and think 'Why can't you just let the baby die?' They have to keep going. (Nurse 11)

The nurses all thought it likely that the medical staff struggled, because they had chosen a career that sought to save lives. One nurse told of a story of a baby the staff had battled for months to save and who subsequently died. This nurse observed the neonatologist and his anguish,

I couldn't help but feel that the doctor on the day that he died, was on when he [baby] came in. I think he felt like he was responsible that the baby had ended up in that condition...even though he's an extremely prem infant. He was feeling like he was a failure in he hadn't done his job well enough. I think he felt really guilty. I felt that he just couldn't bear to stand and watch that baby die, and he came in as the baby was dying and he left...I don't think even then he'd accepted it, because he came up to us said, 'What's happened? What's gone wrong.' And we thought... 'the baby is dying for God's sake.' (Nurse 7)

Another nurse told of a 24 week gestation baby who was still treated even when diagnostic technology revealed the baby would have a poor outcome. This nurse explained her concern:

Scans showed that he had absolutely very little brain function. He had eye surgery... not going to have any vision. His limbs were so deformed from infantile rickets and so many breaks [fractures],...weren't growing normally. He wasn't going to be able to walk. He wasn't going to be able to move his arms. On X-Ray, his lungs were so tiny and his heart was so huge and his gut was stuffed. There wasn't very much left. We've done MRI's and done scans that show that the brain is really malfunctioning, and very little left is just your respiratory centre. To push a child like that I think it's wrong. (Nurse 9)

This nurse was troubled and could not understand why this baby was kept alive. The parents had not insisted the baby receive treatment. The medical staff had not informed the parents of the prognosis. It worried the nurses when parents were not given the, '*big picture*' (Nurse 20) about their baby. There was a desperation in the nurses as they wanted parents to have an accurate picture of their baby's condition and outcome. One nurse explained:

I sometimes feel that they're [parents] not told complete stories. They're only told what the medical staff feel they should know, or they need to know. They're not really told how this will affect them. A baby with the Grade 4 bleed...they're not told that their babies are probably going to end up with Cerebral Palsy or blind or deaf or all of those things, and never grow beyond being a child. (Nurse 21)

The nurses experienced difficulty providing care to tiny babies when their care brought about deterioration necessitating resuscitation. One nurse explained her anxiety:

I've turned babies over and they've died, just in the bed. You've done something, put your hands in the crib and they've virtually died on you. You have to resuscitate them as we say 'Look how many times do we have to revive this baby? What's it doing to the neurological outcome.' We have 24-week twins and every time you turn one over, he

would die. Just die. You'd have to either bag him or do something to get the heart rate up, the saturation, everything. (Nurse 12)

The nurses could not understand why they were expected to continue providing treatment. One nurse explained:

You can't understand why they're putting you in the situation and you obviously wonder why. The worst scenario would be when the baby is quite hopeless and you're still obviously expected to continue care. (Nurse 15)

Even though the nurses were distressed they managed to provide technically perfect care to the baby. One nurse stated:

They're still looking after the baby to the best of their capabilities, and the baby still is perfectly looked after, and looks nice and comfortable on the bed. (Nurse 15)

The care was described by one nurse as, '*...mechanical...baby doesn't have to say thank you, they just keep living.*' (Nurse 18) Distancing or moving themselves to the "emotional periphery" (Kraemer 2006, p. 153) allowed the nurses to function and yet not be there. The nurses provided care in an automatic way and this was protective for them. They provided care to the baby and emotional support to the family, however, the essential part of what made the nurse a complete person was missing from this interaction. Perhaps the essential element is a vital core without which it was like caring for, without caring about. This is not to say that the nurses did not care about the baby, but when they experienced powerlessness they concentrated on technical aspects thus preventing their emotions from overwhelming them. Caring required an investment of emotions, and the nurses in such situations were unable to commit themselves. Detachment allowed them to continue to function in situations of conflict.

The nurses all believed that babies sent them signals about their intention to die. One nurse discussed a peculiar smell she believed babies emitted. She stated:

I know of babies that have a particular smell. You know people who are dying have a particular smell and you can smell these babies dying and you know, 'Give up, give up, give up.' Nobody listens to you. The babies, because we're with them, you can actually smell that they're going. You get these feelings and inputs from the baby saying, 'I want to give up.' (Nurse 12)

When this nurse noticed this smell of death the knowledge that the baby would die sooner rather than lingering seemed to allow her to cope. It was as if knowing the baby would not suffer anymore gave the nurses the opportunity to ensure a peaceful death. McHaffie and Fowlie (1996, p. 91) found that providing a good death experience for the baby and family gave neonatal nurses a sense of satisfaction.

Witnessing a baby being resuscitated could be distressing for the nurses. One nurse related a distressing story about a resuscitation attempt:

At one point, we're [nurses] saying, 'Stop, stop.' But he [doctor] couldn't stop. He was asking for... We all stood back and said 'No, it's gone too far. No we're not doing anything'. 'Well I'll do it myself.' He was doing CPR, bagging, the works, but we all stood back and finally he got the message. Then he walked out and he felt the failure that he wasn't able to resuscitate the baby, but it had gone too far. (Nurse 8)

The nurses in this scenario did not want to participate in repeated attempts to resuscitate, they stood back and refused to contribute. Possibly, it was equally hard for the medical staff to stop treatment. A consultant might reduce the infant to a set of pathologies, because seeing the baby as a whole and part of a family might underscore the inherent ethical issues in the situation (McHaffie & Fowlie 1996, p. 9). In this situation the powerlessness of the nurses was reversed. They assumed a position of power, in refusing to resuscitate a baby they were convinced could not survive. Refusing to participate was in itself empowering. On addition, the nurses' actions were supported by their clinical knowledge of the baby. In refusing to participate they influenced the consultant and possibly influenced the outcome.

Nurses have been found to be more likely to consider withdrawing treatment earlier than neonatologists, or parents (Streiner et al. 2001, p. 152). They noted when a baby became unresponsive to their handling and began to worry about the situation. They relied on both qualitative and quantitative data to inform their opinions. The nurses' reliance on qualitative data brought them into conflict with the neonatologist. One nurse explained:

Sometimes we have a meeting about a baby and we can voice our view on it and often we're shouted down in saying, 'But there's nothing wrong with the head'. Ultrasounds can only see so far. (Nurse 18)

There are problems associated with relying on quantitative data. Cranial ultrasounds are unable to detect all problems with the brain. Half all premature infants diagnosed with CP have normal NICU ultrasounds (Harrison 2002a, p. 1; Kitchen et al. 1990, p. 60). The nurses held firm to the belief that qualitative data about infant cues and behaviour was significant.

8.2.3 Left to care

The nurses worked with neonatologists who were adept with caring for families, yet they all spoke about being left to care for the family when the baby died, *'It's left to us'* (Nurse 19). The nurses became angry when they were left to care for the parents. Their anger was ignited because they had been excluded from the decision-making but were expected to manage the outcome. One nurse explained how she felt in this circumstance:

Angry. Not that I want to be there to make that final decision, but we're the ones that are left with the parents when the baby dies. We're the ones that have to comfort them, because the doctor doesn't hang around. (Nurse 21)

Anger is ignited in situations of unfairness, or when others behave irresponsibly and they are left to pick up the pieces (Thomas 2004, p. 6). It was the understanding of most nurses that care of the dying baby and its family was not considered important by some medical staff. One nurse stated, *'...the doctors... more or less aren't on the scene and*

we're left there. So it's us that the parents turn to' (Nurse 21). The resentment was obvious when one nurse explained, *'...we're completely excluded. But we're left there to pick up the pieces'* (Nurse 21). McHaffie and Fowlie (1996, p. 125) found the responsibility devolved to the nurses to manage the withdrawal of support and care of the family, yet they were often not involved in the discussions. Nurses can experience problems related to job performance and satisfaction, as jobs with high demand but little decision-making authority increases nurses' stress and emotional exhaustion, resulting in decreased work performance (Thomas 2004, p. 22). One nurse identified such stress:

If you're in other places [not nursing], you'd probably get the stress leave and time off after some of this experience... What we get is, 'Oh no, you have to turn up and come back and there's twice as much coming in.' So you turn around and cope with something else. (Nurse 9)

Conversely, being left to care could also be a positive experience for the nurses. The cleaning up after death, marks the end of the patient – nurse involvement. This cleaning up can be both physical and metaphorical, as the nurse removes the reminders of the baby's existence in the NICU, but not on them as a caring professional, and prepares for another admission. The cleaning up phase also helps to 'clean up' the grief so that the nurse can continue to function. It is the cleaning up phase that allows the nurse the opportunity to review the situation in a personal and professional manner (Maeve 1998, p. 1141). One of the respondents in Maeve (1998, p. 1141) stated "watching people die gives you a lot of courage".

The nurses all held caring and supporting the parents to be an important part of their job. They understood they were supporting parents through one of the most difficult situations they will ever face. They needed, however, to develop strategies to prevent the parents' situation from overwhelming them.

8.2.4 Summary

Problems of an ethical nature could be a source of tension between health professionals. Much of the conflict was between the medical and nursing staff. The nurses realised the importance of understanding the perspective of the medical staff, yet experienced difficulties. It could be that the key difference between doctors and nurses was that doctors made the decisions, while nurses had to live with the decisions (Oberle & Hughes 2001, p. 708). Doctors and nurses could benefit from engaging in discourse to understand the ethical burden carried by the other (Oberle & Hughes 2001, p. 708).

8.3 Anger and resentment

There were many experiences in the care of extremely premature babies that provoked anger and resentment in the nurses. This finding raises concern as there could be negative consequences for the nurses' health by harbouring anger. Mismanaged anger is associated with fatigue, depression, cardiovascular disease, hypertension, substance abuse, addictions and altered immune responses (Thomas 2004, p. 29-30). Frequent job related anger predisposes the nurse to burnout (Thomas 2004, p. 32).

8.3.1 Advocacy

The nurses were all committed to the belief that they were advocates for the baby and family. An advocate is one that argues for a cause, or one that pleads on behalf of another. The nurses took their self imposed role of patient advocate seriously, and with it sometimes came anger. This finding is confirmed by Archibald (2004, p. 55). Thomas (2004, p. 72) suggests, "...the gift of anger can enable nurses to risk advocacy for patients, lessening moral distress". Advocating in situations where they were unable to achieve results could ignite anger. One nurse stated, '*...in that situation, the nursing staff are just very, very angry, because they're trying to be an advocate for the child*' (Nurse 1). One nurse told of a baby who was hopelessly ill, and the parents had decided after

much soul searching to withdraw treatment. The consultant continued treatment because he had not heard this from the mother. The nurse explained:

The mum had made that decision and through his stubbornness or whatever, he [neonatologist] had decided to continue. Now ultimately that child died. His death was prolonged by another couple of weeks, but the child did die. (Nurse 3)

Anger and frustration was evident in many of the nurses' stories. Even after many years had elapsed anger and resentment seemed to simmer beneath the surface. Nurses in a focus group told of a colleague who advocated for a baby and became angry when her efforts were thwarted. This family had decided treatment should be withdrawn. The nurses agreed but the neonatologist did not. The focus group explained the powerlessness of their colleague:

She [the nurse] can no longer do what she wants to do [advocate] for the child, in the best interests of the child. (Nurse 1)

Well she [the nurse] does, but it's a bloody lost cause. (Nurse 3)

She [the nurse] does it, but it's a lost cause. And she's very angry and frustrated because she knows what the outcome is going to be, and feels that she has been let down by her peers, [medical staff] because they're not really following through the wishes of the family...What she knows is going to be best for that child, and ultimately that's what we want, the best for that child. (Nurse 3)

The role of advocate involved the nurses speaking for the baby and family. Advocacy meant they might be verbally challenged or castigated. When this happened they sought an alternate registrar or consultant to help with their problem. Seeking backup from other medical staff was not uncommon. Many nurses had a rapport with the consultants. One explained:

I have gone above a doctor. I have felt there have been times when it's been inappropriate to maintain this little life where the neonatologist would not make the decision, or discuss issues...child was obviously going to die. I consulted a second neonatologist and he then

voluntarily took it into his hands. There are times where you all wish we could ask someone else. Maybe we're not comfortable or not sure of who to ask. I think there are often times when we think maybe I should talk to someone else. This child deserves something better and their family deserves something better. They [baby] deserve a better ending. They [parents] have chosen to give up on this life. It's their decision and their child. The parents found a harmony with that second person, with their decisions and their child was allowed to die, the way they wanted the child to die. (Nurse 1)

Such an intervention could be seen as an act of courage by the nurses. Conversely, it could be considered a betrayal of the registrar or consultant. Whatever the perception, the nurses' desired effect was achieved. The nurses were all convinced they were morally obliged to do what was necessary, however, the professional ramifications might be heavy. The nurses all made it clear that regardless of the consequences for them, they would continue to advocate for a baby in this manner.

The nurses, in seeing themselves to be advocates were, however, unable to be advocates in the true sense of the word, because of the institutional constraints associated with their employment. Regardless, the role of advocate was taken seriously. When the nurses' attempts at advocacy were thwarted they became frustrated, but they were also resourceful. It seemed that a win-win situation was the goal. They were able to maintain their professional integrity and achieve the desired effect of treatment withdrawal in many instances. It was possible that their anger jolted the nurses out of passivity. The nurses might initially feel demeaned but were not totally powerless. An inability to effect resolution of situations resulting in anger and frustration can cause nurses to feel powerless. Powerlessness is a major cause of job dissatisfaction (Thomas 2004, p. 237). Valentine (2001, p.70) suggests nurses generally deal with conflict in five ways. These are avoiding (avoidance of the conflict), compromising (use of trading or bargaining), collaborating (being part of the decision making team), accommodating (incorporation of ideas) and competing (being in competition). Nurses in this study frequently used avoidance, suggesting crucial disputes were not resolved. It could mean the nurses prioritised problems, and avoided ones unlikely to be resolved to their satisfaction. These nurses chose when to be confrontational, or using an analogy, they chose their battles

carefully. They frequently used compromise to solve problems. This approach is not unusual. The nurses concentrated on the interests of others. They frequently collaborated with others and accommodated the ideas of others. Competition did not feature significantly in the problem-solving repertoire of the nurses.

8.3.2 Anger when the baby is suffering

The prolonged suffering of the baby triggered anger in all the nurses. One nurse explained:

When you know that child hasn't got a good chance, it makes you angry. We're prolonging the suffering. We're going to enable this child to survive so it can sit in a bean bag for the rest of its life ...How would you like it if you would never be able to recognise who your mother was, you don't know how to recognise yourself. You wouldn't be saying thank you very much to me, would you? You'd be cursing, if you could. If you were aware of what was going on, you'd be cursing me for the rest of your life. (Nurse 12)

The nurses were committed to the belief that discontinuation of treatment should occur when the baby was suffering. Loewy (1992, p. 139) has suggested that suffering be used as a basis for ethical decision-making, as an entity's ability to suffer gives it moral worth. The capacity to suffer 'distinguishes 'being alive' from 'having a life' (Loewy 1992, p. 139). The nurses were all convinced the baby could suffer, and this suffering provoked frustration in the nurses. One nurse stated, '*...sometimes the baby is suffering a lot. You don't like to just watch it suffer*' (Nurse 23). The resentment in this nurse was palpable as she spoke of watching a baby suffer. The nurses suffered in watching the baby suffer. When the nurses were powerless to intervene and prevent suffering they became angry and anxious. The relief of suffering was held by all the nurses to be part of their fundamental nursing role. When their attempts at intervention were thwarted they distanced themselves or retreated into themselves. In finding themselves to be angry the nurses were dealing with the often daily reality of awfulness, as they fought for humane care for the baby.

The nurses sometimes refused to care for a baby who caused them to experience ethical distress. This action was not uncommon. Refusal to care and taking a stand prevented the nurses from feeling powerless. One nurse stated:

I remember one baby...and she [nurse] just refused to look after it. She said so to the neonatologist. She said she couldn't agree with what was going on and she refused to look after that baby anymore. (Nurse 14)

This nurse could be said to be experiencing moral certainty, where she was absolutely committed to her moral/ethical belief that this baby should not suffer anymore. This nurse was certain about what should happen or what action she should take. Acting as she did could pose a professional risk for this nurse. Actions related to moral certainty generally are related to “speaking up, taking a stand, or refusing to participate...it entailed a lack of qualms and was described as ‘knowing the thing to do’. With moral certainty there was swift action, no doubt, and absolute conviction” (Wurzbach, 1999, p. 290). Here was a claim of conscientious objection. For claims of conscientious objection to be valid, there must be a distinctly moral motivation, as opposed to motives of self interest, prudence, convenience or prejudice (Johnstone 1994, p. 397). Refusing to care was the last resort for the nurses. They all genuinely believed, too, they would suffer by providing care. The nurses also recognised that if there was no alternative they would provide care to the baby. They also believed that a nurse who did not experience an ethical dilemma when caring for the baby, might provide better care.

The relationship between the nurses and parents sometimes became strained when there were differences in opinions about treatment withdrawal. One nurse explained, *‘...we’ve had the odd one die on the ventilator, just because the parents wouldn’t or couldn’t make the decision. We were very angry with them... you get an awful lot of anger when the parents won’t turn them off’* (Nurse 23). The nurses spoke of experiencing difficulty interacting with parents when they were angry. They attempted to hide their displaced anger. Anger is possibly a wasted emotion serving no useful purpose other than causing them to experience emotional distress. In these situations the nurses posed the

philosophical question, ‘...*Why am I doing this?*’ (Nurse 2). Nurses have been shown to position themselves as protectors of the babies (Fenwick, Barclay & Schmied 2000, p. 200; Lupton & Fenwick 2001, p. 1020), even safeguarding the baby from its parents (Fenwick, Barclay & Schmied 2000, p.200). The relationship could become adversarial (Savage 1997, p. 99), when an “us versus them dynamic has developed” (Kon 2006b, p. 8), suggesting the nurses believed only they knew what was right for the baby.

The nurses’ anger seemed to manifest itself when they saw no other options available for the baby other than the withdrawal of treatment. Desperation seemed to trigger anger.

One nurse explained:

This...makes nurses angry, because they can see that the child is actually being kept alive unnecessarily, and in pain and suffering unnecessarily, and it really should have treatment withdrawn. (Nurse 10)

The nurses could feel resentment towards the family, and one nurse stated, ‘...*it’s very frustrating. I think you feel sadness while you are looking after that baby...I think deep down a lot of nurses feel a little bit of resentment*’ (Nurse 5). There were times when the nurses perceived the family were considering their own needs rather than those of the baby. One nurse stated:

You almost think they’re [parents] not thinking about the wellbeing of their child. How many times have you heard people say ‘they’re just thinking about themselves, and they’re not really thinking about the...consequences are for this baby’?
(Nurse 5)

Another nurse stated:

It makes you so angry because people aren’t thinking of the child. They’re thinking of their own self. They don’t see the baby. We know what a normal 24-week baby does and what one that has a big IVH or a very ill 24 weeker does. You [nurse] can see things happening that people don’t understand. (Nurse 12)

It was not only the nurses who experienced anger. Mothers in a study by Lupton and Fenwick (2001, p. 1020) suppressed their anger and frustration at neonatal nurses' behaviour. The mothers believed expressing their anger could have a negative impact on their nursery experience. This suggests the mothers believed the care of their baby could be jeopardised. This shows that power relations exist. The nurses in the current study might be surprised by this finding. Lupton and Fenwick's (2001) research was carried out in a level II nurseries, not nurseries caring for extremely premature babies. The nurses acted as gate-keepers and controlled the mothers' access to their babies. The nurses had definite ideas about what constituted a 'good mother' (Lupton & Fenwick 2001, p. 1020). Unlike Lupton and Fenwick's (2001) research I saw no evidence of gate keeping. The nurses all spoke passionately of wanting the parents in the NICU. They did, however, have ideas about the 'good mother' and the 'good parents' as being those who took the advice to withdraw life support.

The nurses all understood the importance of parents spending time with their baby before he/she died. This requirement could mean a baby was kept alive longer than necessary. Yet, the nurses were troubled when they perceived a baby was, '*...in pain and suffering unnecessarily and it really should have treatment withdrawn*' (Nurse 10). The nurses were caught between the baby suffering, and the needs of the parents. For the nurses, '*...the dilemma is never solved until the baby dies*' (Nurse 19). They did, however, understand the parent's needs:

We have a lot of happy mothers and fathers who probably have never had a baby, that have been happy to have one [baby] for 12 hours or two days or three weeks, even though they've seen the writing on the wall. They've been happy to have that baby for that period. (Nurse 14)

The nurses emphasised that life support was not withdrawn before parents had come to the realisation that nothing more could be done. This realisation was important for the parents, and one nurse stated:

We've never actually withdrawn treatment until the parents are ready and they've decided that there's nothing else that can be possibly done. We've done everything. We've waited those extra few days, prayed for a miracle. It's not going to happen. (Nurse 20)

Some parents, according to the nurses, never came to this realisation, and the baby died on life support, instead of being held by its parents. The nurses all spoke of being saddened by this outcome. The nurses experienced difficulty understanding why parents would not permit their baby to die. Conversely, they understood that making this decision might overwhelm their coping mechanisms. These nurses experienced severe anxiety and had trouble balancing the needs of the parents with the needs of the baby. The needs of the baby were deemed to be more important by the nurses.

8.3.3 Feeling unappreciated as a neonatal nurse

Many of the nurses, at times, considered their efforts were unappreciated. They spoke of feeling like, '*...part of the furniture*' (Nurse 7), and being, '*...so totally overlooked and you're just taken for granted so much*' (Nurse 9). Three nurses in a focus group told a story of a NICU with no available beds and a mother in early premature labour. The nurses explained to the medical staff the unit lacked experienced staff and suggested the mother and unborn baby be moved to a hospital with an available NICU bed. The nurses became worried when they were unable to get the medical staff to listen. One nurse explained,

'Look, you're going to have to send this mother away before it [baby] delivers. We can't get any more staff.' To be told, 'You can just get any pair of hands will do'. I had a fight with that doctor that lasted two days, because I wouldn't talk to him. I just told him, 'If that's how you feel, we'll just leave now and you can stay here and do the job.' But just 'any pair of hands' will not do. That to me was so typical of how we are viewed generally. (Nurse 9)

The assumption of medical staff that nurses were able to make NICU staff materialise, meant the medical staff had little or no understanding of the staffing requirements of the NICU. The nurses were convinced the medical staff had little idea about their role, because being told, '*...any pair of hands will do*' (Nurse 9) signified a lack of understanding of the complexity of their role. One nurse explained the difficulty,

Even the doctors don't understand what we do. They just think we change nappies and we feed and we suction. They just see the actual physical things. They don't see or understand that it's much more and it's something that's really intangible, the caring side of things. They just feel that the caring is the physical, whereas it's emotional. It's things that can't be defined. (Nurse 12)

The nurses frequently felt resentment towards the medical staff in a range of situations. The role of the nurse was to ensure the NICU was safely staffed and all babies received optimal care. When medical staff accept admissions without considering the staffing needs of the NICU, it showed a lack of insight into the world of the nursing staff. It has traditionally been a nursing role, yet neither the nurses board and health authorities do not issue directives on who is responsible for safe staffing of the NICU.

8.3.4 Having the door slammed in your face

Anger was ignited in the nurses when their professional expertise was ignored or not welcomed. One nurse explained her resentment,

The nurse will be pushed into the background. The person caring for the baby is actually pushed out of the picture. They'll have these really deep and meaningful discussions with the physiotherapist and seek opinions and make changes ...The nurse will be standing behind...12 backs of doctors and physio and the nutritionist and anyone else. They're things that I find really offensive. (Nurse 7)

This described situation emphasises powerlessness, yet the nurse could have moved back into the middle of the discussion, thereby not accepting the position in the background that had been seemingly allocated.

The nurses spoke about wanting to take part in discussions about the management of babies, yet were not invited to be involved. One nurse described such an incident,

I indicated to the nurse looking after the baby to go with the consultant and the registrar while they discuss this, but they went into his office and closed the door. Obviously she was not invited, which I thought was a bit rude because she came back to me and she said, 'Well, he just closed the door on me.' (Nurse 15)

This nurse went to her colleagues and told them what had happened. She did not consider opening the door, entering the room and taking part in the discussion. In another account nurses in a focus group related a story about being denied access to a discussion. Two of the nurses were the baby's primary nurses, yet they were not invited to the discussion while many other people were. One of these nurses related the incident,

Dr, the parents, the relatives and we're going out to discuss the baby's progress. 'Oh' says I. I pushed my way in the door and there's parents and the social worker and as I went through the door, he said, 'This is not a cast of thousands, what are you here for?' I couldn't fit in the room anyway. I thought well, 'Stuff you. Get on with it.' (Nurse 21)

The nurses resented this exclusion. One nurse said it was, '*...like having a door slammed in your face*' (Nurse 23). Another said, '*...literally, those women [registrar and social worker] just got up and pushed the door shut in my face*' (Nurse 21). The anger that was generated in the nurses and subsequently in their colleagues lead to further conflict. This particular conflict remained unresolved. Demeaning and devaluing nurses can generate anger (Thomas 2004, p. 6) as seen in this situation.

For these nurses being excluded was as if they were invisible. In being invisible they did not exist in the eyes of the medical staff. If they did not exist they could not have

opinions, they were not members of the team, and they were not valued. Feeling invisible meant they were not heard or did not have a voice. Not being heard is a common anger-producing experience in nurses (Thomas 2004, p. 22). Feeling invisible and not valued has detrimental effects on professional self-esteem. More importantly, the care of the baby can be compromised especially if the nurses refuse to co-operate with the medical staff. In this situation the nurses did not feel completely powerless. They exercised their power through indicatives of, 'I told you so,' after the fact. The difficulty with this type of behaviour is that it represents a passive-aggressive stance, which by its very nature can only be a short-term solution.

8.3.5 Summary

Many situations around the care of babies of extreme prematurity provoked anger and frustration in the neonatal nurses. Conflict has negative connotations and, while some conflict can be a positive motivating force, most conflict faced by the nurses was of the negative type. The nurses spoke of being excluded from the discussions surrounding withdrawal of treatment, and such exclusion could have professional consequences.

8.4 The inner conflict of neonatal nurses

The nurses experienced conflictual emotions when they were providing care to a baby in circumstances that raised ethical dilemmas. Such dilemmas arose from their inability to alter the course of events. Many treatment decisions were a source of anxiety and distress for neonatal nurses. Their anxiety and distress could, at times, overwhelm them.

8.4.1 Hope

It was the understanding of the nurses that parents would hope and pray for a miracle. The nurses spoke of situations in which treatment was not withdrawn because the family were hoping for a miracle. One nurse explained:

It [baby] probably wouldn't even be able to do anything, and would probably be a baby for the rest of his life if he survived. And there was this mother saying, 'God will send me a miracle'. (Nurse 16)

The nurses understood that hope for a miracle was probably related to parental desperation and despair. Parents too, have been found to oscillate between hope and despair (Sallfors, Frash & Hallberg 2002, p. 495). Despair might trigger hopefulness, as people hope when facing significant negative events (Morse & Penrod 1999, p. 146). The determination to endure is part of the hope cycle (Morse & Doberneck 1995, p. 278). Hope involves a realistic assessment of the threat, the realisation of its severity and the implications for the person involved (Morse & Doberneck 1995, p. 278). Hope entails the envisioning of alternatives and setting of goals, while bracing for possible negative outcomes. If the assessment of threat is realistic, the negative outcomes are not ignored. The person will seek out supportive relationships, including family, friends and spiritual comfort. It is not uncommon for individuals to pray to get through a possible life altering event where the outcome is uncertain. This faith in divine intervention might increase the person's confidence in a positive outcome (Penrod 2001, p. 241). Praying for a miracle might be important for parents. The nurses all spoke of their frustration when parents prayed for a miracle. Perhaps the nurses did not understand that when the parents lost hope, they lost everything.

It was the experience of most nurses that parental hope was heightened when parents were given unrealistic expectations of what neonatology could offer tiny babies. These nurses had to temper this hope with the realism that the baby might not survive. This realism was explained by one of the nurses:

Especially if you've brought it [baby] around [from labour ward] and they've [parents] been hyped up by the obstetrician that the baby is going to survive, when you know that it's not necessarily going to be. You don't want to take away all their hopes, but at the same time you want to be a little bit realistic. (Nurse 17)

The nurses all knew it was unrealistic to believe every baby could be saved. There were suggestions that they felt they had failed when they were unable to live up to others' expectations of them. When the expectations of others were high, they had difficulty in tempering hope with reality.

The nurses were all convinced there were some parents who could not *'let-go'* (Nurse 12). They understood the ties that bind a family, but they could not understand the relentless pursuit of life by the parents. They wondered if the obligations created by loving and meaningful interactions, even in the short time their child has been in existence, were not easily relinquished (see footnote).

The nurses could all see that those who hope and pray for a miracle held deep religious beliefs. The nurses understood that hope was important for the parents. They might not have understood that for parents to admit a higher power was unable to provide a miracle might make them question their religious beliefs. This might be too confronting for parents at this time.

8.4.2 The myth of the miracle baby

The nurses were all critical of the unrealistic expectations, fostered through the media, for the survival and future capabilities of extremely premature babies. The nurses emphasised that, *'...society doesn't know what goes on behind closed doors'* (Nurse 19). They thought that the public did not know about NICUs and might believe all babies could be saved. It was the understanding of the nurses that, *'...the ordinary Mr and Mrs Joe don't know anything about a 23 weeker except what's in the magazines'* (Nurse 19). The nurses were convinced the media only broadcast good outcomes. They did not report on negatives, giving a false impression about the outcome of extreme prematurity.

One nurse explained:

see also Thomas & Latimer 1989, p. 391.

Usually they get the good stories. They rarely get the bad ones, because the bad ones people don't want to talk about it. Media stories are generally good ones, because they want feel-good stories. But rarely is a negative one shown... I think it's all of the really nice feel good stories is what they get. (Nurse 24)

The media's fostering of the miracle baby myth generated anger within the majority of nurses. They described how the media might do an initial story on a tiny baby, but rarely did they follow it up. The nurses examined these articles and their accompanying pictures and believed the baby's outcome was not as the story claimed. One nurse declared:

It really doesn't help when you get articles in the newspaper and in the magazines saying 'Miracle Baby! He was born at 5 months, perfect'. You look at the baby and you think, 'I don't think you're as perfect as what you say.' There's just that little sign that maybe it's a droop on the side of the face, or the way they're holding their hand and you know you're not as fine as what you're [media] making out that you are. (Nurse 12)

In addition, the media's portrayal of extremely premature babies was, for the nurses, *'...quite dangerous because people then expect every 24 weeker to survive and... be perfect and healthy, which we can't guarantee'* (Nurse 12). The nurses were all convinced the public obtained their ideas through television, newspapers, and magazines with headings such as, *'Miracle Baby 300 grams'* (Nurse 22). They knew that parents sought information from a variety of sources including the media. Bogdan et al (1982, p. 13) suggest parents view the mass media with, "...an eye to clues to how to understand their child".

Miracle baby headlines were problematic and one nurse stated, *'I sit and cringe'* (Nurse 11). Another nurse exclaimed, *'Oh God, don't you hate the magazines'* (Nurse 23). The nurses were convinced the stories fostered too much optimism and hope in the parents. This is in keeping with Schneiderman (2005, p.236) who confirms the media portray more optimistic survival rates than in the medical literature. Shivas (cited in Catlin 2005, p. 172) suggests that such optimism could prevent those who read magazine articles from evaluating the risks of death and disability associated with extreme prematurity. The

nurses in the current study thought parental optimism might prevent them from understanding the reality of care. A focus group commented:

I don't think they [parents] see they're putting them [baby] through anything. This is the 21st century, babies don't die. (Nurse 23)

We can work miracles. (Nurse 21)

The technology is there for them. (Nurse 23)

Put them in a crib [isolette] and it makes them well. (Nurse 21)

One nurse spoke of telling people she worked in an NICU. People generally replied with, *'Mmm, it must be lovely'* (Nurse 18). It troubled this nurse that the public, *'...never ask, 'Do babies die? They just assume that they all live'* (Nurse 18). Another nurse understood the public thinking, *'...well 'Joe Blogg's kid got through OK. Bit of medicine, they gave him everything'* (Nurse 24). The unrealistic portrayal of extremely premature babies meant, *'...they [the media] actually give a lot of hope to people, where there really isn't probably a lot of hope.'* (Nurse 16) This nurse spoke of a magazine that followed up a baby several times, and she was concerned because:

This baby is not doing as well as they make out that she's doing. They just sort of gloss over, 'Oh, yeah she's had a few learning problems or whatever.' They just gloss it all over. (Nurse 16)

Miracle baby stories meant the public, *'...don't see the heartache and everything behind it all,'* (Nurse 16), because *people don't tell their bad stories very much'* (Nurse 24). One nurse said:

Of course, the parents are going to say, 'Oh well, yes we wouldn't change it for the world.' I mean, are they going to say in those sort of women's magazines, 'Oh, no, we wish we'd never saved our child.' (Nurse 16)

The nurses noticed that when parents with an extremely premature baby in the NICU read about miracle babies they held onto such ideas. One nurse told of an incident where a mother came to the NICU with stories from magazines. She stated:

That mother used to come in and say to the neonatologist, ‘Oh I read this in this magazine and it’s really true’. And [the neonatologist] would say to her, ‘Well, I don’t know where you got your information, but that’s wrong.’ She was very blunt about it all.
(Nurse 16)

Such a mother might also be getting optimistic views from others, including family and friends, who had read articles. When an article appeared in a newspaper or magazine the nurses seemed to prepare themselves for questions about extreme prematurity. Miracle baby stories frustrated the nurses. The nurses all spoke of wanting the media to publish their version of the reality.

8.4.3 Unrealistic hopes of the obstetric staff

There were times when the nurses considered that obstetricians gave too much or too little hope to expectant couples. Obstetricians could also choose to intervene, or not intervene when a woman was experiencing extremely preterm labour. One nurse told spoke of a mother who was labouring at 23 weeks gestation,

Her obstetrician told her there was absolutely nothing she could do...just basically transferring her [to a perinatal centre] because the staff were hassling for him to do so.
(Nurse 19)

This mother had been told the baby would die. She had not been given any steroids to enhance fetal lung development or any measures to suppress the labour. The baby, ‘...*came out full blown labour, pop!*’ (Nurse 19). This was distressing for the nurse, she realised the chances of saving a baby so immature were virtually zero, yet she knew that suppressing the labour and keeping, ‘...*the baby there [uterus] for three more weeks, that’s something better to deal with*’ (Nurse 19). The nurses all spoke about obstetricians

who they considered too optimistic about the capabilities of the NICU. The optimistic obstetrician will tell parents, *'Oh, NICU is wonderful...23 weeker, everything will be fine. Here is the best'* (Nurse 19). This optimism, according to one nurse:

It irritates me. You go into delivery suite...it's only 23/24 weeks and the obstetrician is telling the mother how good you are. How good you are!!! 'Here is the best person that can be here at your delivery. She'll do everything for your baby and everything will be fine.' I think 'Shit!' (Nurse 19)

Obstetricians attend refresher courses and would be familiar with the data on outcomes of extreme prematurity. It was confusing for the nurses when some obstetricians wanted them at the delivery, whereas, *'...others wouldn't want you there at all, would like you as far away as possible'* (Nurse 17). There could be tension between consultants because, *'...the neonatologists think they are obliged to be there, especially for a 25 weeker'* (Nurse 17). Midwives in the obstetric unit could also have unrealistic expectations. One nurse stated:

If obstetric staff [midwives] worked in the Nursery and saw the weeks and months of battling with a 23 weeker, they might not be quite as keen and eager to do what they do. It's just pass it along. It dies around here, not around there. Like pass it along, not my problem. (Nurse 19)

This was ironic because when there was continued care given to a baby, the baby sometimes physically outgrew the NICU beds. The baby was then admitted to the children's ward.

When it gets to certain times, they get a big cot. We took them down to Children's Ward. We passed the buck along. So it doesn't stop with us really does it? (Nurse 19)

The nurses felt guilty about passing on a disabled child, but it meant they no longer had to experience the baby's existence as an ethical dilemma.

8.4.4 When caring and torture are the same thing

Extremely premature babies require intensive and extensive treatment. A point was reached when the nurses could no longer justify performing procedures on a baby. They came to believe their efforts to care for the baby were like torture of the baby. Nurses in a study by Gill (2005, p.262) believed at times “treatment is tantamount to torture”, while a nurse in Catlin’s (2006, p.744) study stated “I frequently felt we were torturing the child just doing daily care”. The nurses in the current study had to perform procedures on the babies that caused the nurses distress, as did the nurses in Archibald’s (2004, p.55) study. The procedures included multiple heel lancements for blood for diagnostic purposes. The nurses began to fear performing repeated procedures on the baby. One nurse explained:

It concerns us a lot, too. Those babies are still going to need reintubating with a tube. They’re still going to need some long lines replacing...blood taken. No one wants to torture a baby just for no good reason because it’s going to be a futile outcome. (Nurse 20)

Another nurse spoke of her difficulty:

All those body systems that aren’t developed that means they’re going to have so much intensive treatment to get them through. They’re going to go through so much pain and their parents are going to suffer along with them. It’s going to be, I think, agonising for them. (Nurse 17)

The nurses considered that at times they were torturing the baby, yet they understood the parents needed time to come to terms with the inevitable death of a baby:

That’s what it’s like, isn’t it? It’s like torture you think the baby is going through. If it’s from a parent’s perspective, the parents aren’t quite ready to stop..., and so you continue for a few more days..., I know it’s really cruel and really tortuous. (Nurse 19)

The nurses all held strong beliefs about what should happen when they believed the baby was being tortured. One nurse stated:

What you have to remember deep down...you are pulling this tube [ETT] out because being dead has to be better than being alive. That's how it evens up. Being dead has to be more pain free, peaceful, than what we're actually doing. It's cruel. With no chance of anything being anywhere near normal. (Nurse 19)

It was overwhelming for the nurses to feel they were hurting the baby. For these nurses, their part in torture was anathema to how they perceived their role as a nurse. Torturing the baby was, they believed, unacceptable and a personal agony. They could not reconcile their role of carer with acts of torture. In finding themselves to be torturers the nurses were dealing with the reality of awfulness. Questions arise about the effects on a nurse when a carer becomes a torturer.

8.4.5 Taking matters into your own hands

There were times when the nurses considered taking matters into their own hands and helping a baby die. This was the result of having to perform procedures on a baby, who they believed was not deriving any benefit from remaining alive. One nurse spoke of her inner turmoil:

It is frustrating because we're coming into work, we're putting all this in, we're trying to do things. Especially if you have to resuscitate them a few times. You're doing cardiac massage and you're thinking, 'What are we doing this for?' But you know that's what you have to do. Then you think, 'Well, why should we do this?' (Nurse 16)

The nurses all experienced high anxiety in these instances when they did not want to keep treating the baby. One nurse stated, '*...maybe we should just say 'This baby has gone. There's nothing we can do about it.' You feel like pulling out the tube yourself'*' (Nurse 16). Another nurse emphasized, '*I think we should be able to say as nurses that we don't agree with this and we don't want to have a part of it'*' (Nurse 17). Clearly, the nurses

experienced profound moral distress. They were in turmoil because, '*...even though you are sedating them, you wonder how much suffering they're going through*' (Nurse 18).

Painful procedures could be justified while there was a chance of a positive outcome, but when, '*...there is little chance of the baby surviving, why do we do these things to them?... It's cruel. It's heart rending*' (Nurse 21). The nurses struggled with performing procedures when they saw, '*...the grimacing and the drawing away, and still we do terrible things to them*' (Nurse 23). The inner dialogue of one nurse revealed rationalised thinking:

I guess I compensate a lot by thinking, 'Well they're probably brain dead anyway'. Well, I guess, I just keep telling myself, you hope that they're brain dead. (Nurse 23)

The moral distress about a baby's existence could be so awful that several nurses had thoughts about ending the baby's suffering. One nurse explained:

You just feel like sometimes going in and pulling the tube yourself or accidentally, which is really awful when you think about it. You just want to end it for the poor baby and for the parents, because they're suffering. (Nurse 16)

Most nurses had momentarily considered helping a baby die. They were very clear that they had never attempted to relieve a baby's suffering by shortening its life, but they emphasised they were tempted out of pity for the baby and parents. Here, the nurses were showing compassion towards the baby. Compassion implies sensitivity to another's suffering, and the subsequent desire to relieve that suffering (Raholm & Lindholm 1999, p. 530). One nurse spoke of the temptation:

I know this seems terrible. I was looking after a baby who was withdrawn from care, and she seemed to have stopped breathing and then she would gasp...I almost considered putting something over her face, because it had just gone on for days, and I just felt so sorry. Young mum and dad, and I thought, 'This has to end'. I mean I didn't, but every

gasp. The parents...they knew there was no hope and I just wanted it to be over for them. It was really tempting. (Nurse 21)

Another nurse suggested it would be easy to put a baby out of its misery by using, '*...a whole syringe full of morphine*' (Nurse 23) and they described their imaginings,

You think, 'Oh could I have tripped over the tubing [ventilator tubing] or something.' [laughs]. You talk about that sort of thing, but I don't think any of us could actually do it. (Nurse 24)

There was a sense of desperation when the nurses were convinced a baby should be allowed to die. This desperation was about powerlessness. The nurses considered themselves so powerless they gave thought, if only briefly, to taking matters into their own hands to end the baby's suffering. What is more revealing, in order to get to this stage of desperation suggests there is something in nursing and the NICU environment that needs immediate attention. The major source of moral distress for the nurses was knowing their role was one of relieving pain and suffering, yet, conversely they knew it was illegal to intentionally take another human life. The overwhelming conflict could result in distancing and avoidance behaviours.

8.4.6 Summary

There was much inner turmoil, anger and frustration for the nurses when they cared for extremely premature babies. Society's belief in the miracle baby and the media's fostering of unrealistic expectations of NIC was a source of frustration for all the nurses. Obstetricians could also have unrealistic expectation of the NICU and its staff. The nurses understood that the parents hoping for a miracle was about desperation and despair.

Constant anxiety and distress inner were experienced by the nurses as they grappled with their caregiving dilemmas. There were times when they believed the baby was being

subjected to unbearable pain, likened to torture, during caregiving. At times the nurses seemed paralysed by their inability to allow the baby to die.

8.5 Communication failure

Truth can be defined as accuracy, honesty, and integrity. Truth is often thought of as not black and white, but having shades of grey. If parents are to make informed decisions they need to be told the truth. While fidelity (accuracy) and veracity (truthfulness) are bioethical ideals, the nurses experienced difficulties with how much information constituted the truth. It was the experience of all the nurses that parents might be told the truth, yet omissions meant it was not the whole truth.

8.5.1 The art of communication

The nurses all held communication with families was important. A good relationship between the nurses and parents was considered essential. The nurses may not have fully realised how crucial these relationships were, in light of findings that the mother's relationship with the nurse is the single most important influence on her ability to mother her child following discharge from NICU (Fenwick, Barclay & Schmied 2000 p. 201). The way professionals communicate with parents affects the quality of the relationship, as trust and respect are earned during this time (Ahmann & Lawrence 1999, p. 221). The relationship between staff and parents needs consideration as Reid, Bramwell, Booth and Weindling (2007, p.72) report communication difficulties in the NICU, and Claasen (2000, p. 192) found families experienced relationships with health care providers that did not match the professionals perceptions.

The nurses all applauded consultants who were excellent in their in their communication with both nurses and parents. At times the nurses worked with consultants who had poor communication skills. These consultants could interact with the nurses, but not the parents. One nurse spoke about such neonatologists:

The parents are usually filled in fairly well. It mightn't be as tactful with certain ones or as clear. Some spread garbage...just mumble away and run out the door. Others they spend time and talk. (Nurse 18)

The inadequate communication skills of the medical staff could be a source of concern for the nurses and a source of conflict between the parents, nurses and medical staff. One nurse spoke of such difficulties:

Being very short with them [the parents], not explaining...in too much of a rush. Talking to the parents is put across as being a bit of an effort. Some people don't realise how they come across. (Nurse 18)

Another nurse related an incident between a consultant and a father.

I think he's [the father] still quite angry at the consultant for the way that she'd been speaking to him. She'll [consultant] speak to us face to face and make a lot of eye contact with us, but with the parents, she'll look to the supporting nurse or she'll look up and down the corridor. She won't make a lot of eye contact with the parents. (Nurse 15)

The nurses classified doctors as either "good or bad" on the basis of their ability to talk to parents (Bogdan et al. 1982, p. 11). From the nurse's perspective good doctors are straightforward, they ensure the parents understand, and they use non-technical language. Bad doctors by comparison are less than straightforward. They fail to make sure parents understand their baby's condition, they do not take extra time, and do not tell the nurses what they have told the parents.

For all the nurses communication between the medical staff and parents was important and the language used was thought to be equally important. One nurse stated, '*...I think doctors don't tend to bring it down to the same level as the parents understand. They don't make it into simple language*' (Nurse 24). The nurses saw that some parents were able to understand the issues involved because they were educated but other parents were not as educated.

They [parents] don't have a lot of medical training and they need to have it as honestly in non-medical terms as possible. Even if you do have some medical background, you often need to have it put in layman's terms, so that you really do appreciate what's going on. (Nurse 24)

The nurses were all consistently passionate that parents were entitled to information about their baby's condition. They understood how important information was for parents. The nurses talked about the need to interpret for the parents following a meeting with the medical staff. After such a meeting one nurse stated, '*...usually I just say 'Look did you understand what they said?' And if they say 'No', and I'll go through it. It's not always an ideal situation'*' (Nurse 18).

Those medical staff who attended the follow up clinic and saw the results of the NICU treatment were admired and respected by the nurses.

The consultant who actually goes to the follow up, she's much more in tune with what these children's prognoses are. She has the history of the child and then when she tests them, she knows, yes, that's as a result. The other three [consultants] I don't think they see it. She had a meeting with the parents and said, 'This child is going to be severely disabled.' I read her notes, she outlined everything. Two other consultants were handing over to each other and one of them...said, 'Yeah, but I think she was very pessimistic in her approach.' I'm thinking, 'Well she sees what's going on. You don't. She sees the results of what happens in here, so maybe she had every right. Where are you coming from to say that she was pessimistic?' (Nurse 12)

Several nurses thought some consultants were too optimistic about the prognosis and outcomes when they spoke to the parents. It was not that the neonatologist was not telling the truth but it was, as one of the nurses suggested, '*I think they're not totally truthful by omission of what the outcomes could be'*' (Nurse 17). The same nurse explained:

Sometimes [doctors] paint a rosy picture, probably to the detriment of the baby and the parents. Not really saying how hard...to keep the baby alive at that gestation and how hard it will be for them emotionally watching all of this happen. (Nurse 17)

The nurses were convinced they had a role in illuminating the truth for the parents. The nurses might have been correct in their estimation. Parents in a study by Wocial (2000, p. 81) perceived information was truthful when it was, "...up front" and not, "...sugar coated", while mothers in a study by Raines (1999, p. 38) preferred clinicians who were able to, "...talk the truth". Communication with parents can suffer when euphemistic language is used. Parents in a study by McHaffie (2001, p.87) voiced their need for the unvarnished truth. If parents perceive clinicians hiding information, it could be, "...very hard to trust the people that were involved" (Snowdon, Elbourne & Garcia 1998, p. 159).

8.5.2 The truth is never black and white

The nurses considered honesty to be extremely important. For them, honesty implied truthfulness, while dishonesty meant a lack of truthfulness or integrity. One nurse explained:

Honesty would have to be up there as being one of the most important priorities. After all...we are dealing with a tiny life and it behoves the specialists and the neonatal nurses to abide by that principle. (Nurse 10)

The nurses all understood that if parents were to choose between options, they needed an honest appraisal of those options. There were situations where a consultant disguised the outcomes, or, '*...they just gloss it all over*' (Nurse 16).

It was the belief of all the nurses that parents needed the truth to make informed decisions. Several wondered about the honesty of some neonatologists. Honesty was not a black and white issue, there were many factors to consider. There was no suggestion that neonatologists lied to parents. There were shades of grey in terms of how

information was given. Several nurses thought that neonatologists erred on the side of caution when speaking to parents.

I suppose they [neonatologists] don't want to be seen to be wrong when things change. Some babies have remarkable recoveries. If they're talking doom and gloom and then suddenly the baby improves, they'll be seen to be less than what they hope to be seen as. I suppose they're erring on the side of caution. (Nurse 14)

In such circumstances there seemed to be a certain amount of desperation in the nurses for wanting the parents to know the likely outcomes. It was a fundamental belief of all the nurses that parents have the right to be informed of all aspects of the baby's treatment and the probable outcomes. It was not uncommon for parents to ask the nurses if the NICU had, '*...any successes. How do other babies go*' (Nurse 18). The nurses all remained committed to their belief that they must be honest with parents. One nurse explained:

I tell them the truth. I say, 'They can go along quite nicely for a little while and then they'll go backwards.' I try not to hide anything from them. I say, 'It's going to be a long haul.' I think you've got to tell them that it's not going to be smooth, so they half expect the baby to get sick once or twice or even three times down the track. (Nurse 18)

The nurses maintained that information was essential for decision-making. They emphasised there were ways to give sensitive information to the parents. Sometimes the truth, as suggested by the nurses, '*...is in the telling*' (Nurse 19), rather than the actual words used. Being blunt for example, could have negative consequences,

You can become blunt and if you're really blunt then what happens is you end up hating that person that's told you, and they start screaming at you. But if you phrase it differently, maybe they're more accepting. (Nurse 12)

It became clear that what the staff told the parents might not be exactly what the parents heard. This observation is confirmed by Bogdan et al (1982, p. 13) who found that

although the medical staff stated we “are completely honest”, and the nurses stated “everything” when asked what was told to the parents about their child’s condition. When the researchers spoke to the parents about what the “hospital staff thought they said to parents was often not what parents heard” (Bogdan et al. 1982, p. 13). Micommunication has been noted to be a serious problem in the NICU (Thomas, Sherwood, Mulhollem, Sexton and Helmreich 2004, p. 556). This surely has ethical and legal implications especially as poor communication has been linked to patient complaints and malpractice claims (Brinkman, Geraghty, Lanphear, Khoury, Gonzales del Ray, DeWitt & Britto 2006, p. 1372).

The nurses were all convinced that hearing bad news was awful for parents. They spoke of situations where bad news had been imparted to the parents but they did not seem to hear. The nurses said this occurred because, ‘*...the parents are extremely emotionally distressed, they often forget a large proportion of what’s actually been said to them*’ (Nurse 10). One nurse added:

There are the odd parent for whom even simple explanations are just too overwhelming with everything else that they have to deal with at the time. (Nurse 10)

The nurses told too, of parents who seemed to focus on the information they wanted to hear. These parents selectively filtered out the information that was unpleasant for them to hear, because it brought them face to face with facts they would rather not face up to. Pinch and Spielman (1990) found that parents had little understanding of the medical problems of their babies. It could be assumed the parents were not given adequate information, yet documentation existed in the hospital records that substantiated that information sharing occurred. There was discrepancy between what the parents had been told, and what they remembered (Pinch & Spielman 1990, p. 712). King (1992, p. 20) emphasised the important link between information disclosure and parental understanding.

The nurses experienced a dilemma when the parents had been told the likely outcome, yet did not seem to grasp the serious nature of their baby's condition. These parents were seen as not hearing what has been told to them. The nurses desperately wanted the parents to know and understand what was happening to their baby. It is likely that the parents were experiencing the psychological state of denial (Bogdan et al. 1982, p. 10). Schlomann and Fister (1995, p. 246) found parents clearly understood the serious nature of their child's condition, but experienced tension between hope for the child's survival and the ramifications of the child's survival.

A "temporal gap" has been described where parents need time to assimilate information in detail (Ward 2005, p. 31). Parents are being asked to, "...think clearly enough to make decisions they will have to live with for the rest of their lives" (Claasen 2000, p. 190). It is understandable that parents do not want to, or are unable to, make decisions because, "...parents feel the burden of deciding the impossible" (Claasen 2000, p. 193). Anderson and Hall (1995, p. 15) sum it up when they suggest the decisions faced by families are the, "...stuff of nightmares".

Although the nurses wanted parents to understand the message they were trying to convey, they understood parents would protect themselves from the harshness of reality. This understanding is confirmed with statements such as, '*I don't think sometimes it matters how honest you are, the parents want to hear what they want to hear*' (Nurse 19), and, '*...they [parents] don't even hear what the possibilities are going to be at the end of the day*' (Nurse 9).

The nurses spoke too, of times when the parents seemed to '*switch off*' (Nurse 12). One nurse spoke of a situation:

They'll [medical staff] come back in and you say, 'Well, how did that go? 'I've got no idea'. 'They [parents] just sat there blank look. Mum turned off after the first sentence or Dad did all the speaking, Mum didn't say anything'. (Nurse 19)

These were situations when the nurses thought the information should be imparted in a different manner, leaving out words that helped soften the blow of the impact of the information. In the previous example the neonatologist went back and spoke to the parents, and came back into the NICU and said, *'I think they know what we're saying now, because I've left Mum and Dad in tears'* (Nurse 19). The nurses knew that finally the parents were, *'...at that point they figure that the things aren't very good'* (Nurse 19). This communication with parents is clearly not ideal.

Another nurse told a different story about how telling the truth was helpful,

We had a baby recently where he'd gone through so much. The parents were finally talked to in such a way ... 'Do you want to have this baby, deaf, blind, broken arms, legs, everything else? Do you want to take him home?' And the parents said, 'No, he's had enough, let him go'. (Nurse 9)

The nurses had learned that where the neonatologist imparted information to the parents was an indication of what would be discussed.

If they [neonatologist] come out of the unit to talk to the parents, you know it's talking about discontinuing treatment. If they sit with the parents at the bedside or looking at head ultrasounds, you know they're going to tell them bad news. They're not going to tell them, 'We're discontinuing treatment'. When they come out of the unit, talk the parents out here, it doesn't matter how the telling is, the outcome is the same. They're aiming for discontinuing the treatment. (Nurse 19)

The nurses' thoughts were confirmed when they watched where the consultant took the parents to impart information. They knew that withdrawal of life support might be on the agenda

There was a pattern of communication with parents in the NICU that can be described as honest at best, but unsubtle and brutal at worst. The brutal approach was coercive with

information giving designed to change the parents' thinking and behaviour.

Communication with staff can have lasting effects on parents, as parents remember these encounters vividly.

8.5.3 Upfront and honest

Several nurses pondered on truth, misrepresentation and dishonesty. They wondered if there was a major difference between information omission and lying, or if such acts meant parents were not given the information they needed to make decisions? They spoke of their frustration when they could see medical staff were not totally honest or truthful with the parents. Even if the medical staff had not lied the parents were led to believe a different reality. One nurse explained her concern:

The frustration is when you've got a really sick baby, trying to get decisions... confirming that this baby is not going to have a good outcome... You're looking after a baby who is blind, whose brain is nearly all gone, who's got multiple deformities and doctors saying, 'Oh, no, there might be a chance.' But never saying, 'Yes, but the chance is that you're going to have a very deformed baby at the end'. And holding that into yourself at the same time as trying to be positive looking after the child in that state is frustration in its extreme. (Nurse 9)

The nurses experienced frustration when everyone seemed to know the truth about the baby except the parents. One nurse explained this difficulty:

I've been there when the doctors were talking to them [parents] on several occasions, and they [medical staff] were still telling these parents there was still a chance. At no time did they say that they thought it was time to let him go. It was still being talked about that there was a chance. (Nurse 9)

It is interesting that several nurses suggested there were times when everyone knew the truth except the parents. Philosophically truth is a concept difficult to define. The issue could be more about what might be truth at a given point in time. If considering a truth

and time continuum, truth can be different at a given point in time. That which could be true for a baby today can differ tomorrow. Extremely premature babies are subjected to many diagnostic tests, the results of which add more information to the true situation as it relates to the baby. The results may be objective but the ramifications are subjective and, due to uncertainty, is neither relative or absolute. The reality is that it is not possible to be clear about the prognosis in the early stages because so much uncertainty exists. Only over time and weeks and months have elapsed and the baby for example has failed its hearing test, developed ROP and shows signs of CP or neurological problems, does the outcome become obvious.

The calibre of information given by medical staff was a source of concern for several nurses.

You just have to wonder how honest and upfront they are with some of these parents, because I think a lot of the times they don't get time to sit down with them. (Nurse 7)

The nurses all found it intolerable if they thought parents were not being told the truth. Several nurses had taken steps to direct parents to obtain information. They had given parents literature, referred them to internet sites or suggested they visit the medical library. Giving parents options represented a win-win situation for the nurses. The parents obtained much needed information and the nurses rid themselves of guilt. They were happy if they knew parents had the opportunity to access appropriate information. Their motivation suggested they expected honesty and would find ways to help parents become informed.

The written communication of the medical staff could be a source of concern at times. The nurses discussed the reluctance of some medical staff to document meetings in the patient's continuation notes. They believed that the outcomes of meetings with families should be documented in the patients' continuation notes. One nurse stated that, *'...it should be written so that everybody is consistent and so when the final decision comes,*

the parents are still getting consistent information' (Nurse 8). The nurses all emphasised that all staff would benefit from knowing what the parents had been told.

If you felt a bit uneasy about something...it's there in black and white, it might make it easier for the nurses involved. A lot of things are said and not written down and nurses like to see it in black and white. (Nurse 24)

Fowlie, Delahunty and Tarnow-Mordi (1998, p. 63) found less than half of neonatologists documented their discussions with parents of sick premature infants. Discussions were more likely to be documented in the notes of sicker babies. The poor documentation of consultants was also discussed by McHaffie and Fowlie (1996, p. 125) and Abe, Catlin and Mihara (2001, p. 141). One nurse spoke of a baby who had been in the NICU for a week and a half. The nurses had tried to get the medical staff to sit down and discuss the baby with the parents. This situation was current at the time of interview and, *'...they're still yet to do that. I don't know why they don't do it'* (Nurse 7). The nurses were convinced that communication skills were fundamental when working with babies and families. Poor communication skills could lead to parents receiving messages the medical staff might not have intended. One nurse stated, *'...there's a lot of communication breakdown between various people like the parents, the doctors, the nurses'* (Nurse 7).

The nurses understood that honesty was essential because it enabled parents to, *'...know what they could be letting themselves in for'* (Nurse 24). They emphasised that if medical staff were honest at the beginning, *'...when the time comes, if there needs to be a decision to pull out, they've already had education towards it'* (Nurse 24). There were situations when parents did not realise the possible outcome until it was too late. The nurses spoke of parents harbouring resentment towards the staff and as recounted by one nurse, *'...this mother was very, very, very angry for years'* (Nurse 14). Another nurse suggested:

Those parents are going to be the ones that are going to be left with a kid that could be damaged. If they weren't given the right to say, 'Alright stop' early on, who are they going to blame? It's going to be us. (Nurse 18)

Another nurse related a situation where she believed the medical staff were not completely honest with the parents and they suffered as a consequence.

[The baby] had very little brain function. They [doctors] knew he was completely blind. His rickets were so bad, he had broken legs, broken arms. He had lungs that were not even functioning...he was so nearly dead, that you'd have to resuscitate him several times every day. (Nurse 9)

When the medical staff spoke to the parents they said, '*oh yes, your baby is still very sick but there's still a chance*' (Nurse 9). This approach caused severe distress in the nursing staff because the baby was,

150 days old, he's still totally dependent on CPAP, [continuous positive airway pressure]. If you took the CPAP off he'd die in 10 minutes. They were still telling these parents there was still a chance. (Nurse 9)

The situation continued for several months. The nurse recalled:

I'd heard it [chance of good outcome] go from 30%, to 10%, but they were still saying 1% chance, and giving these parents some reason to think that there was some reason to keep this child going. (Nurse 9)

This nurse's distress arose because the parents were not given a realistic appraisal of the baby's chance of survival and outcome. This nurse expressed concern for the parents, '*...they feel it's going to be fine. The baby is going to be okay, and you think, 'Woah'*' (Nurse 9). The parents' situation touched this nurse:

You just feel so much empathy and sympathy for that family that they've not been given the facts. It's certainly a situation that nurses should not have to tolerate. (Nurse 5)

Truth telling or veracity was fundamental to the relationship between the medical staff and parents. The nurses became angry when parents were led to believe that there were

reasons to continue treatment. Moral conflicts between nurses and doctors generally centre around truth telling (Maeve 1998, p. 1140). One nurse in the current study explained:

Still talked [doctor] that there was a chance and that he [baby] might be quite handicapped, but they still had a chance of having a living child. They never really clearly stated just how severely handicapped that child would be. We can understand it, but it was never clear. Very rarely do the doctors really spell it out. (Nurse 9)

The nurses thought the way information was given could be a factor in the reality debate because, according to one nurse, '*...they [medical staff] use nice words to make it sound nice. Because this parent wants a baby*' (Nurse 9). Perhaps the real reason is as suggested by Gill (2005, p. 268) that "doctors do not like bearing bad news any more than the rest of us".

Several nurses had, on occasion, considered giving the parents a more realistic portrayal of the situation, however, they remained loyal to their medical colleagues. One nurse explained her dilemma:

If the doctor tells you that you've got a good chance, then if the nurse comes and says 'Well, you know it's a long way and there's a lot of problems to face yet'. 'Oh, but the doctor said ..' You don't want to disagree with the doctor. You don't want to make the parents feel that the doctors don't know. (Nurse 9)

The distress was often great for the nurses, and one nurse stated they, '*...don't feel like you're of any worth*' (Nurse 17) to the parents. It was however more distressing when a nurse believed that nurses had a right to be open and honest with parents.

You are entitled to tell parents what's happening to their child. You've got every right to, and they have every right to be informed of what is going on. (Nurse 17)

In speaking of situations where parents were shielded from the truth the nurses argued that parents, as the legal guardians of their babies, were entitled to the truth. One nurse observed:

No matter what we think personally, or what we think the family can tolerate, we have to be upfront and honest. Apart from the moral issue, these days there's a legal issue there. People expect to be told. (Nurse 5)

The nurses call continued to state that parents should always be told the truth, unless '*...telling the truth may be harmful to those parents, so then you've got to weigh up the pros and cons*' (Nurse 16). The nurses need to understand that deciding what would be harmful to parents and making judgements about the level of truth parents could handle, means the staff would be acting paternalistically towards the parents. Decision making cannot be informed when the staff are not completely honest with the parents.

In grappling with the difference between honesty, truthfulness and lack of truth, three nurses in a focus group attempted to define.

I don't think it's a lack of honesty, I think it's a lack of truth. (Nurse 1)

Isn't honesty and truthfulness the same thing? (Nurse 2)

No. I think there's a difference between honesty, and therefore dishonesty, and not giving them every bit of truthful information. To me if someone is not honest with me, I take it to mean that they're being dishonest and they're in fact telling a lie. (Nurse 1)

Untruthful? (Nurse 2)

Where someone who is a neonatologist and in the position of giving them information is perhaps just not giving them 100% of the situation, but perhaps 75% of the situation. (Nurse 1)

It was interesting that the nurses perceived the issue to be about truth and honesty. It is probable that the medical staff would perceive it to be an issue about uncertainty. There are many variables associated with extreme prematurity and medical staff would have to disclose the uncertainty in the talk with parents. Katz (1984, p. 35) suggests that

physicians will acknowledge uncertainty only when its presence is forced into their conscious awareness and they will continue to practice as if the uncertainty does not exist. Some physicians will not discuss the uncertainties associated with treatment because they, "...had learned that patients neither wish to nor can engage in such conversations" (Katz 1984, p. 36).

The nurses were all convinced that for some medical staff telling parents that their baby would die as too difficult.

They [the medical staff] will say every word but die. The parent will always say to you, 'Is my baby going to be alright?' I cannot bring myself to say, 'Yes' or even a, 'Maybe' if the baby is going to die. I say to them, 'It is unlikely your baby is going to do well. I believe your baby will die.' I say the word and then you'll get tears and everything. At least you've said it and you know they do know. If you beat around the bush like a lot of the doctors do, they never come to that terminology. (Nurse 11)

The nurses believed that some medical staff, *'...have a problem with not being successful and they can't bring themselves to say it [that a baby will die]'* (Nurse 11), whereas they stressed, *'...most nurses can actually bring themselves to say it [that a baby will die] and I think the parents appreciate being told the truth'* (Nurse 11). Perhaps the explanation was related to expectations of treatment, *'...you don't like for the baby to die, but I don't feel like it's my failure, whereas they [medical staff] feel like they've been a failure'* (Nurse 11). For the nurses, death was not always a failure. In many situations, death was seen by the nurses as a blessing. This could be one of the significant differences between the medical and nursing staff.

8.5.4 Summary

Communication between the staff and parents was considered important by the nurses. Honesty was considered to be an ethical imperative. The nurses all wanted the parents to be told the truth, but the subjective nature of truth meant it could change frequently. The nurses were concerned when they perceived parents did not have the information they

needed to be involved in decision-making. At times, parents were given information but they were unable to grasp the seriousness of their baby's situation. The way that staff and parents communicate needs exploration and a possible overhaul because at times it seemed that distrust, suspicion and poor communication were endemic in the NICU.

8.6 Families in conflict

The birth of an extremely premature baby is a crisis situation for the parents, making them emotionally vulnerable. Parents of extremely premature babies can experience conflict during the long hospitalisation of their baby. Experiencing conflict when they are already in crisis could have serious ramifications for the family unit. The family unit could be irreparably damaged.

8.6.1 Stress of hospitalisation

The NICU was a cluttered, claustrophobic environment where parents spent extended periods of time. During hospitalisation, parents might encounter conflict with their partner or extended family. The nurses understood that the stressors on the family were extensive, *'I think we forget where the stresses actually start and end. I don't think we know where they start'* (Nurse 2). One factor that contributed to the stress experienced by parents was thought to be related to different ways of coping with problems.

Once, when we partnered with people who came from the same village, then our beliefs, expectations, behaviours would be similar given certain circumstances. Now we partner with people of different nationalities, different religions, and the different approaches to the problems raised by being parents of a 24 weaker can cause conflict. (Nurse 6)

It was difficult to know all the reasons why parents experienced conflict. One nurse suggested parental conflict occurred because there was, *'...altered expectations between partners...differences between how the mother and the father cope with the NICU experience and being a parent'* (Nurse 6). The support parents received from their

partners were thought to ameliorate the situation. Helping partners cope, however, would be difficult,

We live in such a sanitised world, where we are not taught to cope with the distressing awful parts of life. When it happens, few people know how to cope with their own reactions, let alone how to support their partner. (Nurse 6)

The nurses could see that parents' different perspectives of the baby and priorities might cause stress for the family. Each parent could experience their situation differently, *'I think you have problems developing between a couple, if they see things differently, if they have a different perspective on what's happening with their baby'* (Nurse 4). This could cause a *'domino effect throughout the extended family'* (Nurse 4).

The nurses were convinced stress on the family could emanate from the mother being at the baby's bedside for long periods, coupled with the father returning to work or caring for other children. The nurses understood the conflict between the parents could centre around the bond the mother developed with her unborn baby during uterine life. The mother might have a deeper need to be with her child. The nurses imagined, *'...the mother is probably torn in pieces, between that baby who she's got more of a connection to because of the pregnancy, than possibly the father does'* (Nurse 24). One nurse observed:

The mother can't tear herself away from this newborn child. She's got the hormonal things...the child is on the brink of life and death day in and day out, so how can you turn your back on a baby like that. At the same time the father's gone home, he's trying to keep the job going because of expenses and he's running the family. (Nurse 9)

The nurses were convinced that mothers could be torn between their sick baby and other family obligations.

They want to be with their baby all day. They feel that they should be there, because they're their [baby's] mother...They've got to have time out for themselves and the other

children, the husband. We've had mothers who just practically live in the Nursery and they'll come in at 7 o'clock in the morning and won't go home until 10 o'clock at night, which I think must be really difficult for them. (Nurse 16)

Many families were geographically distanced. The mother and baby could be hundreds of kilometres away from their support networks. This situation was considered to be, '*...really traumatic for them. Families are just torn apart*' (Nurse 7). Another nurse lamented, '*...we separate parents from their family all the time*' (Nurse 9). The father and siblings experience stress,

We've had...fathers that have become so stressed out because they haven't seen their wife for weeks on end, and the children being so stressed... 'Why won't mummy come home with us today?' (Nurse 9)

It seems that regardless of how supportive the family was, there were likely to be problems.

It doesn't matter how supporting and loving and emotionally close a family is. First of all there is the sleep deprivation that comes following this child's delivery and the initial period when everything is so very uncertain. (Nurse 4)

It was the experience of the nurses that miscommunication between parents could cause conflict. One nurse stated, '*...conflict happens at the bedside as well*' (Nurse 1). The nurses had witnessed hostility between the parents, and one nurse commented, '*...you can see a bit of conflict, and you can usually tell that they've been fighting. Not speaking to each other and on opposite sides of the bed*' (Nurse 16). Separation from the usual support networks was stressful, and one nurse stated, '*...we've actually had all sorts of fights and split-ups happen because of that sort of separation*' (Nurse 9).

8.6.2 Being on a roller coaster

It was the understanding of the nurses that parents of an extremely premature baby lived their lives as if their, “...*emotions are on a roller coaster*” (Nurse 24.) The nurses were aware of the emotional ups and downs the parents experienced when their baby was in the NICU. Parents of extremely premature babies are the, “...agonized bystanders, acutely aware of the stakes, but rendered helpless to aid their newborn” (Richardson 2001, p, 1501). One nurse explained how she helped parents survive this difficult time:

We always say to the patients ‘having one of these babies is a roller coaster ride.’ It is because one day you know they’re doing really well, the next day they look like they’re going to die, and then they pull through again. (Nurse 17)

In addition the nurses expected conflict to occur because of the continual ups and downs of the baby’s condition.

I think they can all end up fighting...their emotions are on a roller coaster over a long period of time. I don’t think as people, we can sustain these ups and downs for long times. I just think it wrecks us as people. (Nurse 24)

The nurses were all convinced that the length of stay could jeopardise a parent’s emotional wellbeing. Extremely premature babies could be hospitalised for greater than six months. One nurse spoke of the difficulty:

At 24 weeks it’s four months, even more, until you are expecting to raise that family. That four months is a long time for a family to be institutionalised and...many things can happen. (Nurse 6)

Parents seemed to put their lives on hold during hospitalisation, which brought them high levels of stress.

Having to make the trip every day to see the baby. The stress of the baby being here, and being sick, and the roller coaster ride, and it all builds up. It's like building blocks and gets to a point where the tower can't stand any longer. Like LEGO [building blocks] you build up and build up and then all of a sudden it just starts to lean at the top and down she goes. (Nurse 21)

Another nurse spoke of the effects of long term hospitalisation.

Puts so much pressure and so much strain on those adults...people become increasingly institutionalised and quite often go through the many lows that are associated with long term hospitalisation. (Nurse 6)

The nurses noticed conflict emerged when parents did not agree on treatment decisions. The nurses were convinced it was important for the parents to find some consensus. They needed to,

come to a mutual agreement...in the end they are going to go home as a couple. They are going to have to face life's consequences. They have to...go home and live the rest of their lives, hopefully together. (Nurse 1)

Parental conflict was thought to be inevitable. It is possible that in a crisis situation, uncertainty might prompt conflict. Conflict was not necessarily negative for the nurses, because it meant there was communication between the parents.

In the experience of the nurses some babies were hospitalised for most of their first year of life. Some parents maintained a bedside vigil, leading to problems within their family. One nurse explained:

I was talking to a young father... He was determined that he would not leave that hospital and go home to have a shower, have a shave or change his shirt...anything, until the baby came home. That was likely to be three weeks down the track. He was only young, but that was his response. That decision of his...placed a lot of stress on the rest of the family.

It had a domino effect throughout the extended family, the grandparents on both sides, not to mention his wife of course, who was under a lot of stress. (Nurse 4)

The nurses knew families would experience some difficulties. Triggers for conflict and stress were sleep deprivation, the guilt and grief associated with delivering an extremely premature baby, and the concern about the immediate outcome for the baby.

I think if you do end up with a 24 weeker, no matter how well bonded, well loved, well supported and well connected your family is, you can still end up in a mess. (Nurse 1)

The nurses spoke of watching mothers spend extended periods of time at the hospital.

You see parents...mother doesn't go home literally for eight or nine months. She lives in hospital until that baby is well enough to go home. (Nurse 4)

The mothers could be maintaining a vigil over their baby. Mothers in a study by Hurst (2001, p. 42) believed their active presence at their baby's bedside was critical to safeguarding their babies.

The nurses emphasised that living at the hospital was not a good life for the family. In the short term it could be managed without long-term friction between the parents. If the arrangement were to continue for six to nine months for example, severe family problems might develop. One nurse summarised, '*I think there's a lot of damage done to a family unit*' (Nurse 18).

8.6.3 Surviving the experience

The nurses experienced sadness that some parental relationships were unable to survive after the baby had been discharged. All nurses had seen relationships and marriages breakdown, and for one nurse, '*...it seems to be, a prem baby, sort of destroys it*' (Nurse 16). Another nurse offered, '*I think marriage breakdown can ensue from a 24 week*

delivery' (Nurse 4). There are reports of parents' relationships dissolving (Leifer, Leiderman, Barnett & Williams 1972, p. 1213) though the overall picture is inconclusive. Trause and Kamer (1983, p. 461) found parents were still together eight to 26 months after the birth of the premature baby.

The nurses all realised that parents could not imagine what might happen to their relationship when their baby was discharged. One nurse commented:

I've seen these parents come back, many of them have split up. They've got problems within their family, they've got problems with support networks. (Nurse 10)

The reality of taking the baby home might not be realised until the baby had been discharged. One nurse explained:

They're [parents] going through such an emotional time...at that time none of that was actually taken in. When they are at home with a damaged infant who needs a lot of care, it sinks in. You know their family life falls apart and their support networks become fragmented. (Nurse 10)

The nurses reflected on the difficulties that families faced at discharge. A father might feel abandoned and, '*...they just can't cope anymore because they're not number one and they sort of just drift. Some come back*' (Nurse 18). Siblings' lives were disrupted. One nurse stated, '*...they're not ignored but not full attention is given to them, because there's so much needed for these other children*' (Nurse 18).

We're sending the child home who isn't complete. If they've got other children, or they plan to have other children, what sort of life is it going to be for them? They're never going to be able to be a family. (Nurse 21)

It was clearly understood by the nurses that the parents' lives would be changed forever. One nurse remembered a baby with grade 4 IVH and hydrocephalus. Her contact occurred many years ago yet this nurse still wondered about the baby and family.

I still wonder what have we put on these parents. When something really major happens, you wonder, well, 'why do we go ahead'... You wonder what burden is it going to put on their life later. (Nurse 24)

The nurses hoped the parental relationship would survive. They had all seen relationships that did not survive the NICU experience. While it cannot be assumed that children who are chronically ill or handicapped are the cause of marriage break-up (Eddy & Walker 1999, p. 10), parenting an ill child requires a considerable amount of time and energy, and increased costs. Caring for a chronically ill or disabled child could interfere with the marital quality, but it does not impact on the marriage duration (Eddy & Walker 1999, p. 15).

8.6.4 What are we sending this child home to?

Most nurses agonised over whether certain babies should go home with parents. They spoke of babies whose parents were violent, or substance abusers. In thinking about the future they were troubled, '*...you think 'Oh no we're sending this child home to these parents.' But you have to*' (Nurse 12). One nurse told of a situation she encountered:

There was a history of the father and the mother both bashing the children... quite a violent history. Even if you got this kid home by some little miracle, there's no way that this child would even survive the first year with such a violent family. (Nurse 16)

Several nurses gave examples of babies referred to the Department of Community Services (DOCS) who were neglected or abused. Several nurses had cared for extremely premature babies who had died following discharge due to parental abuse and neglect. A higher incidence of child abuse amongst the surviving premature infant population has been reported (Elmer & Gregg 1967, p. 596; Koel 1969, p. 565; Klein & Stern 1971, p. 15; Sills, Thomas & Rosenbloom 1977, p. 26; Escalona 1982, p. 670; Sachs, Hall, Lutenbacher, Rayens & Kaye 1999, p. 22). Parenting attitudes are of concern in families of low birth weight children. It was the understanding of the nurses that child rearing is

demanding for any parent, but parenting a growing premature baby might be more difficult because of their ongoing health and developmental problems.

The nurses felt desperate when a child required child protection services. They questioned, '*...Oh, what are we sending them home to?*' (Nurse 16). The nurses experienced both sadness and relief when such a baby died. The dilemma inherent in sending the child home was resolved. One nurse spoke of her relief:

When the baby did finally go [die] you feel sad because she's lost a baby, but you know for both of their sakes, I think it was a bit of a relief even though it was a sad situation.
(Nurse 12)

The nurses were often caught in situations with parents with fertility problems and abusive parents who experienced little difficulty conceiving. They thought it a wonderful idea, in principle, for the healthy baby of a chemically addicted mother to go home with the family who desperately wanted a baby. This was, of course, not an option, but the nurses allowed themselves to imagine happy-ever-after-endings. They supported the idea that substance-abusing mothers should be given an opportunity to care for their babies. The nurses were not easy about their skills being used to save a baby who might later be at risk. Conversely, they were happy if the baby had a positive outcome.

8.6.5 Summary

The birth and treatment of an extremely premature baby is a crisis for the family. The baby's hospitalisation brought the parents a roller coaster existence with the ups and downs in the baby's condition mirroring the parent's emotions. During this time their lives were placed on hold while they grappled with the enormity of the situation, and their future life. The nurses all questioned whether more could be done to support the family through the crisis. They understood that some parental relationships would not survive. The nurses were distressed about sending some babies home with their parents

because they feared the child would be a victim of abuse. They could experience sadness and relief when such a baby died.

8.7 The law

The laws relating to saving babies were a source of anxiety for all the nurses. They were convinced the law should not have a role in decisions to resuscitate and treat extremely premature babies. The nurses spoke of being concerned about the lack of hospital policies. They were convinced that hospitals should have policies about dealing with extreme prematurity. The nurses considered guidelines would be helpful because, *'...sometimes in hospital you do need a bit of direction, because doctors don't always agree on things, so maybe for a bit of uniformity'* (Nurse 17). Many nurses assumed incorrectly that in following hospital policies they would be afforded protection within the law. One focus group discussed their concerns:

Hospital policy means very little when you actually have to sit there in front of a coroner.
(Nurse 2)

It's a guideline, not black and white. (Nurse 1)

Institutional policies are often referred to in order to resolve conflicts, however, most policies generally serve the needs of the institution. Institutional policy and ethics could collide, because policies are not necessarily ethical. Policies need to be evaluated and critiqued to assess their ability to help those confronted with clinical ethical dilemmas.

8.7.1 Viability as a legal entity

The nurses all deemed there to be a difference between real viability and legal viability. They were convinced that viability in Australia was not realistic, as a 20 week baby could not survive. One nurse spoke about this issue:

I think the law is a tricky thing. I don't think the law should make you resuscitate a baby who you know hasn't got a great chance. They [lawyers] only see things in black and

white. Viability, they've changed it to 20 weeks and so they're viable 20 weeks, which I have a great problem with. I think they've made a bit of a rod for themselves there, saying '20 weeks you're viable'. (Nurse 16)

At the current level of viability at 20 weeks the gestation, '*...could be 2 weeks out, these kids could only be 18 weeks*' (Nurse 21). This meant that if the staff were resuscitating a 20 week gestation baby, they might really be resuscitating an 18 week fetus. In such a circumstance one nurse said, '*...it makes me feel physically ill*' (Nurse 21). The nurses held firm beliefs about the gestation they would resuscitate. One nurse believed that, '*...25 [weeks] is a much more feasible, or 26 [weeks]*' (Nurse 21). Another nurse stated, '*I personally wouldn't go and do anything about a 22 weeker at this stage*' (Nurse 14), while another exclaimed, '*...we have resuscitated the odd 22 [weeker], and you wish to God they hadn't*' (Nurse 13). Another nurse explained her concern:

The smaller they are...I think it's more dangerous territory you're getting into. I look at the pain that we inflict on them, even for the short time that we keep them alive before we decide that there's no hope. We do create a lot of distress. There's no doubt about it. (Nurse 13)

The nurses held that if the law were involved they might be obligated to provide, '*...more heroics than what we're used to for the end product, which we know might not be as salvageable as you know some others*' (Nurse 15). The nurses expressed concern that a law would mean, '*...the doctor's hands are tied and the parents can't have a say and then you've got to do everything from 20 weeks*' (Nurse 18). Conversely, with a law, it might prevent babies from being saved who might have a chance. One nurse explained her anxiety:

I don't think you can legislate against life. It would be a very Big Brotherish to actually legislate against the sanctity of life in that way. (Nurse 10)

The nurses were convinced their medical and nursing colleagues needed to be knowledgeable about Australian law as it relates to extreme prematurity: One nurse stated:

I think... it's very important that our neonatologists and neonatal nurses actually be reasonably well-versed in how the law stands. It's something that's not addressed terribly well in education programs. (Nurse 10)

8.7.2 Summary

The inability of the law to prevent the over treatment of extremely premature babies was a source of concern for the nurses. They were troubled that the law would compel neonatologists to save every baby from 20 weeks gestation. It was clear that for the nurses, that which was legal was not necessarily ethical.

8.8 Research “v” experimentation

It was the belief of the nurses that research was essential in neonatal medicine. Research has enabled the frontiers of viability to be pushed back successfully in the last 20 years. There is no doubt that babies of 28 weeks gestation and greater have an almost 100% chance of survival, and that lower gestation babies are surviving with greater frequency. Research has enabled many extremely premature babies to live, however most nurses questioned where the line between research and experimentation began and ended.

8.8.1 Research as a double-edged sword

The nurses all found experimentation on extremely premature babies disturbing. They considered the medical staff's approach of, '*...let's see how far we can go with this one,*' (Nurse 17) not in the best interest of the baby. It was a widely-held belief amongst the nurses that if the baby was destined to die, then treatment should be withdrawn, regardless of whether other babies could be benefited. One nurse explained:

I think doctors will say, 'Well, we'll see how far we can go with this one.' I don't think that's very nice for the baby involved. I think we should have a little bit more respect for the life. (Nurse 17)

There has been a historical reluctance on the part of neonatologists to insist that every new treatment be subjected to rigorous clinical trials before adopting them (Silverman 1987, p. 403). As the use of a promising treatment spread rapidly and widely, the formal testing followed far behind, by which time the damage had been done (Silverman 1987, p. 403). Even recently, treatments such as high dose steroids for chronic lung disease, assumed to be beneficial, have proven to have serious long-term side effects (Richardson 2001, p. 1503). Many nurses were concerned about the application of research findings. It was their understanding that research trials usually required strict protocols. They assumed the results of the research would not be generalisable, when strict protocols were not in place. One nurse explained:

You're not going to get the same results. I've seen it time and time again. They haven't got the results that they're sprouting off. 'Oh research says that we're going to have this improvement, that improvement,' and you say 'Yeah, but what were the conditions?' 'Oh it doesn't matter, it's just research. The paper said it worked. I read this, let's see if it works. If it works, well then we'll use it and if not, we don't'. 'Which research paper did you get this out of and how do you know that that research is all that well done?' (Nurse 12)

The nurses all understood that research and experimentation were essential and knew that extremely premature babies had reaped the benefits of research on previous generations of premature babies. One nurse explained:

I think a lot of them are used as experiments. The only way to make any breakthroughs and get treatment that really works is to actually experiment a little bit, like probably the earlier prems. They learned what it did to the baby, what worked and what didn't, and that's benefited this generation of prems at the moment. (Nurse 16)

Even so, the nurses experienced distress when extremely premature babies were the subject of experimentation. They found it difficult to accept that tiny babies should be used for non-therapeutic research. Several nurses spoke of feeling horrified that medical staff would keep an extremely premature baby alive to write in order to write up its case for publication. Candee et al (1982, p. 849) found that neonatologists' attitudes towards unsalvageable cases in the NICU were influenced by the possibility of potential research. The nurses all held that if life was valuable to the baby then treatment was warranted, however, tiny human beings should not be used to serve the research needs of medical staff. One nurse recollected a story that illustrated this point:

A baby come over from [hospital]. It was 24 weeks and did peritoneal dialysis on it. It was purely experimental. The doctor accepted the baby on that proviso...never asked the nurses would they be happy to do it, and they were horrified that they had to do it. The baby ended up dying of course. (Nurse 17)

The issue for the nurses was about having respect for the baby as a person and not using the baby as a means to an end. They expressed doubts and personalised the dilemma, speaking about the medical staff and whether they would allow their own baby to be used in this manner. One nurse mused, '*...I wonder if they would be so gung ho if it was their kid*' (Nurse 11).

Being kept alive for the sake of research was seen by all the nurses as a form of cruelty. One nurse told of a situation where a baby developed necrotising fasciitis. Necrotising fasciitis is predominantly a disease of adults and is extremely rare for a baby. Group B Streptococci enters the skin. Treatment involves aggressive surgical debridement and antibiotics. The mortality is high (Kothari & Kulkarni 2004, p. 1071). The nurse described the disease progression.

Coming up from the feet and it's such a fast progress of a condition and it was up to its lower part of its abdomen. They were getting everyone to come and see it. They wanted to write this paper on the baby, because it was such a rare thing on a 24 week neonate. (Nurse 11)

The baby was receiving multiple antibiotics and was being kept alive, in the mind of this nurse, so a publication could be achieved. The nurse used the words, *'just awful'* (Nurse 11). Interest was high among the medical staff, *'...they were getting everyone to come and see it'* (Nurse 11). The baby suffered a pulmonary haemorrhage.

...worst major pulmonary haemorrhage I've ever seen in my life. It was the type that bleeds right down into the ventilator tubing. You can't ventilate. We were told to keep going ...because this baby has to survive. It was only because they wanted this paper to be written. (Nurse 11)

This nurse attempted to disconnect the ventilator briefly, to remove the blood from the ventilator tubing.

I remember I got into trouble, because I disconnected the PEEP [positive end expiratory ventilator pressure] and this baby would die. What's going to happen with research, with this paper that they wanted to write...Feeling like that I was being accused of killing this patient. (Nurse 11)

The experience affected this nurse deeply and she explained, *'...this was going back some years now, and it still was as fresh in my mind as like yesterday. To me that was experimenting and it was wrong'* (Nurse 11).

Research that was likely to benefit a particular baby, as opposed to future babies, was acceptable to the nurses. Here lies the difference between therapeutic research and non-therapeutic research. For the nurses, *'...research when you know that it's going to be a good outcome or that there's a possibility of good outcome, that's fine'* (Nurse 9).

Research and experimentation on tiny babies for the sake of it was seen by all the nurses as offensive.

Experimenting goes on in such a way that the baby is going to suffer, or they're just extending the suffering...it really gets a bit hard to swallow. (Nurse 9)

The nurses objected when the medical staff took professional pride in experimentation. One nurse stated, '*...just to keep them alive to say, "Look how clever we are", I find that horrid and I hate it, yeah, I hate it*' (Nurse 9). The nurses questioned if parents were fully informed of the experimental nature of some therapies.

You just wonder how much the parents would tolerate if they knew some of those things...experimenting. I know they've got to learn, but it's how they learn. (Nurse 9)

Further, the nurses were uneasy when they could see research was detrimental to the baby. Three nurses spoke of a study about PDA where researchers gained antenatal permission to enrol the baby into the study. These nurses questioned the parent's informed consent and the parents freedom to terminate participation in the study, '*...so you really had no choice once the baby was born*' (Nurse 13). During the study an ultrasound machine was required to assess blood flow in and out of the heart:

It was the PDA study. That constant going in with the ultrasound machine and all the drugs, I'm sure was very detrimental to those babies, without a doubt. Especially the one that was sicker and did die. (Nurse 13)

The three nurses perceived the researcher was not interested in the welfare of the babies. One nurse stated, '*...it was his attitude, he didn't want to know about our concerns for the baby. All he was interested in was doing that study*' (Nurse 13). This research was not designed to help the babies under study. While it might have been in the best interest of future generations of tiny babies, however, for the nurses it clearly was not in the best interest of this baby, particularly if the researcher did have the baby's welfare at heart.

8.8.2 Fear of the future

The nurses were all troubled about what the future of neonatology might hold. This was because, '*...ethics hasn't caught up with science yet*' (Nurse 4). For one nurse, '*just keeping them alive is a form of experimentation*' (Nurse 17). This same nurse was

conflicted about keeping babies alive, while at the same time recognising the positives of NICU:

It does worry me. We're playing around with a lot of things that wouldn't happen in nature. Sometimes...some of those babies aren't meant to be. It goes against the grain. At the same time...you can't overlook that we can help as well. (Nurse 17)

The nurses all understood that the 24-week gestation baby of today could be the 28-week gestation baby of 15 to 20 years ago. One nurse asked, '*...as technology changes and becomes far more advanced will the cut-off point be earlier still?*' (Nurse 3). Several nurses spoke of when there was nothing that could be done for older gestation premature babies. They contrasted such scenarios, '*...years ago, babies who were 26/28 weekers were nursed in boxes of cotton wool*' (Nurse 3).

Further technological development will add to the nurses' dilemmas about tiny babies. In foreshadowing the future they spoke of extended choices and frightening decisions, '*...the more technology you have, the greater the decisions, because there's more choices available...if this treatment doesn't work, let's try this one*' (Nurse 16). Another nurse emphasised, '*...now we have to decide who lives and not who dies. Technology allows everybody to live*' (Nurse 1). The inevitable reality of advancing technology created anxiety. One of the nurses stated, '*...they're going to keep pushing back the boundaries. I think that's what this century is all about. I don't like the idea, but I think they will. It's scary*' (Nurse 9).

Several nurses were convinced that if they remained in neonatal nursing they would be required to do things they would find unsavoury. One nurse stated, '*...if they're going to start ventilating 20 weekers, I'm out of here*' (Nurse 21). The nurses hoped that ventilating 20-week fetuses was, '*...not going to happen. Not in my lifetime*' (Nurse 19). The nurses all added humour to their visions of the future, '*...we'll be growing them from the test tubes next*' (Nurse 9), while another joked, '*...one of our male neonatal nurses*

said he has a vision that one day they'll be ventilating fertilised ovums' (Nurse 7). One nurse spoke of her worst fear:

I often joke about this because I remember as a child watching these horror movies...I saw this woman lying on a table, and she had the umbilical cord coming out of her, and in this fish tank was this monster fetus. I said, 'Yes I've seen it on TV.' I said, 'Yes that's always my biggest fear'. (Nurse 12)

Another nurse spoke of a conversation with a consultant who had imagined the future.

...a vision of having a baby in a fish tank, hooked up to an artificial placenta. I said, 'When that happens, I'm out of here.' He said, 'No I think...that's a possibility that something like that could happen in the future.' I thought 'Wow, that's a bit much for me.' It'd be time to retire, I think. (Nurse 7)

To the nurses, the idea of fetuses gestating underwater was, '*...really freaky, frightening*' (Nurse 18), and was reminiscent of Huxley's, *Brave New World* (1932). This technology was frightening, but several of the nurses were aware that an artificial placenta had been developed (Unno 2001), while other technology was available in its experimental form.

In Japan it had these fish tanks with...these lambs ventilated underneath this liquid gel. I'm thinking, 'Oh God. Is this is where we're heading?' (Nurse 19)

The nurses would prefer the current technology to be refined before making more advances in technology. One nurse stated,

I would sincerely hope that they'd fine tune what we've got now, before they start leaping into a whole lot of new technology. I think they need to try to and focus on improving what they've got and what they're doing now. (Nurse 7)

The iatrogenic effects of experimental technologies troubled the nurses. They could see that it might be theoretically possible to attach a human fetus to an aquawomb or artificial uterus, but there was no guarantee of normal development and growth. One nurse stated,

We don't have the technology to nurture a brain, to myelinate a cord, to develop a lung, to grow a lung. We cannot produce a perfect environment for that. (Nurse 1)

Another nurse was candid in her scepticism about the motivation of experimentation when she stated,

The sort of treatment for microprems is based on...the IVF stuff, and it comes from the states [USA]. A lot of the IVF stuff is experimental. It's based on fairly bodgegy premises, and you just wonder, because in the long term it's profit driven. 'Are we doing this so we can generate more money for rich doctors.' (Nurse 6)

Aspects of experimentation were disturbing. The nurses were worried about IVF. One nurse voiced her concern, '*...when they start implanting elderly ladies, which they've certainly been doing, which I find terribly wrong, personally anyway*' (Nurse 5). The nurses came to believe that technology should not be used in this manner. It would appear the nurses concerns were based on reality, as an Italian woman gave birth to a son through assisted reproductive techniques at the age of 65 years (Pita, 2002, p. 1). One nurse summed up,

I think with all the technology, we really need to step back and look at what is real and what isn't real. Look at nature and you've got to accept sometimes what's given to you. (Nurse 17)

The nurses all experienced anxiety when they perceived the medical staff were pushing the boundaries of science, without consideration of the ethics and social consequences. The nurses were continually, '*...questioning the motives for why are we making these babies survive*' (Nurse 6). One nurse found it offensive with, '*...the big Professor saying, 'I did this, I'm fabulous. I'm just so good*' (Nurse 5). The motives of large corporations

who made high technology equipment were questioned. One nurse suggested, '*...it's not based on "are we making happy, healthy babies who will do well, and make a happy, healthy family unit". It's money, and that to me is a form of experimentation. It's not what nature generally does'* (Nurse 6).

Several nurses talked about how consumers with access to the internet might demand unproven therapies. One nurse said:

My worry is it is USA driven, and really it's about making money in the end. The so-called advances that they make...we are virtually forced to adopt the practices that derive from that. The public demand that it in certain parts of the world...they are achieving those results supposedly...here in Australia we want this for us. (Nurse 6)

The nurses would be accepting of technological advances if they could be sure that advances would herald better care for the babies. Better care meant better outcomes, not just survival (Roze & Breart 2004, p. S32). It was clear that for these nurses, future technologies would add to their dilemmas.

8.8.3 Summary

The nurses became uneasy when they perceived that babies were the subject of experimentation, with little thought given to their humanity. The nurses were in a quandary. They knew that progress came at a price, yet they were not sure if the baby should be expected to pay that price. There was a fine line between research and experimentation for the nurses. The nurses believed that valuing the baby meant it should not be used as a means to an end.

The nurses all knew that research was essential. They understood that the physiology and disease processes of extremely premature babies were different from those in full term babies, children or adults. The nurses saw the baby as a human being entitled to respect but did not believe all researchers shared their philosophy. They had encountered

researchers who did not consider the best interests of the baby a priority. This belief often placed the nurses in direct conflict with medical staff.

8.9 Conclusion

In this chapter, *dealing with awfulness* the neonatal nurses experienced a range of conflicting emotions as they grappled with saving tiny babies. These nurses were experiencing the blessing and burdens of the baby's mortality in line with other nurses in research reports (Jonas 1992, p. 34). The conflict, anger, resentment and frustration was recurring and consistent. The nurses had to find ways to deal with the ethical dilemmas associated with every aspect of the birth, life and death of these tiny babies. The nurses endured, however the dilemmas seemed to be never ending and were related to unrealistic hope fostered in parents, miracle babies, thwarted advocacy, poor communication, viability and experimentation on tiny humans who were unable to give consent. The parents, family, nurses and medical staff were all affected as they all attempted to make sense of the baby's situation. Parental emotions could swing up and down, and the stress and conflict within the family could see the family unit disintegrate. To deal with awfulness could be overwhelming. Conflict was expected, and experienced by the nurses. These nurses took their role of patient advocate seriously. At times the ethical dilemmas became unbearable and they developed protective mechanisms to help them through with their emotions intact. Other nurses left the area completely.

The following chapter 'reflecting on the outcome' explores the nurses' experience of the outcomes of extreme prematurity baby, including the impact of uncertainty, notions of success and failure and the meaning of quality of life.