

CHAPTER 9 REFLECTING ON THE OUTCOME

9.0 Introduction

The neonatal nurses all expressed deep concern about the outcomes of babies of 24 weeks gestation and less. The nurses all emphasised it was specifically babies of extreme prematurity that caused them concern, as babies of greater gestation had a better chance for a positive outcome. The nurses all reflected on every facet of the baby's existence; resuscitation at birth, continued treatment, survival to discharge, and the home life of the family. The nurses all understood that many extremely premature babies would require a number of services to help them gain speech, milestones, mobility and socialisation. These services, according to the nurses, were in high demand and yet were not readily available.

In this chapter the relevant dimensions of the theme, 'reflecting on the outcome', will offer an understanding of what it is like for the nurses to believe they know the probable outcome for the extremely premature baby, live with the uncertainty and unpredictability, and to hold themselves responsible for the outcome.

A disability is any restriction or lack of ability to perform an activity. An impairment is a loss or abnormality of structure or function which can be psychological, physiological and/or anatomical. The disturbance is at the level of the organ and includes defects, loss of structure and function. A handicap is the disadvantage for an individual resulting from an impairment or a disability that limits or prevents the fulfillment of a role that is normal for that individual (WHO, International Classification of Impairments, Disabilities and Handicaps 1980). The extent to which the disability, handicap or impairment impacts on the individual and family will depend on the severity of the problem, the attitudes and ambitions of the child and family, the adaptation of the physical environment for the child, and societal reactions and prejudices (Gatford 2001a, p. 109).

Not every nurse held the same definition of severe disability. The terms severe and profound describe children at the lowest levels of functioning who have a limited ability to communicate and care for themselves (Savage 1998, p. 53). The nurses all understood that babies of 24 weeks gestation and less were likely to have poor outcomes. A poor or negative outcome represented a baby who survived with significant mental and physical handicaps. A positive outcome would be a child with minimal or no disability. Positive outcomes did include babies who were blind, deaf and minimally disabled. The defining feature for the nurses seemed to be the ability to have some independence and enjoyment of life. Neurological outcome was important, and one nurse made the distinction when she stated, '*...we're talking extreme neurological damage as opposed to somebody that's got a physical handicap that is neurologically intact*' (Nurse 23). One nurse spoke fondly of a baby who became blind as a result of his treatment. She stated, '*I think he has to hold things up 5 cm from his eyes to see things. He can walk and he's fearless. Because he can't see anything...he doesn't know what to be afraid of*' (Nurse 12). If this child enjoyed his life, this was a positive outcome for this nurse.

There was a large spectrum of what would be defined as a positive outcome, as long as the child was able to achieve its full potential. Conversely, a negative outcome for all the nurses would be the baby who was so profoundly neurologically and physically impaired that the child might not be aware of its existence. A negative outcome was children who would "never be able to speak, to walk, to sit up, or to feed themselves....Their intellectual abilities are extremely limited, often so much so that they have never been able to recognize their own parents" (Elliott 2003, p. 16). It was the understanding of all the nurses that many of these babies required constant care for the rest of their lives. The nurses' experience led them to believe this often entailed daily visits to specialised services, such as physiotherapy, developmental enhancement programmes, as well as the medical follow up for any chronic conditions. Elliot (2003, p. 16) emphasises that the lives of the entire family are structured around the care of these children. Special schooling is also required, and Johnson, Bowler, Yudkin, Hockley, Wariyar, Gardner and Mutch (2003, p. F190) found that one in six extremely premature survivors at age sixteen had severe disabilities and required special schools.

9.1 Reflecting on the baby who is damaged

It was the experience of all the nurses that extremely premature babies were likely to suffer from many ongoing problems. The nurses were all aware that the extent of the damage could often not be fully determined until it was too late to withdraw treatment, and the baby was breathing unassisted by respiratory devices. Neurodevelopmental outcome has become the most important indicator of successful intervention in extreme prematurity (Kent, Casey & Lui 2007, p. 489).

9.1.1 Damaged through survival

It was the understanding of all the nurses that extremely premature babies could suffer from cognitive and physical deficits, and a full range of sensory disturbances. There might be one or more problems in isolation, but it was the experience of the nurses that babies suffered multiple problems. The damage occurred to organ systems that were still developing. The nurses had all seen poor outcomes and this had affected the way they viewed caring for babies of 24 weeks gestation and less. One nurse explained her difficulty:

I think most of our perceptions of babies of this gestation are that they face so many problems and such a stormy path if they do survive, that the outlook is extremely bleak. I think there are an awful lot of negatives. I think a lot of nurses have trouble getting past that. (Nurse 4)

All the nurses had seen what they considered to be more negative than positive outcomes for extremely premature babies. The experience of each nurse and what they had seen other babies withstand, led the nurses to believe there were, '*...unfortunately, so many very negative outcomes*' (Nurse 4). The nurses all experienced difficulty treating the babies because of the negative outcomes. One nurse stated, '*...we have the technical ability to resuscitate these babies, I think a lot of us have a very great dilemma in actually treating them*' (Nurse 4). It was hard for the nurses to accept they were part of

the NICU team responsible for saving the babies, and then expected the mother to care for the baby when it went home. These nurses all felt a sense of social responsibility when it came to the babies and their family. They perceived mothers as abandoned by the system that took pride in saving the baby.

The nurses commonly believed that a poor outcome was more devastating for an extremely premature baby, than it would be for a full term baby. In the full term baby all organ systems had developed. Conversely, in the extremely premature baby, the organs including the brain were still developing and maturing, and were prone to damage. One nurse stated that with the premature baby, *'...you not only have the neurological disabilities, but you are going to have the disabilities of being very premature, so that you've got double the load'* (Nurse 6). The nurses all emphasised the premature baby was more likely to have more than one disability. One nurse explained:

If you have two or more abnormalities together, it tends to cascade to being vastly loose, so you're talking about probably blind, ... little bit of deafness. It won't just be learning difficulties, intellectual disabilities, it will be cerebral palsy. It will be the full gamut of problems. (Nurse 6)

The same nurse stated,

Poor neurological prognosis is determined from the single entity only. Premature plus poor neurological prognosis are two entities. (Nurse 6)

In the extremely premature baby with other problems, one nurse stated, *'I think that 24 weekers have so many problems to overcome that having a bad neurological outcome is just the icing on the cake'* (Nurse 14). It could be that the difference was about the quality of life experienced by the baby. This nurse stated,

A preterm with a poor neurological prognosis will probably not only have that affliction. There will probably be impaired vision, hearing, perhaps NEC [necrotising enterocolitis], perhaps VP [ventriculo-peritoneal] shunt. With the term infant, the poor

neurological prognosis usually means only that. If you are developmentally delayed, there is more hope of some quality of life than a developmentally delayed, blind and deaf person with short gut syndrome. (Nurse 6)

It was clear that the combination of problems would make all the difference to the baby's outcome. It was the nurses' understanding that parents would experience difficulty gazing at their baby and realising how the baby had been damaged. Parents are unable to see the injury inside their baby's head. It is possible that the parents were experiencing cognitive dissonance where they were unable to equate what they were seeing with what they were told about the baby. One nurse stated,

It is hard for parents to accept that they have what looks like a perfectly normal baby. They find it really hard to believe that that baby is never going to be able to function completely normally. Because it looks so perfect. (Nurse 21)

The nurses all conceded that the brain is highly valued in our society. The nurses spoke about the importance of a functioning brain. They believed that a neurological disability was far worse than a physical disability, and were convinced that cognitive disabilities had further-reaching consequences than did physical disabilities. The nurses all agreed that neurological impairment was worse for the extremely premature infant than the term infant. They were convinced that those with a physical disability could still achieve their potential and have rewarding and fulfilling experiences. The nurses, too, valued the brain, thinking that existence is inextricably linked with cognitive function. At times, the nurses believed that extremely premature babies with poor neurological prognosis should be allowed to die. There is a difference between the neurologically devastated premature baby and a baby born with Down syndrome, yet society may not understand the difference. Gustafson, cited in Paris and Bell (1993, p. 470) spoke of a baby with Down syndrome where a decision was made not to correct a duodenal atresia. When asked why this baby was being treated differently the physicians stated "there is a tendency to value life on the basis of intelligence" (Gustafson, 1973, cited in Paris & Bell 1993, p. 470).

9.1.2 The lottery of uncertainty

The nurses contemplated the random and often unpredictable medical course and outcomes of extremely premature babies. One nurse likened the outcome, ‘...it’s like *Russian roulette, isn’t it? Pick a number. It’s like a lottery*’ (Nurse 19). Tisdale (1986, p. 69) speaks about a lottery when she states, “...what a wonder, how we are given the children we receive...Here is another riddle, science. It is like a lottery – you stand in line for a ticket and the person in front of you gets the winning one”. The outcomes of extremely premature babies can be likened to a lottery because they are so variable. A lottery implies chance, the chance to win and gain a prize. In the nurses’ comparison of the outcomes with a lottery is the idea of chance and uncertainty. The lottery involves the life of the extremely premature baby with the chance of an uncertain outcome and the hope of defying the odds. The uncertainty associated with the chance was troubling for all the nurses.

The nurses all understood that uncertainty was associated with predicting outcomes. The nurses were committed to the belief that it was not possible to give parents a 100% accurate picture of the outcome for their baby. Prognosis prediction is not an accurate science. One nurse explained:

We can’t turn around and say, ‘I’ve looked at this head ultrasound and I can guarantee you this is what is going to be wrong with your child at 6 years of age’. If we could do that, we wouldn’t have a problem. But we can’t. (Nurse 1)

While this seems to contradict earlier findings that parents should be given a clear picture of what is happening with their baby in order to make decisions, the reality is that uncertainty usually overrules. All the nurses had cared for babies who had a stormy course and yet had survived with minimal problems. They had also cared for babies who had a relatively smooth course, and who became significantly physically and cognitively impaired. Some babies’ outcomes defied explanation. There were babies that the nurses expected to have a poor outcome who were not as impaired as predicted. Hale and Levy

(1982, p. 105) acknowledge that dealing with the uncertainty associated with caring for extremely premature babies could be stressful for neonatal nurses. One nurse in the current study explained her uncertainty:

I don't know which one is going to be fine. One will come through and it's really a disaster and the kid is fine. One will come through and basically have a really nice course, and it's a disaster on the other end.

(Nurse 19)

The nurses all passionately believed that seeing a good outcome could make the whole experience, '*...really worthwhile, especially if you do see the baby go home, what you consider in fairly good shape, minimal handicaps*' (Nurse 11). When a baby survived with what the nurses considered a poor outcome they all questioned the decisions to treat. One nurse stated:

We've all seen the end results that you start to feel a bit negative about it. Babies will come back later on and you'll see what you've actually done. Some of them come back and they're really good and you'll think 'Great!' and another one will come back with severe cerebral palsy, blind, and you think 'Was this worth it?' (Nurse 11)

Uncertainty seemed to be linked with hope. The nurses knew the outcomes for extremely premature babies. All nurses had seen at least one baby who had defied the odds and, '*...has all these problems and is fine, for whatever reason is for all accounts, normal*' (Nurse 12). They were hopeful when caring for tiny babies, as stated by one nurse, '*...they're hoping maybe this is the one child*' (Nurse 12). Seeing the occasional baby with a positive outcome was enough for the nurses to continue working with tiny babies.

It was difficult for all the nurses to deal with the uncertainty of the outcomes. They recognised there were no guarantees when it came to extremely premature babies. One of the nurses stated, '*...it's a bit hard because we have had successes, but how many are we knocking off at the same time*' (Nurse 18). In using everyday language this nurse was showing concern about causing damage to the baby during treatment. Everyday nurses'

language could be an example of secret nurses' business. This form of language is unlikely to be used outside the confines of nursing. The nurses spoke of what they call '*disasters*' (Nurse 13, 14 & 19) when referring to outcomes. A disaster can be defined as an occurrence causing widespread destruction and distress. A disaster implies devastation and three nurses perceived some babies in this way.

It was disappointing for the nurses when a baby they believed would have a positive outcome, went on to have a poor outcome. One nurse told of a 23-week baby who had an uncomplicated course. The baby had a few minor setbacks in the NICU. The staff anticipated this baby would be a success, however, when the baby was being discharged the staff were informed the baby had multiple problems. A negative outlook for the baby forced a grey mood to descend on to the NICU. The staff were devastated, one nurse explaining:

We found all these disastrous things with her, just everything. Hearing and eyesight, head, everything. Absolutely everything. And it just put a pall over the place [NICU]. You know when everyone had heard these [outcomes]...No one could believe it. 'Oh no!' you know 'Here is one that we thought would do well.' (Nurse 14)

Uncertainty was difficult for the nurses, but while uncertainty existed there was hope. McHaffie and Fowlie (1996, p. 254) suggest that tolerance of the greyness of uncertainty is hard for some staff members. The nurses spoke about how they managed the uncertainty by stating, '*...you don't think, "Well this is wonderful, everything is going to great." You're thinking about all the things that can go wrong*' (Nurse 13). The nurses' experience with uncertainty could change the way they gave parents information. One nurse spoke of how she explained the baby's condition to the parents,

Once upon a time I would have said to the parents, 'You know your baby is doing really well, hardly this, hardly that. This has happened, that's happening.' But, see, I don't do that anymore. I say, 'Yes it's looking very good. But you know it's early days yet.'

Uncertainty prevails in human life. It is, however, an individual's perception of the amount of uncertainty that is important (Penrod 2001, p. 243). There are cognitive, emotive and behavioural strategies which help the nurses manage the uncertainty. Cognitive strategies allow for informational gaps to be filled by increasing knowledge. Emotive strategies are those which help to diminish the anxiety associated with uncertainty, while behavioural strategies are associated with either engaging or withdrawing from the situation (Penrod 2001, p. 241). It seemed the nurses used cognitive, emotional and behavioural strategies. One nurse indicated:

The uncertainty of the situation was very unsettling for the nurses as they continually attempted to find anything, which might indicate a good or bad outcome. (Nurse 14)

The nurses were all cautious and did not want to raise the parents' hopes for the survival of the baby because of the uncertainty of outcomes, as one nurse stated, '*...you don't want to raise their hopes up and have exactly the same thing happen*' (Nurse 14).

9.1.3 Nurses and outcome predictions

Nurses might not get to see the outcomes of extremely premature babies. McHaffie and Fowlie (1996, p. 255) suggest the NICU is an artificial world, and that staff need to glimpse the realities of NICU survivors to increase their understanding of what families endure. The nurses in the current study had all read literature on the outcomes of tiny babies, and had seen babies return for follow-up. It was the opinion of the nurses that, '*...the literature it's still a bit weighted to make things look really good. There would probably be hardly any babies on the end of any study that came out unscathed*' (Nurse 19). Not all neonatal nurses are aware of the outcomes of extreme prematurity, however, the nurses in the study knew about the possible long-term outcomes. One nurse explained:

That's something that we can demonstrate by the amount of reading that we've done and the facts that we have gathered...The experience, what we've seen, what we have nursed. You know the outcomes that we've seen. (Nurse 1)

Many nurses spoke of how they heard about the outcomes of babies. Word filtered back to the NICU. Most nurses, however, focused on the poor outcomes.

We do hear of all the follow-ups and there are a lot of positive follow-ups as well. I guess we tend to hear more of the disasters. (Nurse 13)

The nurses did not often see the good outcomes in tiny babies. It was difficult because, *'...we hear more of them [poor outcomes] than the ones who do well. That's the problem isn't it, we hear about the ones who are disasters'* (Nurse 14). The nurses all liked to hear about positive outcomes. One nurse explained:

Occasionally we get to see how babies are doing years down the track. That's positive. It's not that often, though. (Nurse 14)

Several nurses spoke about their colleagues who were optimistic about extremely premature babies, but who were not familiar with outcomes nor attended the follow up clinic. This situation was not uncommon, according to the nurses, because of the way that NICUs are structured, with an acute area separated from another area for less acute babies. Nurses who chose to work in intensive care might not get to see babies come back to the unit once they had been discharged. One nurse stated:

We see a small facet. We don't see it [the baby] often down the track, or it's walking around blind. We don't see those issues, and if you don't see something you don't realise. (Nurse 5)

Another nurse explained that when she undertook her neonatal nursing course the consultant neonatologist was adamant the nurses should go to the follow up clinic to see the babies they had cared for. Here they, *'...saw the so called bad outcomes'* (Nurse 6). This was beneficial for the nurses, one nurse stating, *'I found that extremely confronting in there...for a long time I'd always thought that the children who didn't survive intact were the mistakes'* (Nurse 6). One nurse emphasised she knew about the poor outcomes, but chose to focus on the positive outcomes. This nurse explained, *'...it's probably a*

survival mechanism. You switch them out of your brain as much as possible' (Nurse 24). Another nurse was convinced that constantly focusing on the negative outcomes made it difficult for her to continue working in the NICU. She stated, '*...you just want to see that baby go home and not really think of what's going to happen later on*' (Nurse 11). The nurses held it was easier for them to concentrate on the positive aspects. Dwelling on the negative aspects might have been too confronting for them professionally.

All nurses interviewed believed they knew which babies would do well, and which babies would have poor outcome. They based their predictions on technical information and the baby's reaction to handling and its response to caregivers. Several nurses acknowledged they had been wrong in their predictions for extremely premature babies. The nurses all spoke of times when they believed a baby would not survive, and yet it survived. They emphasised that survival was not related to outcome. This means they might not be correct in predictions of survival, but were often correct in predictions about outcomes. One nurse explained:

When it comes back for follow up, you think 'Oh yeah you're not as good as what they hoped'. But the fact that you merely survived, is quite miraculous. (Nurse 12)

The nurses all told of being troubled when predictions of survival and outcome were not accurate. They spoke of situations when parents were asked to withdraw life support, they refused and the baby lived and defied predictions. One nurse stated:

Nobody knows the outcome of any of these kids, so it's very hard. A couple of babies that we've talked to parents about turning off have turned out great. Yet, we were wanting to turn that baby off. (Nurse 8)

One nurse, who had seen two of these babies have good outcomes, still had a spark of hope:

I might think the child needs to be turned off. I thought a couple of times babies... I really thought they should be turned off and they should die. They [medical staff] have persevered and these people have come back OK. (Nurse 24)

This thinking is in keeping with McHaffie and Fowlie (1996, p. 90) who found that when nurses saw children running around enjoying what was considered a relatively normal life, they realised the child's life would have ended if treatment had been withdrawn. Several nurses in the current study wondered how many babies who had treatment withdrawn might have had a positive outcome. In their hearts and their minds they thought they understood that when withdrawal of treatment was suggested it really meant the baby had no chance. In reflecting on this issue one nurse concluded that any decision will carry some uncertainty, '*...we know a certain amount of the picture, but we don't know the full life picture*' (Nurse 17).

The medical and nursing staff were occasionally wrong in their predictions of outcomes, but mostly their predictions were correct. All nurses spoke of observing one baby who had defied predictions and do well, but very few spoke of more than one. Doctors and nurses have been found to be wrong in one third of their predictions about the baby's survival, however, nearly 90% of those predicted to die but who lived developed severe neurological problems. Doctors and nurses were accurate in their predictions of neurologically intact survival (Frain, Ren, Meadow, Lantos and Meadow 1998, p. 29A).

Five nurses were aware that some of the uncertainty associated with predicting outcomes could be reduced. A scoring system CRIB (Clinical Risk Index for Babies) I and II (The International Neonatal Network 2005; Parry, Tucker & Tarnow-Mordi for the UK Neonatal Staffing Study Collaborative Group 2003, p. 1789) exists, which if used in the first 12 hours of life in babies less than 1500grams and less than 31 weeks gestation, is designed to predict early death, and the risk of disability after 18 months of age. It is believed this scoring system is more accurate than birth weight or gestation for making predictions (Tarnow-Mordi, Mutch, Parry, Cockburn, McIntosh and Scottish Neonatal Consultants collaborative Study Group and International Neonatal Network 1995, p. 58).

CRIB can remove some of the uncertainty associated with predictions related to death and disability (Broughton, Berry, Jacobe, Cheeseman, Tarnow-Mordi, The NICUS Study Group, & Greenough 2004, p. 389)

9.1.4 Reflecting on success and failure

The nurses all felt a sense of despair when they reflected on the babies they perceived to be failures. This feeling was not uncommon because of the incidence of poor outcomes. One nurse stated, '*...I don't know whether we've actually had anyone come through that's completely normal*' (Nurse 19). It was common for the nurses to consider their work in terms of success or failure. They invested much in order to achieve a positive outcome for the baby.

...doing the damndest to make sure that this is going to be a very positive outcome. That you are going to have someone who survives intact and intact well. (Nurse 6)

Success is an event that accomplishes its intended purpose, while failure is the fact of not achieving the desired end or ends. A focus group of three nurses spoke of failure:

For the one success, you've got all those fails. (Nurse 23)

In our eyes failures. (Nurse 22)

They're not complete. (Nurse 21)

No, the outcome is not positive. (Nurse 22)

To the nurses, success represented a child with minimal or no disability. A negative outcome or failure would represent the profoundly impaired child. These professional nurses wanted to see the outcome of their work. It brought the nurses enjoyment when parents brought babies who were regarded as successes back to the NICU. The baby with a good outcome reinforced the positives of the NICU for the nurses. At times it was difficult for the nurses to feel a sense of professional achievement about some of the results (Chatfield 2006, p.217). When the nurses encountered a baby they perceived a failure they questioned whether the outcome could have been different. The nurses'

desperation made them feel awkward when they observed babies with poor outcomes. Several nurses told stories about babies with poor outcomes visiting the NICU. The nurses said they could not face the parents, because they did not know what to say to them. One nurse questioned her role in saving the baby, '*...it's only if they come to haunt you, like this child comes back to visit one day and I'll see what he's like and I think 'What did we do?'*' (Nurse 24). The nurses explained that encountering the baby and family brought guilt. Positive outcomes were part of their professional self esteem, giving them professional pride. The nurses all considered themselves partly responsible for the outcome of the baby. This responsibility was, at times, hard to bear, hence their avoidance of the situation. For many nurses this behaviour lessened with experience, as they came to recognise a baby's outcome was not their responsibility. They also realised the family's intention, when visiting the NICU, was not to blame the staff for the child's outcome but to show off their child and his/her accomplishments.

The nurse and family could differ on their perception of success. One nurse told of a family with a 23 week gestation baby. The baby had been discharged home. The nurse encountered the baby's father while visiting a patient in hospital. She was reluctant to enquire after the baby and was guarded as she asked about the baby. The father explained his baby was doing well. The nurse stated, '*Oh that's fantastic news*' (Nurse 11) and felt more able to continue the conversation.

I said, 'Has she got any handicaps?' He said, 'Oh some.' I said, 'What?' and he said, 'Oh she's blind'. I said, 'Oh, that's a shame.' He said, 'Oh, she can't communicate at all. She doesn't speak.' I said, 'Oh OK.' 'She can't walk yet, she's five.' I said, 'Oh!'. 'Oh, she's got real bad cerebral palsy.' I said, 'Oh, OK' I said, 'Are you happy with what she's achieved?' 'Oh, yes, she's a lovely child, we love her to death.' (Nurse 11).

This nurse found it difficult to understand the parent's perception of this child as a positive outcome. She was pleased the child was happy and loved, yet she could not equate the father's and her own ideas of what constituted a positive outcome.

To me that was just so eye opening. He was really proud of this child...she doesn't communicate, she's blind, she's got bad cerebral palsy and at five she doesn't walk, she goes to a special school. I think to me that's not a save. (Nurse 11)

This situation opened the eyes of this nurse to an understanding that these parents had accepted the reality of their child's disability. Seccombe (2006, p.46) suggests it is important for nurses to have their values and beliefs confronted. Such confrontation of beliefs could herald positive change for the disabled.

The same nurse told a similar story from almost 15 years ago, and that she occasionally saw the child.

I see her sometimes when I go to church...she's dreadful. I can't even look at her. I know I was there at the time and he [doctor] kept this baby alive and he shouldn't have. This baby, this child cannot walk, cannot see. She sits up in the church choir shaking and rocking, and I don't think that's a good save. I believe that child should have been turned off. (Nurse 11)

The nurse was able to acknowledge that the child had an acceptable quality of life, she had a family, a community and was loved. Yet, for this nurse, this child was perceived as a failure. Nurses might hold negative attitudes towards the profoundly disabled because of fear, cultural and societal influences. The disability could become "the distinctive characteristic masking other traits and potentials of the people with disabilities" (Lee & Rodda 1994, p. 231). It is likely that nurses are influenced by the medical model of the NICU which would see disability as a failure to cure.

9.1.5 Summary

The outcomes of extreme prematurity were a major source of concern for all the nurses. They pondered their role in saving babies who would not have what they considered to be a future. They gave their ideas about what constituted success and failure. The nurses

were troubled when they were confronted with the reality of the outcomes of extreme prematurity.

9.2 Reflecting on quality of life

One of the most difficult issues for the nurses about the outcome of babies 24 weeks gestation and less was quality of life; how it was defined and interpreted. There are two main views about the value of human life. The sanctity of life view holds that all life has benefit regardless of quality. The quality of life view holds that quality of the life saved should determine whether the life should be lived (Kuhse 1995, p. 104). Several issues related to quality of life emerged from the data. Firstly, the nurses all believed that quality of life was a personal construct. They considered quality of life to be confusing and subjective, yet they all overwhelmingly believed quality of life determinations were important. Secondly, the nurses all believed having quality of life meant the person would have some degree of independence and employment. Thirdly, cognitive disabilities were considered to be worse than physical disabilities. Fourthly, the nurses all emphasised their belief that biological existence without the possibility of a meaningful life was not easy to accept. The nurses understood that life should have purpose and meaning for the individual who lives it.

In the questionnaire the nurses were asked if quality of life was important when making decisions about babies of 24 weeks gestation and less. The response was an overwhelming affirmative. When, however, they were asked the open ended question “How would you define quality of life”?, their responses made clear that they had difficulty in defining quality of life, yet believed it was important. Quality of life was intangible, though they said they knew what it was but were unable to express it in words. Although they might not be able to define it, they thought they could recognise quality of life when they observed it.

9.2.1 Brain function and quality of life

The nurses were all convinced that quality of life involved possessing a functioning brain and being able to think. They held that having a functioning brain meant the person would be educable, thus have some control over his/her life. One nurse suggested that, *'...to me if you didn't have the brain working, I don't think that would be a great life'* (Nurse 16). The nurses were not sure what degree of cognitive disability would constitute a poor quality of life. They supposed an ability to earn some sort of a living would contribute to the quality of life. One nurse put forward,

You have to have a small amount of brain, but you wouldn't have to have an intact brain. Your functioning centres, your cognitive ...so you know what's going on. So you can do something to get your money. Some way that you can support yourself. A moderate amount of brain function. (Nurse 24)

An ability to use the brain and being able to make decisions was considered essential.

Quality of life constitutes a brain to think, feel and make decisions. The ability to be able to have a relatively independent existence free of pain. The ability to fulfil most dreams and expectations of life. (Nurse 5)

Another nurse was vocal in her belief of the importance of a functioning brain, and to her a life without a brain would lack quality.

I am mostly in the head person. I would probably associate most things with heads. I think that quality of life, for me anyway...I would like to think that I have a fair amount of reason and can think about things in an intellectual kind of a way. I don't think that someone who is brain damaged for numerous years is enjoying a quality of life that I would consider to be a quality of life. There may be a life, but I would question the quality. (Nurse 10)

The nurses all considered cognitive disabilities to be worse than physical disabilities, even extreme ones. One nurse suggested, '*...if you're a spastic quadriplegic too, with a good brain...then there's ways around*' (Nurse 24). Several nurses gave the example of Stephen Hawking, one of the greatest minds of our time who, because of motor neurone disease, exists in a wheelchair. The nurses saw him as having quality of life, '*...as long as he's still got his mind*' (Nurse 12). Not all physically disabled persons, or able-bodied persons with intact brains have the brainpower of Stephen Hawking. He was not born at the edge of viability. Stephen Hawking is a good example of a person with motor neurone disease, but not the survivor of extreme prematurity. A newspaper article spoke of an Australian adolescent with cerebral palsy who was wheelchair bound, yet achieved amazing marks in her Higher School Certificate (Milligan 2003, p. 11). This adolescent is an inspiration for others with cerebral palsy, however, she was not born extremely premature. Major differences exist between the brain that has developed, and the brain that is still developing when the damage occurs.

The nurses all emphasised the importance of communication and knew that a functioning brain allowed people to communicate their needs. One nurse explained:

If you've got your brain, at least you can think of things. You can sit down and you can think of things. You would be aware of things that are going on around you, and you could communicate to people. (Nurse 12)

Several nurses were concerned about the level of negative stimulation, such as noise, babies received in the NICU when the brain was growing, developing and prone to potential insults. Perry (2001) acknowledges that negative stimulation can disrupt brain development. The ramifications of this could be profound as explained by one nurse:

All that constant negative stimulation that they get turns them into...I can't see how they can be a normal human being. I don't see how we can expect them to function...The way that their brain has been put together at that stage, because they've just been totally stimulated from the word go. (Nurse 6)

Damage to the brain cannot be seen. For this reason several nurses thought the public could believe a baby born with physical defects might have a worse outcome than a baby with neurological damage. Their experience also led them to conclude the size of an external physical defect was not an indication of the outcome for the baby. One nurse explained:

I think the layperson can't see the bleed in the head. The baby still looks relatively normal. Whereas something that you visualise like a gastroschisis [abdominal wall defect], something that's so horrible to look at, is so shocking for them, and they feel like they will have bad quality of life, where it's going to be perfect. (Nurse 11)

Most nurses thought that parents would have difficulty accepting a child with a major neurological disability.

I think most people could accept a child who is blind, even cerebral palsy quite often is manageable, mild cerebral palsy, but I think when you have major neurological problems the quality of life is...no use. (Nurse 11)

The nurses were convinced that families also considered brain function to be important and neurological damage could be the reason the parents withdraw treatment. One nurse emphasised:

They [parents] seem to think if the brain is OK, then they they'll cope with anything. If there's a problem with the head they're more likely to pull out, or they seem more likely to pull out. (Nurse 16)

9.2.2 Quality determinations for nurses

The nurses all attempted to form quality of life conclusions by projecting themselves into a situation they would find either acceptable or unacceptable. One nurse stated, *'I think nurses have to put their own values on what they think a good quality of life will be'*

(Nurse 16). One nurse used the example of her sister with severe eyesight problems, making it impossible for her to drive a car. She admitted:

I find that mortifying...I can't be independent by driving a car and doing what I want to, when I want to do it by having my own car. I see that as a major handicap. (Nurse 1)

Another nurse explained:

I suppose I look at quality of life in how I would like to be. I think if I can hold down a job, it doesn't matter to what extent the job is. (Nurse 2)

And for another nurse quality of life was being, '*...able to experience the joy in life. I think that's a very important component. To have the neurological ability to experience joy*' (Nurse 4). Joy relates to pleasure and satisfaction, and to one nurse:

Everybody feels joyful about something different...I think laughter and family. My job satisfaction is tremendously important. I actually get a real buzz out of my job and that contributes to my joy in life. I think it would be quite soul destroying to have to go to work every day and do something that you hated doing. (Nurse 4)

Joy for this nurse was linked with family, friends and having a worthwhile purpose in life equating with employment. Another nurse stated, '*...my definition of quality of life would be to live life independently, that is to be able to support myself*' (Nurse 4). The nurses held that holding down regular employment, regardless of what it was, would make them feel worthwhile.

You don't have to have two arms and two legs to hold down regular employment. There are plenty of people out there, quadriplegics that are holding down a regular job. (Nurse 10)

Employment gave this nurse a sense of self worth because she would be, '*...able to contribute in a worthwhile sort of way*' (Nurse 17), which would also give her, '*...some and control over your life*' (Nurse 17).

The ability to interact and communicate with others was held to be important.

Communicating your wishes to others was also seen as important. One nurse explained:

Quality of life for me is if you're aware of your surroundings so that you could interact with other people, and people knew what you wanted and could fulfill your wishes. (Nurse 12).

One nurse considered that quality of life was about, '*...the ability to enjoy. The ability to sense love and affection*' (Nurse 6). The nurses all held that quality of life was about having some independence and not relying on others to have basic needs met. One nurse suggested, '*...if you could do things for yourself to a degree that you didn't have to rely on other people all the time*' (Nurse 12). The nurses were committed to the belief that '*you certainly need to be able to look after your own personal care and hygiene and feed yourself*' (Nurse 23). Another nurse emphasised '*I would like to bathe myself and go to the toilet by myself, and not have to rely on people for the basic necessity of life*' (Nurse 2). It was clear these nurses would find it intolerable for other people to attend to their most basic needs.

Autonomy and the ability to make decisions featured in the quality of life discussions.

One nurse emphasised, '*...being able to do what I want, when I want, how I want to the extent that I want, to me that's quality. I can make my own decisions*' (Nurse 21).

Another nurse explained that her quality of life was about being able to use her hands as she did a lot of handicrafts.

If I was paraplegic, that wouldn't mean anything to me, because I'd still have the use of my hands. For me my hands are very important. Take my hands away, you've taken my life away (Nurse 12)

Another nurse experienced similar feelings and stated, *'I'd be useless, if they took away my sight. I wouldn't be able to sew. My God, I'd die'* (Nurse 23). It is interesting that in the discussions on quality of life the nurses focused on what could not be achieved, rather than what could be achieved. It seemed as if through projection of themselves into the future without the qualities they valued, they could not imagine a future. There did seem to be some room for compromise when they considered what they could live with and what they could not live without.

It was easier for the nurses to decide quality of life for themselves than deciding it for a baby of 24 weeks gestation or less. They all understood, however, that quality of life projections were, like all things associated with extreme prematurity, very uncertain. One nurse suggested that, *'...for the 24 weeker, you cannot possibly anticipate what quality of life the child will ever have. It is something intangible'* (Nurse 4). There was much uncertainty, yet the nurses did go on to discuss what would constitute quality of life for an extremely premature baby. One nurse suggested, *'...we should think more of quality of life, rather than the numbers that survive'* (Nurse 8). Productivity was mentioned, and one nurse suggested decisions should take, *'...into account whether or not they'll be a productive member of society'* (Nurse 15). One nurse told how she stood at the end of the bed and tried to imagine the future for the baby.

You can just see it lying there, and you wonder how is this kid going to be. Is he going to end up lying in bed all day, not doing anything or in a wheelchair. Is he going to get something out of his life? (Nurse 17)

The nurses thought that adults could not imagine themselves having poor quality of life. Bopp and Coleson (1996, p. 133) suggest this could be because those unfamiliar with the experience of living with a disability might think it would be easier to accept death for persons with a disability, than life with a disability.

There were further difficulties for the nurses because the babies were growing and developing and the full potential of a baby might not be known for several months. The unknown was difficult.

You don't know the quality of life until they're 6 or 8 months old. This is the hard thing when you say, 'Oh, well, turn this one off and leave this one on.' You just don't know. You can have a kid that has a Grade 3 bleed, might turn out all right at the end, you don't know. (Nurse 18)

The nurses were all adamant that the surviving extremely premature baby should, '*...know that you're alive to enjoy life*' (Nurse 23). This notion of being alive to enjoy life would be difficult to assess. When it came to determining what was acceptable, one nurse suggested:

I think if you've got a baby that's going to never grow, never feed, never know anything of life other than more pain, that is not quality of life. But a child that is at least going to be able to receive something, hear something or see something, touch, taste, feel something. Have some of his five senses...he can receive something. He's going to have an amount of quality of life. If you take all of those away, what have you got? Just a body! And that's not quality of life. (Nurse 9)

To this nurse, the body was the corporeal being only, without a functioning brain to ensure the baby experienced life. This idea was commonly expressed. Another nurse suggested that:

My quality of life would be that a child might not necessarily walk, he might not necessarily talk, but as long...able to do something for himself. He's going to be able to get something out of that life that he's given. It's not just going to be left on a bed and be a vegetable. (Nurse 9)

To another nurse the important aspects were being active and able to be educated. One nurse explained, '*...if you're looking at children, my definition of quality of life for*

children is that they're active, they can learn basically in mainstream education' (Nurse 19).

Overall the nurses had problems in defining quality of life, and many could not devise definitions that fully represented their beliefs. One nurse stated:

I don't know how my definition [of quality of life] went, because I couldn't actually find one. There's a lot of talk about it, because when I thought about it, I thought, 'Well, what does it really mean?' I ended up with a very messy sort of arrangement that got close to my definition of quality of life. (Nurse 14)

The nurses all experienced difficulties with the definition and concluded that quality of life was a personal construct. One nurse articulated, '*...everyone has their own values and my value of Quality of Life is different to somebody else*' (Nurse 16), while another nurse suggested that, '*...everyone has a different idea of what's important*' (Nurse 18). Their confusion was expressed by another nurse who stated, '*...there's no consensus. There's never going to be a consensus*' (Nurse 20).

The nurses all struggled with ideas about a life that lacks quality and whether it was better than no life at all. The subjective nature of quality of life was important. The nurses all judged the existence of others by how they believed they would or should exist. One nurse believed health professionals need to be cautious when making decisions based on quality of life assessment when she stated, '*...we have to be very careful in decision making about whether children live or die*' (Nurse 13).

Several nurses realised that if they experienced difficulty in thinking clearly about this topic, they should try to imagine how difficult the parents found the concept of quality of life.

If nurses can't define it, how can parents define the same thing? What do they think is the worst they'd expect their child to survive with? What is the worst that they'd cope with? (Nurse 24)

One nurse when asked by parents to define quality of life said she experienced great difficulty.

It's very difficult to define. I even had a parent say , 'You doctors and nurses, you always talk about quality of life. What do you mean?' And I was umming and aahhing. What one person thinks is how we should live our life to someone else's are totally different.

(Nurse 17)

The difficulty for the nurses lay in thinking that if quality of life determinations are not used, what do they use. Such thinking could mean every life should be saved, a position in keeping with the sanctity of life philosophy. The nurses, even those who identified with a Christian ethic, did not identify with a sanctity of life perspective. For all the nurses, quality of life seemed to be about choice, and if parents believed their child's life had quality then they accepted that judgement. After all, the nurses might agonise over decisions while the baby was hospitalised, but once the baby had gone home, they hoped for the best.

9.2.3 Future shock

The nurses all tried to imagine the future for the family. Several nurses believed the parents of the extremely premature baby might also try to project themselves into the future. This projection could be difficult, because the parents might not have had the experience of caring for a disabled child, a child who was blind or required full time care. On the other hand, parents may have friends and relatives who were disabled, therefore their decisions could reflect their own experiential knowledge. One nurse explained:

It's a personal decision of what you think is critical. Someone who is told that their child will probably have very poor eyesight. You have family members who have very poor eyesight who have managed, and don't see that as a problem. Someone who has a mild degree of cerebral palsy and there is a family member, relative with a mild degree of the cerebral palsy. You may not see that as a poor quality of Life. Down Syndrome. Some people are mortified...they've got a Down Syndrome infant and other people think, 'Oh

well...I have an adult who is Down Syndrome who works where I work, and they're a happy person and they're independent in life'. It's very much what you define and from your experience and knowledge of what is to you quality of life. (Nurse 1)

The nurses noted that societal attitudes to disability had changed in recent times. The example given by most nurses was children with Down syndrome, and how it was once acceptable to deny surgery and treatment. This approach was the basis of the famous baby Doe case in the USA (Singer 1995, p.19). The nurses recognised that children and adults with Down syndrome make a meaningful contribution to society. One nurse stated, '*...we can see over the last 25 years the change to Down syndrome. There's no need to dismiss them as a non productive member of society*' (Nurse 15). Another nurse stated, '*...a lot of them do very well... they cope quite well*' (Nurse 16). It remains difficult to know whether productivity is an essential component of what was considered a meaningful life for the person involved, or whether it is related to a person's worth. Productivity for the nurses was not necessarily associated with earning money and paying tax, it seemed to be more about the individual making an impact on others.

The nurses all believed families needed to understand the reality of taking a disabled baby home. One nurse explained:

Most of these parents have never had anything to do with babies who haven't turned out well...having a child who is going to be someone who totally changes your entire life. They're going to probably outlive you. Do they know what it's like, and what it means? (Nurse 14)

The nurses were all further convinced that the quality of life for the parents and family was of equal, or greater importance than the quality of life for the baby. It was clear for the nurses that the best interests of the baby were entwined with the best interests of the family. For one nurse the important thing was, '*...quality of life [of the baby], quality of family life, quality of sibling's life, everyone's life*' (Nurse 14). Another nurse suggested:

I think as they [baby] become more that person, they gain more right to life. I think down this end of the spectrum, the family has more right to their life than that baby does. Sure it's a life, but the life that that family has...the siblings and everyone, they've got a life, they've got expectations,...plans. They've got a right to that, more than that baby has.
(Nurse 14)

The nurses had experienced situations where parents made decisions about withdrawing treatment based on how they would manage the possible outcomes of extreme prematurity. One nurse told a story about parents:

Could not give up their quality of life for this child. Be that totally selfish, many people thought so. Totally honest, many people thought so. Looking at the big reality of life...the impact of a 23 plus 6 weeks is going to have on their life. It is 160 days...these 24 weekers stay in hospital for. That's a long time. That's...5 months this child is going to be in a hospital for, and that is going to disrupt their lives majorly. These people chose their future and their stability as a couple. The child was going to have all these difficulties...and they just thought 'No. We cannot. We're not prepared for this.' (Nurse 1)

This nurse expressed her sadness at this situation, yet she believed the parents had the right to make that decision.

The nurses all continued to express their deep concern about the quality of life for the parents following discharge. One nurse stated:

It's very hard on the parents. You've got to think of them as well. Can they cope with this and do they know, really know how hard it's going to be? (Nurse 16)

The nurses spoke about the major disruption families endured, and according to one nurse:

The family is completely disrupted geographically and emotionally, at least for the period of this initial crisis management, and most probably in the long term. That disruption can

go on for years, depending on the child's condition and how long it survives, and whether it ends up with a profound and long term illness. These people are under tremendous strain. I think it strains every aspect of your life. What happens to the family? (Nurse 4)

Another nurse maintained that having an extremely premature baby, '*...does break down families and cause total disruption to people's lives*' (Nurse 13). The nurses were all convinced that the lives of families could be changed forever, and they constantly worried about whether the family unit would survive long term hospitalisation.

9.2.4 Being saved to be institutionalised

Several nurses had problems in reconciling the saving of a baby's life and then for the baby to be institutionalised. Many of the nurses had seen babies placed in institutions. They believed this happened when the parents did not understand the ramifications of their decisions.

That family had a child that ended up in [hospital for disabled babies]. They wanted everything done, they insisted on it. They were given the option a couple of times to pull out. The doctors did not want to go any further with resuscitation and they wanted to...do everything. A couple of years down the track, they said. 'No, we weren't told what it was going to be like.' They didn't really understand, even though they were told. (Nurse 24)

The nurses' stories were full of regret and disappointment. They agonised over whether the baby would have a good life. The nurses experienced guilt, believing they had contributed to the baby's institutionalisation. They were convinced they had the baby's long term welfare at heart, but they had entrenched notions of life in institutions.

Parents can say, 'Oh yes I want this child', but then if they're going to dump it off into some institution, what's the point? You still haven't got your child. You may as well have taken the hard decision and let that child go without suffering. You don't know how much they're suffering in these institutions. These institutions no matter how good the staff are, they're never your own family. (Nurse 12)

The nurses were troubled when parents insisted their baby was treated and then became institutionalised. They spoke of parents who were told the outcome would be poor, yet insisted their baby's life be saved. One nurse commented that, '*...even when you give them a totally bleak outlook like this baby is going to have severe cerebral palsy, they still sometimes say, 'We want everything done'*' (Nurse 13). Several nurses noted that parents could forget they had been told the severity of the expected outcome.

The parents...we gave them the option of withdrawing and they wanted everything done. Later they don't remember us saying that and they blamed the hospital for helping this child survive. (Nurse 24)

It is interesting how the nurses thought about parents making decisions about their child. They accepted it would never be an easy decision for parents to have their child institutionalised. The push from the Australian Government to keep children at home has made institutional placement difficult to access (Bain 1998, p. 598). It is possible that prolonged, intense and recurrent sorrow could induce such severe psychic pain in the parents, they choose to withdraw from the relationship with their severely disabled child, resulting in institutionalisation (Teel 1991, p. 1317). The nurses knew it would not be easy for parents to have their child institutionalised. Admission to institutions are restricted to non-ambulatory, non verbal children with severe physical and cognitive disabilities (Savage 1998, p. 56). Bain (1998, p. 598) speaks of anecdotal reports, "...that a cat-and-mouse game ensues as parents are required to demonstrate their trauma". Such game-playing to access institutions may involve making the child a state ward, manufacturing homelessness, or following the child protection route associated with child abuse (Bain 1998, p. 598). This clearly is not an easy process.

The nurses in the current study considered their efforts wasted if the baby was institutionalised. They assumed that if parents desperately wanted their baby saved, the baby was likely to go home to a loving nurturing family. The nurses spoke of their disappointment when they were informed a baby had been institutionalised. They understood that some parents were unable to care for a severely impaired child but questioned whether the baby's life should have been saved. They also questioned whether

their professional nursing skills should be used in this manner. It was difficult for the nurses to see babies institutionalised knowing that babies who are institutionalised before the age of six months suffer long term developmental delay. It is preferable that children less than three years old not be placed in residential care without the presence of a parent or primary caregiver (Brown 2005).

The question arises about who the nurses believe they are nursing when they care for profoundly damaged and disabled babies. Families of patients who are brain damaged experience the permanent loss of a loved one, even though the person is still alive. The living body serves as a constant reminder of the loss (Hainsworth 1998, p. 41). A living baby is a constant reminder to the nurses of the parent's loss and the loss of the baby's future. This is loss without death.

9.2.5 Summary

The nurses all held firm to using quality of life as a basis for decision making. It was difficult for the nurses to operationalise a definition that encompassed the qualities they believed necessary for a life to possess quality. They all believed in the concept, yet when asked to elaborate, many faltered. They spoke of knowing what they would want for themselves and the difficulty of deciding for another. Quality of life for the baby was seen as important, however it was equally important that quality of life for the family be considered.

9.3 Reflecting on the burden

The nurses believed there were many burdens in the experience of caring for babies of 24 weeks gestation and less. If the baby had a poor outcome and became severely handicapped, the baby was seen as a burden on the family and community. The nurses all emphasised it was babies who survived with severe disabilities requiring constant care that worried them.

Society places high value on beauty, intelligence and sporting prowess. Although there are many disabled citizens who manage well in a society designed for the able-bodied, this is not the case for those who are profoundly physically and mentally disabled. Children with disabilities have traditionally been seen as a tragedy from which the family will never recover (Kearney & Griffin 2001, p. 582). The negative perceptions of the nurses might have led them to believe that having a disabled child is a, "...deadly pall of tragedy that hangs over the family" (Summers, Behr & Turnbull 1989, p. 27). The nurses adopted this viewpoint, although there was recognition of the positive contributions these children make.

The nurses all experienced anxiety when they labelled a baby a burden. The baby as a burden was about not being able to care for oneself, and having to rely on others for basic needs. The nurses emphasised that all babies were unable to care for themselves, however, there was an expectation as they grew older they eventually developed independence. It was the understanding of the nurses that a baby who was severely impaired state would require life-long care. Brinchmann (1999, p. 137) suggests "it is like having a baby who never grows up". This idea is mirrored by Savage (1998, p. 54) who suggests that the profoundly disabled child, "...has the needs of a newborn".

9.3.1 Reflecting on the family burden

The nurses were all committed to the idea that if extremely premature babies survived in an impaired state there was an obligation for society to care for them. They held that society should shoulder the ongoing financial responsibility for disabled babies. The nurses spoke of collective responsibility.

The hospital has kept some of these children alive that once would not have survived...
Society then still does have to bear the burden of what we've done. (Nurse 9)

The nurses regarded the baby's life long care as the responsibility of society, not just the parents. They understood that sharing the burden might decrease the parental burden.

Professionals might err on the side of saving the life of an extremely premature baby, however, the parents are the ones to bear the burden of the child's survival (McHaffie & Fowlie 1996, p. 258). The shift of healthcare to the home setting has resulted in a dramatic increase in the day by day responsibility placed on the family. It is recognised that wherever possible, children with disabilities should be care for at home (Gatford 2001a, p.110). The home is considered the optimal environment for the disabled child's social and psychological development (Leonard, Johnson & Dwyer Brust 1993, p.94).

The nurses could all see that family members were expected to accept responsibility, provide care, and assume the caregiving role without regard for the emotional, physical and financial consequences. The burden of giving care to chronically ill or dependent family members can be overwhelming (Clark & Stannard 1996, p. 58). The effects on the parents of providing this care is often overlooked (Gatford 2001a, p. 110). Elliott (2003, p. 16) states that the, "...parents often look like war veterans, exhausted and shell shocked". The nurses were all concerned about the load they believed parents carry. The burden of caring for the extremely disabled child can be thought of as any negative consequence to the family, or the mediating force between the child's disability and the impact of caregiving on the family. Caregiver burden results from the imbalance between the child's demands and the caregiver's resources (Chou 2000, p. 398). Caregiver burden is related to the persistent hardships of caregiving, which are the physical, psychological, financial, and social problems experienced by those providing care. When the caregiver's resources are not sufficient to meet the specific demands of the child, the caregiver can experience overload.

The nurses all held that the burden on the parents should be decreased. It was their understanding that life for the parents had irrevocably changed. They believed families of disabled children had major stressors which might impinge on their ability to care for their children. In addition, the burden could be increased as families who care for a child with a severe disability are likely to be socially excluded (Gatford 1999, p. 32).

It was the understanding of the nurses that it was the mother who provided the majority of care for the baby when discharged. Women provide care in over 75% of situations (Kasuya, Polgar-Bailey & Takeuchi 2000, p. 119). Nelson (2002, p. 515) states there are both positives and negatives associated with “mothering other-than-normal children”. Caregiving could be without help and support from others. Most nurses considered this situation could be a burden for the mother. This view is confirmed by Davis, Logsdon and Birkmer (1996, p. 263) who stated mothers of disabled children received less support than they expected would be available. It was the belief of all the nurses that there were not enough resources in the community.

There are concerns for how the family may actually deal with a very small baby, if the baby does survive, sick, disabled or damaged child in some way. It’s a huge concern. There are often not enough resources in place to actually help those parents deal with those concerns. (Nurse 10)

One nurse emphasised, ‘...we’re often very concerned about how they’re going to cope in their home and what community supports they actually have available to them’ (Nurse 10). This concern is confirmed in an account by a mother of a disabled boy (cited in Gatford 1999, p. 33) who stated that she had learnt to become a fighter, and learning to deal with difficulties had become a way of life as she battled with authorities to obtain services for her son. In contrast, a mother of a disabled adolescent in Chambers, Hall, Datta, Harpin and Gentle (2000, p. 16), found, “...everything is there when they’re children...it’s handed to you on a plate, but suddenly they get to nineteen and everything disappears”. For this mother, the transition to adulthood for her profoundly disabled son meant services were no longer available. This situation is confirmed by Fiorentino, Datta, Gentle, Hall, Harpin, Phillips and Walker (1998, p. 306) who found that when disabled adolescents leave the domain of paediatric services the quality of their medical care declines.

The nurses knew, too, that parents had difficulty receiving adequate respite care. Respite care services provide relief to the primary caregiver from the intense caregiving demands of the child with disabilities (Cowen & Reed 2002, p. 273).

Although the nurses were very aware that caring for any child required great effort, they all knew that severely disabled children required substantial care, however the nurses emphasised that seemingly normal children required substantial care. They worried about the effects on the mothers.

You realise how hard it is to look after a normal child, and that normal is very subjective. If you had a child who had all sorts of other challenges, providing that care, would make your life and your relationships extremely difficult...makes it more tough if you have a handicapped child. If you have a child who requires constant medical attention. If you have a child who won't fit into the mainstream, then you are the slave and the servant of that child, and you very much lose out on your own life. I would find that extremely difficult. Yet we are asking the mothers to do that. Suddenly their life is just lost, it's not even slightly slipped back, or gets put behind, its just completely lost because they are suddenly turned into the slave and the general 'do it all' for these extremely handicapped children. (Nurse 6)

It was the perception of this nurse that life for the family and especially the mother of the profoundly disabled child would be destroyed. This view was held by of most of the nurses to varying degrees. These nurses did not explain how they obtained their information about disabled children, however, as Kearney and Griffin (2001, p. 582) argue, everyone has assumptions about what life with a disabled child would be like. When questioned, the nurses revealed they had visited homes for the developmentally disabled during their nursing education. They had observed babies who were profoundly disabled and acknowledged their perceptions of quality of life were shaped by children in institutions. Only one nurse had worked in an institution for developmentally disabled children.

I've worked in some institutions...a nursing home for one to 45 year olds. These institutions no matter how good the staff are, they're never your own .. family...so you never have that bond . Leaving your child in one of these institutions is never the same as if you looked after the child, even though it's very difficult. It's always a stranger they're looking after. Even if they become bonded to them...it's not the same. (Nurse 12)

The view of the nurses without experience of caring for the disabled may be “narrow and distorted” (McHaffie & Fowlie 1996, p. 91), and might be different from those who have worked closely with the profoundly disabled. McHaffie and Fowlie (1996, p. 91) suggest those with experience with caring for the profoundly disabled might lean towards two options; the belief that all life has value, or the belief that with the amount of indignity and suffering involved, the baby should be allowed to have an early death with dignity.

It was the understanding of some nurses that parents with a disabled child experience unique difficulties. The severity of the child's disability could be one of the determining factors in whether or not the family manage to care for the child at home (Leonard et al. 1993, p. 101). One nurse suggested some parents might, ‘...*really embrace the situation that they are in*’ (Nurse 5), although she wondered if this presentation was accurate, ‘...*I don't know whether that's just what they want us to think*’ (Nurse 5). Parents of disabled children represent themselves to the world in a number of different ways. Knafl and Deatrick (1987, p. 300) found that families use normalisation to portray an acceptable family life to the outside world. This finding is confirmed by a mother of a disabled child in a study by Brown, Uhl and Baughan (2002, p. 24) who stated, “...people tell me I'm handling this so well...they have no idea that I just put on my ‘happy face’ when I leave the house”. Olshansky (1962, p. 191) has spoken of the need for parents to keep a, “...stiff upper lip” when they leave the house.

All the nurses had noticed that families struggled financially to provide their child with quality care. They knew the family was expected to shoulder the financial burden when their baby was discharged. They were very concerned about how the family would survive financially.

Most of these parents financially won't be able to survive, because it costs such a lot of money, just for a wheelchair. You're looking at thousands [dollars]. (Nurse 18)

Financial complications can develop because of reduced income and the need to make adaptations to the family home (Gatford 2001a, p. 110). Several nurses spoke about parents whose earning capability would be halved if the mother assumed full time care-taking of the child. One nurse questioned how families could manage these difficulties.

How on earth can these parents cope? Most of them are either financially worse off than Mr and Mrs Average. How financially are they ever going to be able to give up work, change their house? (Nurse 19)

Financial hardship would appear to be a relevant concern, as Lukemeyer, Meyers and Smeeding (2000, p. 399) found that children with physical and mental impairments could impose substantial costs on families. These costs included specialised medical care, therapeutic and educational services and transportation needs. The time required to care for the child limited the ability of the primary caregiver to sustain paid employment (Lukemeyer et al. 2000, p. 399).

Although the nurses did not discuss how they obtained their views, they all observed the life of the family and could see that they would be burdened by the existence of the child. This belief might have materialised because they considered how they would be affected in a similar situation. The attempt to walk a mile in the shoes of another does not always allow for an authentic conclusion. There is, however, an abundance of literature that has shown the birth of a child with an intellectual disability is associated with family dysfunction and pathological reactions (Stainton & Besser, 1998, p. 57). There is, in addition, evidence that parents take up the challenge of a handicapped baby and it makes them better and stronger people (Saigal Burrows, Stoskopf, Rosenbaum and Streiner 2000, p. 703). Stainton and Besser (1998, p. 57) found children with intellectual disability could have a positive impact on their families. Mothers in a study by Glassock (2000, p. 410) reported a positive perception of their caregiving role for a child with cerebral palsy and emphasised they enjoyed mothering their children. Green (2003, p. 1) found that the

stigma attached to the diagnosis of cerebral palsy for her daughter was worse than the disability. Luescher, Dede, Gitten, Fennell and Maria (1999, p. 642) found that the degree of parental burden depended more on the parents' coping skills and level of family functioning rather than on the degree of the child's impairment.

9.3.2 The burden on society

Extremely premature babies surviving with severe disabilities were viewed by most nurses to be a burden on society. The frustration of one nurse was palpable as she explained her thinking,

We have so many babies that we see down the track. I mean so many of them are real basket cases. I'm being horrible, but they really are. They put such an enormous strain on the community. (Nurse 3)

Thought was given by the nurses to the financial cost associated with providing care caring for disabled children. One nurse reflected:

I've seriously considered what that family will generate tax wise over the years. If this isn't a good outcome how much this child will cost to the community in terms of handicapped children's care. (Nurse 6)

When there was a chance the baby might survive intact, or with minimal problems, the nurses did not raise matters about costs and contribution to society. They spoke though of the assumption in society that citizens will pay taxes and contribute to the gross national product. The nurses did not think NICU could be cost-effective if extremely premature infants were unable to contribute financially to society. They spoke however, of the joy the profoundly disabled child brings to others beyond financial considerations. It was the continued financial burden that was of concern to the nurses.

No doubt that child is costing a fortune to the whole community, with having all those problems. The love they're getting from that child, you can't measure that. Human life...you can't measure what it's going to cost. (Nurse 11)

The value of a life and the costs in keeping the babies alive pulled the nurses in opposing directions. In speaking about the high cost of care for the community and contrasting that with not being able to measure the love the parents obtained from their child, this nurse was grappling with notions of costs and benefits as applied to the life of a child.

Neonatal nurses are used to the majority of their patients being healthy and thriving on discharge. They are thanked for their efforts in turning a critically ill baby into one ready to be discharged home. Most nurses experienced feelings of failure when they discovered a baby would be significantly impaired. When the nurses' feelings of failure surfaced they questioned the decision to keep a baby alive.

It's not fair to prolong the baby if the baby has had a very big Grade 4 or even massive congenital abnormalities. It's not fair all around. (Nurse 15)

They all gave thought to whether saving extremely premature babies would increase the numbers of disabled children, acknowledging that numbers of extremely premature babies surviving had increased. They also understood that with developments in neonatal intensive care there had been no appreciable decrease in the long-term morbidity for tiny babies. For the nurses this equated with more tiny babies surviving with severe disabilities. This conclusion is confirmed by Lorenz et al (1998, p. 425). One nurse stated:

The numbers are getting bigger that we're saving. We're trying to save more and more little, little babies. Where do we stop? Do we have institutions simply filled with vegetative infants, who then become vegetative adults? We have to seriously look at some of these issues. (Nurse 12)

9.3.3 The burden on siblings

The nurses worried about what would happen to profoundly disabled children when they aged and who would care for them when their parents died. This is a significant issue for the family (Eisenberg & Baker 1998, p. 355). All the nurses spoke of this issue. Many had spoken with parents who had voiced this same concern. One nurse stated, *'Who's going to look after that kiddy when they're 70? They can't handle her when they're 80. Where's she going to go then?'* (Nurse 19). Parents of disabled children and adults are concerned for the future. Mothers of disabled children in a study by Black Mosen (1999, p.p. 160) were described as "living worried", where worry was ever present. These mothers worried about their children's future, and feared no longer being able to provide assistance for them. One focus group discussed the issue:

My concern is the people who are desperate to take a baby home. It doesn't matter what condition this baby is in, they don't mind changing the nappy, bathing. But they're 45, who's going to look after this child in 20 years time when they cannot do it? (Nurse 2)

They don't see that side down the road. (Nurse 3)

I know, but this is my concern and it's really sad. (Nurse 2)

Look how many little old ladies you see who have looked after cerebral palsy kids and they've reared them all their life. As they get older they can't manage them anymore, and they're in a real dilemma when they die. Who's going to look after their kids and they're going to be institutionalised, because there's not going to be anybody there to care for them. (Nurse 3)

The use of language by the nurses when discussing adults with disabilities shows they have probably internalised the, "...personal tragedy model of disability" (Bynoe, Oliver and Barnes 1991, cited in Richardson 1997, p. 1271). It was their understanding that parents often expected the siblings to shoulder the responsibility. This expectation is confirmed by Nixon and Cummins (1999, p. 274) who found that, "...children experience pressure to become extensions of their parents, taking responsibility for and acting as a caretaker for their disabled siblings". The nurses believed this was an unfair expectation and that siblings were not necessarily prepared to take on this responsibility. Siblings

might have had difficulties with the attention the disabled child received during childhood (Fleitas 2000, p. 269), possibly feeling excluded and taking second place to the needs of the disabled child (Gatford 1999, p. 32). One nurse gave such an example,

I have a friend whose younger brother has severe cerebral palsy. The mother cared for the child. The mother has died recently. He loved his brother very much but he couldn't care for him. He's had to put him somewhere. He was jealous. Jealous that all the time while he was growing up, he'd say to his mum, 'Why can't you do this, why can't you do that? And she'd say, 'Well you know I've got [name of brother] so I just can't. I'm really sorry, but you've got to realise that he takes more of my time, so you'll just have to wait.' (Nurse 22)

There was stress and conflict within that family unit and the sibling was not prepared to live up to the expectation that he care for his brother. Siblings of children with complex medical problems, too, could have experienced feelings of resentment for being left out and for being shouldered with increased caregiving responsibilities (Fleitas 2000, p. 269).

9.3.4 Summary

It was the understanding of all the nurses who were interviewed that extremely premature babies who were profoundly disabled would be a burden on their family and society. They were convinced the parents shouldered the responsibility in providing care for the baby. The nurses all were committed to the belief that society had a responsibility to ensure the family were financially able to provide quality care for their child. They held that parents needed to know what lay ahead, and how to access the resources they needed to ensure the best outcome for their child. It was intolerable for the nurses to believe that parents were abandoned and experienced caregiver burden. There was also an understanding by most nurses that siblings were often expected to become extensions of their parents, and provide care to their disabled sibling when the parents died. Some siblings were unable to live up to this parental expectation.

9.4 Reflecting on the family

It was the experience of the nurses that the long-term outcome of the extremely premature baby would be dependent on the family's ability and willingness to provide care. The nurses all expressed deep concern about the integrity of a family unit when the baby was discharged. It was the understanding of the nurses that a functioning family unit heralded a more positive outcome for the baby.

9.4.1 Survival of the family unit

The role of the neonatal nurse is one that encourages family involvement in their baby's care. It was this family centred approach the nurses held as important. They provided care to the baby when it was critically ill, however, they believed that when the baby was recuperating the parents should play a prominent role. When the nurses were convinced the baby would survive, they switched their focus of concern from the baby to the parents.

It's the parents. I think you switch your concern. You're doing what you can for the child. I don't think it's any different from caring for any of the other children, you're doing your best. But it's the parents...it's parents you're caring for most of the time.
(Nurse 24)

Several nurses expressed concern about parental coping and they tried to inform the parents what their life could be like.

It's caring for the parents where it becomes hard. The child is only in your care for a short time. It'll move on and you only see it in this small form. You don't see all the problems even though you know about them. It's more the parents you're worried about letting them know what life's going to be like... let them know in a diplomatic manner.
(Nurse 24)

The nurses were all worried about the level of parental support when the baby was discharged. They spoke of the support available in the hospital, but concluded they abandoned the parents when the baby was discharged. One nurse explained:

When they leave the hospital, security of the hospital, we're often very concerned about how they're going to cope in their home and what community supports they actually have available to them. (Nurse 10)

The nurses all emphasised that the family, but mothers in particular, needed help at home. One nurse stated, '*...these kids turn into big adults. The weight of lifting them, a lot of them are immobile. It's very difficult*' (Nurse 18). The nurses understood that the mothers were incredibly busy and involved in a range of special care activities.

Physio [physiotherapy] three times a week. Callipers if they can't walk. Special schools. Braille reading. Hearing aides. How on earth do they cope? I don't know how they do it. I honestly don't know how they do it. (Nurse 19)

The nurses lamented the parental difficulty of getting help for their children. One nurse suggested, '*...these parents do need some help, even if it's good respite care*' (Nurse 18). Another nurse spoke of a situation in which twins survived, both were profoundly impaired, and the mother needed help. This nurse used harsh everyday terms, not nursing terms, as she spoke of her frustration and anger that the mother was expected to provide constant care to the two children without respite. She stated:

So two children who are vegies. Well one is a vegie, the other one is worse than a vegie, because he screams all the time, around the clock. Those people deserve to either have institutionalised care for their children or a lot of help at home. (Nurse 14)

The use of such language could be seen as offensive. A nurse in Hainsworth (1998, p. 44) also described a neurologically devastated patient as, "...basically a vegetable". It is possible that the use of colloquial language to speak about dark and difficult issues or, in the case of this research, the ethical dilemmas related to the outcomes of prematurity, is a

copied mechanism for nurses. That said, everyday language seems to surface in times of stress, anger and frustration. Elliott (2003, p. 18) suggests that attitudes towards others is built into the language that is used to describe them, making the language embedded in the way society behaves towards them. The non-verbal communication of the nurses when they used everyday language might be just as important as the words. When nurse 14 used the word “*veg*ie” she seemed tense and worried, and she seemed to wonder how the mother coped with her severely disabled children.

Respite care is difficult to access with only a few facilities able to offer short term care for profoundly disabled children (Gatford 2001b, p. 128). Brinchmann (1999, p. 137) found parents required respite facilities for their children, and mothers only infrequently left the house. Brinchmann (1999, p. 137) suggests, “...the home can seem like a prison, from which it is impossible to escape”.

The nurses knew very well that parents experienced difficulties obtaining basic services for their children with disabilities. One nurse spoke of parents who approached charitable organisations to acquire a motorised wheelchair for their child. Another nurse spoke of a family who organised an auction, to enable them to purchase a motorised wheelchair for their child with severe cerebral palsy. This nurse explained:

There isn't a lot of help out there. She [the mother] has to go out through Lions and Apex to try and get funds. She's on the pension, so who can afford a \$4,000-\$5,000 wheelchair? If we're going to create these children, there has to be some support at the other end. (Nurse 18)

The nurses were all convinced the community should reduce the burden on families. This nurse found it incredibly offensive that parents should have to raise funds for a wheelchair. The nurses were all emphatic such necessary equipment should be provided by the community, thus allowing a child to reach its full potential.

The nurses all worried about the functioning of the family unit when the baby was discharged. The nurses had all witnessed relationships disintegrate because of extreme prematurity. Two things seemed to specifically emerge for the nurses. Firstly, it was the amount of time the baby was in the NICU. Secondly, the nurses believed the outcome of the baby was a significant factor in whether the family would be maintained. One nurse stated:

That depends on the baby's outcome at the end, as to whether it's going to cause total family dysfunction. Say they have a lot of hearing, sight, head, cerebral palsy. Definitely. How can it not? You're always going for appointments; you're always focusing on this child. You've got other children. It must be really difficult. (Nurse 13)

The nurses acknowledged the difficulty for the family when a child required extensive long-term care. One nurse explained:

The really severe cerebral palsys I find really difficult to deal with, because they seem to...destroy the relationship, they destroy the whole family. The dream is completely gone and it's just 24-hour hard work and just it's really hard. (Nurse 13)

The nurses expressed concern about the parental relationship. Paternal bonding may be the most important issue associated with relationship survival. Martin and Cole (1992, p. 193) found that father-disabled child cohesion was correlated with marital cohesion. Fathers involved in cohesive relationships with their children were less likely to leave the family (Martin & Cole 1992, p. 193). Several nurses had observed that when the parental relationship disintegrated it was the mother who assumed responsibility for the baby and other children. They spoke of trying to keep the family unit together in the short term to carry parents through the stressors and strains of long term hospitalisation.

My concern is that the families break up. When they break up, it's the mother and the father breaking up. My concern when I look after these people is keeping the mother and the father together. (Nurse 2)

The nurses all believed they understood the difficulties of caring for and parenting a severely handicapped child. They needed to remember that difficult situations are not necessarily signs of dysfunction. They had been told by parents of NICU babies of the harsh realities of life in the community, and they felt a sense of responsibility. The nurses understood they were not personally responsible, but when they projected themselves into the position of the family, they felt deeply for the family.

9.4.2 Traumatized by experience

The nurses all knew that parents could be traumatized by the experience of having a baby in the NICU. They understood there came a time when extremely premature babies who had been growing and thriving became ‘deintensified’. Deintensified describes the stage where the monitoring devices have been ceased. The cessation of monitoring devices is designed to allow parents to feel confident with caring for their baby without monitoring devices. The monitoring devices provided some security for the parents. Ceasing monitoring presented a problem for many parents who continued to think of their baby as critically ill, even though they were considered by the staff to be “growers and feeders” (Allnurses 2002). It could be difficult for parents to accept their baby was no longer seriously ill. One nurse explained:

They’ve had so much monitoring in here [NICU] and even though we do take our babies off the monitoring for a while before they go home, they [parents] still think monitoring.
(Nurse 18)

The nurses emphasised that monitoring devices were not removed until the gestational age for apnoea of prematurity had passed and several weeks after the last apnoea event. They were all aware that sudden infant death (SIDS) was more common in premature infants (see footnote 1) and those with chronic lung disease had an even higher incidence (see footnote 2). Parents were taught cardiopulmonary resuscitation.

1. See also Black, David, Brouillette & Hunt 1986, p. 209; Grether & Schulman 1989, p. 561; Hoffman & Hillman 1992, p. 726; 2. See also American Thoracic Society 2003.

It was the understanding of all the nurses that parents of extremely premature babies with long-term problems continued to rely on technology when the baby was discharged. Using technology adds to parental stress and one nurse stated, '*...oxygen around the house, green tubing that they've got to wander from room to room in*' (Nurse 8). Several nurses spoke of the constant vigil of mothers who feared the baby would die. This tension could affect marital harmony,

Very often the parents don't go back to the marital bed when they take home a premature baby. They sleep with the baby, until they're sure that baby is alright in their home situation. (Nurse 8)

The nurses expressed their concern about mothers of extremely premature babies when they were discharged home. Several nurses believed the mothers were at risk of postnatal depression (PND). They looked at the risk factors associated with PND, and were led to that conclusion. Postnatal depression is the name given to clinical depression which occurs in the months following childbirth. It affects 15% of mothers. There are many risk factors for PND, however the risk factors for mothers of extremely premature babies include labour and delivery complications, including caesarean section, initial and ongoing health problems for the baby, and having a baby with a difficult temperament (NH&MRC 2000b). One nurse stated her concerns:

We should be looking at Postnatal Depression after the baby goes home, rather than mucking around after birth. I think once they actually get a baby home, that's when the reality sets in. All the triggers are there. (Nurse 14)

The nurses' concern was well founded as there is evidence that mothers of premature babies experience higher levels of psychological distress in the neonatal period (Singer, Salvator, Guo, Collin, Lilien & Baley 1999, p. 799). Davis, Edwards, Mohay and Wollin (2003, p. 1; 2003/2004, p. 20) found mothers of premature babies reported depressive symptoms after the baby's discharge from the NICU. These mothers could be experiencing post traumatic stress disorder (PTSD) (Holditch-Davis, Bartlett, Blickman & Shandor Miles 2003, p. 162). PTSD results from the mother attempting to come to

term with not carrying the pregnancy to term, not being prepared to take the baby home, and the fear the baby might die.

It is possible that depressive symptoms could be part of “chronic sorrow”. There is some evidence that mothers of premature babies can experience chronic sorrow (Fraley 1986, p.115). Chronic sorrow is a term coined by Olshansky (1962) to describe the ongoing and unending grief that parents of developmentally delayed children experience throughout the life of their child. While the work of Olshansky has been revised (Teel 1991, p. 1311; Burke, Eakes & Hainsworth 1999, p. 374) some elements, such as loss following the cognitive disability of a loved one, the sadness being recurrent and permanent and, “...interwoven between periods of neutrality, satisfaction and happiness” (Teel 1991, p. 1311), still exist. For the mother of an extremely premature infant, chronic sorrow can be a normal response to events that emphasis the disparity between her expectation and reality (Burke et al. 1999, p. 383).

In chronic sorrow the intense sadness or sorrow varies for each person (Fraley 1986, p. 115; Hobbel & Deatrck 1996, p. 62; Mallow & Bechtel 1999, p. 34). Krafft and Krafft (1998, p. 60) found parents of a “...profoundly retarded 32 year old man functioning at a 1-year old level”, spoke of chronic sorrow not as a permanent state of despair but as, “...a dark emotional cloud that can quickly appear at times of crisis when missed milestones events trigger more intense sadness” (Krafft & Krafft 1998, p. 61). Parents may never fully resolve their feelings of loss as they grieve over the growth and development of their child, and experience periodic sorrow. The discrepancy in their child’s actual development with what should have been, had the child been normal, seems to be a common denominator (Fraley 1986, p. 115). The realisation of the continuous unrelieved responsibilities associated with caregiving is a significant factor (Burke et al. 1999, p. 383).

The nurses were convinced that parents of extremely premature babies were emotionally traumatised by their experience. They based their beliefs on observations of the families in the community, and communications with staff in the community.

Our discharge planner was saying...she'd just come across a few people who'd been gone from the unit for a couple of years, who were only just then dealing with the whole emotional business of actually being in the unit. (Nurse 14)

The nurses all emphasised that parents needed continued nursing support in the community, because they were fragile and vulnerable and were still learning to care for their child.

You really could do with somebody in the community full time, just caring for these parents. For someone to talk to them and reassure. It takes so long to feel comfortable with a baby that's been in such an intensive area. (Nurse 13)

The nurses all understood the ultimate outcome for the baby was dependent on the effort the parents, generally the mother, invested in the baby. This understanding is in keeping with the results of several outcome studies that show the level of maternal education has the biggest impact on the child's potential. Maternal education is considered to be the best socio-economic descriptor because it reflects the milieu in which the child was born (Overpeck, Moss, Hoffman & Hendershot, 1989, p. 58). Higher levels of maternal education also seem to be protective against postnatal depression (Hiltunen 2003, p. 22). One nurse gave her ideas about how parents could get the best out of their child:

I often speak to parents. I don't want to make things look too bad. I don't want to give false hope, build hopes up too high and then bring them down. You talk to them and say, 'Well it's going to depend a lot on... the follow up classes and follow up clinics'. You know that if they put a lot in to the child, they get better results. 'The more you put into this child, the more you'll get out of your child.' (Nurse 12)

9.4.3 Parental response to the outcome

The nurses all wondered if the parents appreciated the staff's efforts to save their child's life, and if they were pleased with the outcome. They wondered whether in hindsight if the parents were pleased their baby's life had been saved.

I wonder how many parents are pleased with what we've done. As these kids are growing up and they're not performing the way they would like a normal healthy child to perform. How do they feel about everything we did? (Nurse 18)

The nurses would welcome knowing if parents ever regretted their decisions to continue treatment.

If you did a follow up...with people at various years afterwards, and see if they would make the decision, under the same circumstances...‘Is this a decision that you would recommend to another in your position’? (Nurse 14)

The nurses had all spoken to parents who had intimated they would not make the same decisions, meaning their child would not have been resuscitated. One nurse considered it, ‘...*very difficult for them to be objective, because it's their child*’ (Nurse 16). It was the understanding of the nurses that other parents experienced severe guilt after a decision to withdraw support.

I know some of them have felt that, ‘Oh I'm really bad for letting my baby die.’ Even though they know it's the best for them, they feel guilty. (Nurse 16)

The nurses in thinking about parents and their decision were capable of accommodating ideas about the parents' decisions being subjective and objective. They spoke about parents who had told them they wished things had turned out differently and regretted that they did not withdraw treatment. The parents made it clear that if they had their chance again they would make different decisions. One nurse talked about a child, now eight years old, incontinent, requiring nappies and spending a large proportion of his life on a cushion on the floor. The mother said to the nurse, ‘*I wish that baby had never lived*’ (Nurse 23). Another nurse told a story where the mother said, ‘*If I'd known back then what I, we, would have gone through with him, he would not be here*’ (Nurse 21). These were situations in which parents accepted their children and their ongoing need for specialised care but stated in retrospect that things would have been different. The nurses felt guilty about the baby, believing they had contributed to the parents' burden, ‘...*you*

realise what devastation this has caused' (Nurse 23). They understood that parents were not likely to tell others of their lives and openly admit their regret.

The nurses all agonised over whether it was in the best interest of the baby and family for a baby to survive. They constantly questioned whether extremely premature babies who survived with major disabilities could be happy in their lives.

I think 'Is that really a life for those people? Are they really happy?' I think from my point of view, I wouldn't be happy with it. If you've never known anything else, then maybe that would be OK. (Nurse 16)

It seemed to be important for the nurses to know the child preferred to be alive and was happy with his/her life. This need was not related to children with disabilities, these nurses were speaking about those children at the severe end of the spectrum who had severe physical, cognitive and sensory disabilities. Saigal et al (1999) found that extremely premature infants who became profoundly disabled adolescents valued their life.

It also was important for the nurses to know if parents regretted their decisions. They felt a certain amount of responsibility for the outcome, knowing they weren't responsible, yet emotionally connected is feeling responsible. The nurses talked about medical and nursing teams changing practice. Parents of very low birth weight (VLBW) infants in a study by Lee et al (1991, p. 105) were asked if they could choose again would they save a potentially handicapped baby. Most parents supported the saving of the babies, however, VLBW babies have a more favourable prognosis than ELBW babies. Extrapolation of these findings cannot be relied on. Hindsight is only of benefit at the end of the traumatic experience.

9.4.4 Summary

The nurses had all seen what they considered to be more negative than positive outcomes. The negative outcomes would have been easier for them to accept if they knew the child was happy with its life, and the parents were happy their child's life had been saved. The nurses believed they tried to keep the family together. They employed much empathy through projecting themselves into the life of the family, in order to understand how their lives have changed.

9.5 Conclusion

In this chapter, *Reflecting on the outcome*, the outcomes for extremely premature babies were a major concern for nurses. Conceptually it was as if the outcomes were the central point under which everything else was situated. The nurses constantly questioned whether they should be involved in saving such tiny babies. They were, at times, besieged by their own anxiety about the outcomes.

There were many burdens associated with caring for an extremely premature baby who survived with major impairments. The nurses understood that many of the children brought joy and enriched the lives of their families, however, they also believed some families suffered heavy burdens. The majority of nurses experienced guilt because of they believed they had contributed to the parents' and child's burden.

The nurses showed empathy and compassion for the parents. They grieved the loss when they heard about the poor outcome of a baby. There was bewilderment for the nurses when they considered quality of life issues. They had good intentions towards the baby and strived to ensure it had the best possible outcome. They learnt to deal with the horror of wanting a child to die. The humanity of the nurses drives them to respond to such issues with deep thoughts and feelings.

The following chapter will discuss in detail the most salient issues arising from the analysis. One issue has been selected from each of the theme chapters. From *it's all about this baby* there is an exploration of the symbolic difference between fetal infants and babies. From *having a voice* the issue of nurses involvement in decision making is explored. From *dealing with awfulness* the nurses' difficulty with inflicting pain is explored. Two issues from *reflecting on the outcomes* are explored, because it was noted early in the interview process that some strong thoughts and ideas emerged around disability in general, and disabled babies specially that warranted further attention. Dealing with uncertainty and disability as a burden are both explored.