

## CHAPTER 10: DISCUSSION

### 10.0 Introduction

Caregiving and ethical dilemmas predominated in the world of the neonatal nurses when they cared for babies of 24 weeks gestation and less. The nurses found themselves constantly questioning the saving of tiny babies. These questions revolved around such issues as what would the baby choose, the consequences of survival for the baby and family, the use of resources, inflicting pain on a baby who would inevitably die, and would the parents thank them for the outcome. For many nurses, the ethical issues they faced overwhelmed them, and their only recourse was to distance themselves.

The purpose of this chapter is to use selected findings to challenge current understandings of the neonatal nurses' world of caring for extremely premature babies. Many of the findings have been explored and the complexities considered in the qualitative findings chapters. Therefore, in this chapter one issue from each theme will be explored and related issues relevant to neonatal nurses and neonatal nursing practice will be highlighted and examined. An exception has been made to this schema as two issues from the chapter on *Reflecting on the outcome*, are explored. This was done because the nurses' ethical dilemmas centre on whether the outcome will be positive or negative. It becomes important to explore the neonatal nurses' perceptions of a negative outcome and disability, because nurses have been found to contribute to the burden of the disabled (Seccombe 2006, p.461).

### 10.1 It's all about this baby

At times the nurses questioned whether they were caring for fetuses or babies. It seemed that many of the nurses experienced difficulties reconciling providing care to fetuses, or to extremely immature babies. Tiny babies were considered fragile human beings by the nurses, yet the appearance of the extremely immature baby could be problematic. The nurses attempted to modify the baby's appearance to make it more like a baby and less

like a fetus. An exploration of the “changeling” fetus will be used to explain the place the fetus holds within society. There will also be consideration of the difficulties the nurses experienced when caring for extremely premature babies.

### **10.1.1 Nursing a baby or a fetus**

At times the nurses questioned whether they were caring for a fetus or baby. A distinction can be made between a fetus and a baby. The fetus has biological life, whereas the baby has personal human life (Engelhardt 1973 p. 429). The ontological and moral status of the fetus changes with fetal viability. Viability is used to decide when there is an obligation to the fetus. Biology does not equate with social values, and obligation is a social, not a biological category, while viability is purely a biological entity (Engelhardt 1973, p. 43). The most important question is at what stage in gestation does the human individual to whom one is owed an obligation emerge? In the spectrum from zygote to infant there are qualitative and quantitative changes, but it is difficult to know exactly where on the continuum the qualitative change is so marked that an obligation to the fetus exists (Engelhardt 1973, p. 430).

Prior to birth there is rudimentary communication of the needs of the fetus to the mother. Personality is imputed to the baby after birth because of its ability to engage in interaction, albeit it crude in the first days of life. What seems to be important is that the mother-child relationship is markedly different from the mother-fetus relationship (Engelhardt 1973, p. 432). The status of the fetus is therefore socially, culturally and politically constructed, and its status will depend on who is attributing the meaning.

With technology that can visualise the fetus in utero it almost becomes common property. Isaacson (1996, p. 458) has suggested that because of the ability to visualise the fetus, the unborn can be termed “fetus-infant”. This is where the fetus in-utero and the baby ex-utero are blurred as a single entity. The visualisation of the activity of the fetus emphasises the character of the unborn, while ignoring its morphological immaturity. Visualisation of the fetus ensures its personification, where the fetus is seen as a separate

human being with its own identity, personality and character. The fetus in '2001 A Space Odyssey' (Clarke & Kubrick 1993; Clarke 2004) has been portrayed as free floating and larger than life (Casper, 1998, p. 17), and seems to have taken on a life of its own.

Prospective parents in a study by Williams, Alderson and Farsides (2001, p. 229) thought of their fetuses as babies, even as early as 12 weeks gestation. The prospective parents believed the fetus looked like a baby on the ultrasound scan. A newspaper article by Marsh (2003, p. 7) showed ultrasound scans where the facial features of the fetus could be seen. While they are still fetal, it is not difficult to recognise them as human. These pictures could be meant to show the humanity of the fetus, and discourage its termination. Naming the unborn by the parents is the symbolic passage of separation from the mother and acceptance into the community. It also allows the couple to identify themselves as parents, even though birth is the traditional time that future parents become actual parents (Isaacson 1996, p. 464).

Operating on the unborn otherwise known as fetal surgery opens up a whole new world for the pre-viable fetus. The advent of fetal surgery makes the fetus a patient in its own right (Casper 1998). Fetal surgery can be defined as, "operating on an infant who has yet to be born" (Levine 1991, p. 18). It is a treatment approach to alleviating congenital lesions in the fetus prior to birth. Fetal surgery emphasises the fetus as patient and is much like the twilight zone where the fetus could be seen as being suspended between life and death.

The language surrounding fetuses needs exploration. The fetus born at a stage where it is unable to be saved is generally referred to as a baby, rather than a fetus. Williams et al (2001, p. 228) found that health care professionals rarely used the term "fetus" in their interactions with pregnant women. Whether this is for the benefit of the family or the staff is not fully understood. Delivering a pre-viable fetus has a different emotional impact from delivering a baby albeit they are at the same gestational age. The fertilised ovum or non-viable fetus have not reached a stage of maturity where they can be considered to be a baby, but they are a potential baby. Perhaps it is the dramatic exiting of the mother's body that gives it the title of baby rather than fetus, regardless of gestation.

The personification of the fetus, although important for families, can be troublesome for parents and nurses. When the extremely premature infant is born it resembles a fetus rather than a baby. The fetus-infant is reliant on technology for even its most rudimentary functions. Henig (1983, p. 4) stated, "...the majority of preemie parents are frightened, grieved, and sometimes can be repulsed by the first sight of their stunningly tiny babies. It is important to recognise and accept these feelings – and to remember that a very small preemie is still, by rights, a fetus". Henig (1983, p. 3) even titled a chapter in her book on premature babies, "The preemie: more fetus than baby".

The fetus and infant differ in both morphology, development and maturity. The extremely premature infant can be described as being suspended between "womb and air" (Whittier 1999, p. 211). The extremely premature baby has transparent skin because it lacks fat deposits. Its head is too big for its body, a peculiarity that will correct itself with time (Tisdale 1986, p. 29). It is covered in fine hair called lanugo, and this hair could be described as fur-like. This furry-red fetus-infant acts differently from its full term counterpart who resembles a baby, and acts like an acceptable newborn. Whittier (1999, p. 211) suggests the extremely premature infant speaks a different body language in many ways, which is unlike that of its full term counterpart.

The NICU can mean the difference between the life and death of an extremely premature baby. Kinlaw (1996, p. 417) suggests the NICU is not just a, "...ward where sick people are treated; it tides over," almost fetus-like infants until their bodies are sufficiently mature to take over control of their physiological functions or they die. The extremely premature infant nursed in the NICU raises philosophical questions about the nature of what it means to be human. For the nurses in the current study, babies less than 24 weeks gestation made them question whether they were nursing babies or fetuses. Perhaps it might not be their "humanness" that is in question, it could be their "baby-ness". These babies look more like fetuses than babies. Very early in gestation the basic form has started. There are fingers, toes, facial features all encased in a thin covering of skin (Henig 1983, p. 7). The early weeks of gestation are devoted to growth, while the final weeks are devoted to maturity and finishing of the finer details. The baby born at 24

weeks gestation is in no way the finished product. The eyes are fused, the skin is gelatinous, and anything that touches the baby will stick to it. It is physically frail. The heart can be seen to be visibly beating through the chest wall as their ribs are thin. Arteries and veins can be seen. There are certain things that seem to improve the “baby-ness” aspect, and these include vitality (Brinchmann 2000, p. 143), “feisty behaviour” (Guillemin & Holmstrom 1986, p. 135), or a spark of life that shows some sort of responsiveness. If this spark occurs, human qualities are attributed to the baby, and this is seen as the ability of the baby to decide its own fate, and decide whether or not it will live or die. Frohock (1986, p. 201) states “viability is the beginning supplement. Babies often ‘declare themselves’, meaning that they make a kind of decision to live or die early on.” Extrapolation to the baby who is in a persistent vegetative state, or is totally unresponsive, reinforces to the nurses that they are caring for a biological entity only. Caring for babies who are totally unresponsive could be perceived by the nurses as disrespectful and akin to the performance of disrespectful actions on a corpse. As Lawler (1991, p. 29) suggests nursing is fundamentally and centrally concerned with the care of other people’s bodies. Somology, according to Lawler (1991, p. 29), is an understanding of the body as an integration of the object body with the lived body. The nurses do not simply nurse the baby in the bed, they also interact with the baby as a person. For the nurses, it is the interaction between the baby and the nurse that seems to be important. This interaction can be difficult because these babies seem to be virtually untouchable in their isolettes, and barely recognisable as human (Whittier 1999, p. 217).

The fetal appearance of the baby was problematic for the nurses and they used minifisms to help themselves and the baby’s parents. A minifism, according to Lawler (1991, p. 166), is a verbal or behavioural technique, which assists in the management of potentially problematic situations by minimising the size, significance and severity of an event involving a patient. Minifisms are protective and help the nurses behave in a business-as-usual fashion. It helps them maintain their composure. Neonatal nurses used these minifisms to downplay the fetal look of the infant. Each new fetal infant brings shock and dismay to the nurses caring for them. The nurses do not ever become accustomed to the appearance of these babies in the time immediately after birth. Badr and Abdallah (2001)

suggest the attractiveness of the premature baby can impact on the care it receives, although there is no evidence in the current study to substantiate this.

One could claim that the tiny fragile human baby is akin to a prisoner of war. Whittier (1999, p. 210) suggests that extremely premature babies are especially subject to metaphoric interpretation because they are “such ambiguous subjects, distanced from the onlooker in a state of virtual nonrecognition”. Preston (1979) and Schlomann (1999) also speak of tiny babies as ambiguous. Metaphors related to extraterrestism have been used in relation to extremely premature babies. Frey (1995, cited in Whittier 1999, p. 217) has described these babies as being displaced from inner space, described as aliens, proto-humans. The disruption of the visual image by the onlooker has also seen them described as likened to animals, vegetables or even formless matter. Rey (1995, cited in Whittier 1999, p. 217) suggest that extremely premature babies threaten the onlooker’s own somatic image because, “...seeing a human body so altered from its normal state that you feel the top of your skull lift slightly from the shock of it”. While the nurses did not seem to be quite this shocked, it was clear that the nurses in the study experienced difficulty with the appearance of the baby.

The opening of the baby’s eyes was important for the nurses and they wondered how much the baby could see. They wondered how much damage they were doing to the baby during treatment. The science fiction scenario of seeing a helpless human being, who looks more fetus than baby, attached to strange life support devices became a reality for these nurses. The nurses sometimes needed to hide their shock at the physical appearance of the baby. They seemed to mentally prepare themselves when they touched the newly born fetal infant. The sensation of touching this tiny baby would be different than touching larger babies. Part of the role of the neonatal nurse is to emphasise the “babyiness” to the parents, so they can begin to bond with their baby. This facilitation of “babyiness” is what the nurses do well, even though they seemed to be trying to convince themselves of the “babyiness”. The facilitation of “babyiness” is problematic as parents are reluctant to establish a relationship with a baby that distorts reality (Whittier 1999, p.

211). The parents could have difficulty bonding with their baby. Stinson and Stinson (1983, p. 29) spoke about seeing their extremely premature baby:

“I saw the baby for the first time today. All I could think of was Ghandi. He is very tiny...thin arms and legs, reddish-brown with fine hair over much of his body, and he looks curiously very old...I realize, writing this, how strong is the impulse to impute him, barely formed, a fuller, familiar definition...His experience is unlike anything I can know, and he is utterly alone.”

The development of the epidermal layer of skin at around ten days of age seemed to mark a transition from fetus to baby, as the baby can be safely stroked by the nurse's hands. The nurses managed the fetal appearance of the baby by concealment. The fetal appearance of the extremely premature baby could be concealed from all but its parents. Dressing the fetus-infant in clothes adds to the illusion that the inhabitant of the incubator is a normal baby. Dressing the extremely premature baby is as much for the staff's benefit, as it is for the parents' benefit. Making a non-baby appear as baby like as possible fostered the nurse's belief that they were caring for a baby not a fetus. Clothing the infant helped facilitate this transition from fetus to baby.

Attempts to normalise the NICU and personify the fetus-infant can have a positive effect on the staff morale, and may quell doubts about the wisdom of saving tiny babies. The nurses made an attempt to personalise the baby by pointing out to the parents the baby's likes and dislikes. Some parents are able to see behind the facade, as evidenced by Stinson and Stinson (1983, p. 215) who wrote in their journal;

“It's up to the nurses to give mothers the sense that their babies are ‘little people’ and not ‘little things’. Nurses are told to relate little personal anecdotes, ‘even if it's fabrication’”.

Even the smallest and sickest of babies are considered to have a personality by the nurses. Parents are encouraged to bring in toys and clothes to help normalise the NICU environment and make it more reminiscent of a home nursery. Individualising the bed

space with photos and toys normalises the environment, and could be an important part of the attachment process. Stinson and Stinson (1983, p. 50) commented on the normalisation process;

“Who are these toys for? Obviously for me and, I think, for the nurses and doctors as well, to help us – to make us – see past the machinery and our own uneasiness about using it, and even to justify using it. Who can doubt the wisdom of heroic efforts to save an infant kept company by ‘his’ toy rabbit.”

The ongoing search for the threshold of fetal viability was difficult for the nurses. If the nurses experienced difficulty caring for the infant of 24 weeks gestation and less, then caring for fetuses at 20 weeks would be more disturbing. Humour was used as a way of managing the nurses’ distress. Frey (1995, cited in Whittier 1999, p. 213) suggests “the staff jokes that it will soon report for work in scuba suits to treat 20-weekers swimming in a giant tank of amniotic fluid”. Nurses in the current study suggested something similar to Frey (1995, cited in Whittier 1999). Behind the humour the nurses were anxious they would be expected to be ‘fetal farmers’, and that the medical staff will be fetologists. The nurse’s fear of the future cannot be dismissed as fantasy.

### **10.1.2 Summary**

Caring for babies who resembled fetuses was difficult for the nurses. The appearance of the baby was problematic in that it looked more like a fetus than a baby. The nurses managed to find ways of “babyfying” the fetal infant, so they could deal with caring for such a small and fragile human being, a human being that made them question what it is to be human. The concept of a fetus as a separate form is socially constructed, but with ultrasound technology the fetus has been personified as it is possible to visualise its human features. The reality for the nurses is that caring for the fetal infant bears little resemblance to caring for the image as seen on ultrasound machines.

## **10.2 Having a voice**

The decision-making surrounding the extremely premature baby is never straight forward. The neonatal nurses spent many hours with the baby and its family, yet he/she had to witness the consequences of the decisions of others. The nurses emphasised they could contribute to the discussions surrounding the ethical aspects of care, yet were rarely offered the opportunity. They were silenced and felt powerless, reminiscent of the *Child* state as described in the theoretical ideas in Transactional Analysis (TA) (Berne 1964). In keeping with the TA framework the nurses played games to achieve a voice and patient outcomes. It is likely that the nurses have been denied a voice because of outdated doctor-nurse patriarchal dominance. This section speculates on the applicability of TA and the doctor- nurse game as explanatory concepts related to the neonatal nurses who were denied a voice.

### **10.2.1 Playing games**

It was difficult for the nurses when they were excluded from decision making. If they were not allowed a voice, and kept silent, their perceptions of themselves as professionals was negatively influenced. There were times when the nurses' response to a baby and a family's situation was so strong, that they engaged in game playing in order to effect what they considered to be a good outcome. Games are rituals or behavior patterns between individuals that can indicate hidden feelings or emotions (Berne 2007).

Doctors and nurses work in close proximity with the goal of improved patient outcomes. The nurses experienced frustration, hostility and anger when they perceived they were not welcomed into the decision making team. The nurses made it clear they did not want to make the decisions, but wanted to be involved in the process. Historically, the relationship between doctors and nurses was clear and simple. Doctors were superior, nurses were inferior. Doctors, who were predominantly male, had the knowledge that cured illness. Nurses, who were women, were good at their job but not necessarily

knowledgeable. Subservience and obedience were encouraged and expected. McGregor-Robertson (1902) emphasised:

[A nurse] must begin her work with the idea firmly implanted in her mind that she is only the instrument by whom the doctor gets his instructions carried out.

Dock (1917, p. 394) stated:

She [the nurse] will never become a reliable nurse until she can obey without question... [A doctor] told me I was supposed to be simply an intelligent machine for the purpose of carrying out his orders.'

The doctor-nurse relationship has been understood as patriarchal with sexual stereotypes. Doctors assigned themselves the role of the head of the hospital household or husband, while assigning the nurses as females the nurturing and passive role of patient carer, or wife. The doctors undertook the important work, while the nurses looked after the patients and staff who were dependent on them (Fagin & Garelick 2004, p. 280).

Stein (1967) noticed that interactions between the two professionals were carefully managed to maintain the fixed hierarchy and postulated the doctor-nurse game. Nurses showed initiative, but had to appear passive. Nurses were able to make suggestions as long as they made it appear they were initiated by doctors. The nurse needed to communicate her recommendation without appearing to make a recommendation. The doctor when requesting a recommendation, needed to do so without appearing to ask for a recommendation. Open disagreement was to be avoided at all cost. Good players were rewarded and the bad players were punished. The nurse and doctor who played well were rewarded with the other's admiration and respect. Bad players found themselves in difficult and hostile working environments. The relationship was likened to a game or power struggle. Both professions communicated indirectly and manipulatively, showing little warmth or mutual support (Stein 1967).

The divisions between doctors and nurses have included gender, education, money and status. The historical relationship between doctors and nurses influences the roles that each adopt. Changes, including the emphasis on education rather than training, the introduction of nurse specialists, consultants and practitioners have meant that nurses are no longer happy to fulfil the subservient position allocated to them by doctors. The education of nurses and doctors prepares different professionals, and as such they have distinct roles in the team. Working as a team means that each profession is viewed as having equivalent value. The key to working as a team is respect and dialogue.

Stein, Watts and Howell (1990) revisited the doctor-nurse game nearly 30 years after Stein's (1967) first analysis, and found nurses were not prepared to continue to play the game. Many doctors were still caught up in the game. The nurses had changed the way they related to other health professionals. They had grown tired of the handmaiden role, and wanted to be considered professionals. They began to be assertive. Clearly, being a nurse was about being an educated clinician with independent skills and responsibilities. Nursing, for the nurses in this study, held more than treating sick babies. It was about problem solving, and easing the baby and parents' experience of suffering. Being undervalued and left out of important discussions bred resentment in the nurses.

The nurses spoke often about following doctors' orders. They refused to do anything they believed would erode their moral integrity. Following doctor's orders implicitly is not high on the priority of contemporary Australian nurses and the nurses in the current study were no exception. Nurses in Australia are seen as autonomous moral agents and accountable for their decisions and actions (Australian Nursing Council 1993). When asked to do something they did not agree with, the neonatal nurses would discuss it with the medical staff and then would decide whether or not to follow the order. Several nurses spoke of being so outraged by certain decisions, they stood back and made the medical staff perform the required order themselves.

The doctor-nurse game could be viewed as an irrelevant squabble between the professions. The key to the doctor-nurse relationship for the nurses is the baby's and

parents' experience. There was evidence that the nurses played games to achieve the outcomes they desired, for example seeking out an alternate consultant. A power differential existed between the doctors and nurses, and this could be the basis for the communication problems experienced by the team members. The nurses practised subterfuge. It is hoped that knowledge and assertiveness derived from education can replace the oblique and manipulative communication games that result in conflict.

The nurses wanted to be involved in decision making. Involvement would acknowledge their efforts and experience and give them recognition. Berne (1961, p.15) defined a stroke as the "fundamental unit of social action," or interpersonal recognition. A stroke is about recognition, where one person, the doctor, recognises another person, the nurse, either verbally or non-verbally. Berne (1961, p. 14) postulated that adults need some form of recognition, and he coined the term "recognition-hunger" as the requirement of adults to receive recognition or strokes. As the nurses became more experienced, they sought more involvement in ethical decision-making. Their need or recognition-hunger expressed itself in longing to be known as capable of involvement.

TA is a theory of psychology and a method for studying human behaviour, personality and interaction between individuals. It was developed by Eric Berne (1961) who revised Freud's (1929) concept of the human psyche, and postulated three ego states; Parent, Adult and Child (PAC), all of which were largely shaped by childhood experiences. It was Berne's (1961) belief that a person experiences and manifests his/her personality through behaviours, thoughts and feelings. Harris (1967, p. 12) suggests "Parent is our 'taught' concept of life, Adult is our 'thought' concept of life, and Child is our 'felt' concept of life".

In the Parent state the individual behaves, feels and responds in ways parental figures, parents, teachers and elders have acted, and how the individual interpreted their actions. The Parent state is voice of authority and consists of the conditioning, learning and attitudes from childhood. It is a collection of pre-recorded, pre-judged and prejudiced codes for living (The International Transactional Analysis Association 2007). The Parent decides to react without reason to a situation, and decides what others should do. There

are two types of Parent figures; the nurturing Parent and the controlling or critical Parent. The nurturing Parent is caring and concerned and can appear as a mother figure. The mother figure offers unconditional love, keeps the child safe and calms him/her when he/she is troubled. The controlling or critical Parent tries to make the child do what the parent wants (Berne 2007). At times the nurses could be seen to play the nurturing Parent when helping parents manage the crisis of NICU admission and treatment. They also played the critical Parent in interactions with nursing and medical colleagues. There are negative connotation to the Parent, yet when there is no time to think as an Adult the Parent's automatic and scripted behaviour is essential. For the nurses this would include critical episodes, such as resuscitation, where the team leader automatically knew what needed to be done.

The Adult state is the rational person who is able to think and determine actions for himself/herself. When two people are talking to each other as equals, they are in the Adult state. The Adult is reasonable, logical, assertive, who neither controls or reacts. The Adult uses logical thinking to solve problems. Adult is the response to the immediate of here and now, and is a way of using the repertoire of resources and skills to obtain an objective appraisal of reality. The Adult is able to separate himself/herself from the emotions in a situation, because the emotions of the Child and Parent could contaminate the process (The International Transactional Analysis Association 2007). The Adult's answers will be timely and more effective than the answers of the Parent. The Adult is comfortable with himself/herself. The Adult is considered the ideal self. It is the means by which the Parent and Child are kept under control. Changing the Parent or Child must be done through the Adult, therefore TA is about strengthening the Adult (Berne 2007).

The Child state is where individuals revert to behaving, thinking and feeling the way they did between the ages of five and eight (The International Transactional Analysis Association 2007). The Child represents the recordings in the brain of seeing, hearing feelings and emotions which accompanied external events. There are four types of Child states; the adaptive Child which is co-operative and resistant, and the free Child which can be both spontaneous and immature (Berne 2007).

When the nurse experiences extremes of emotion, impulsive, spontaneous or playful, it is called the Natural Child. When he/she is thoughtful, creative or imaginative, it is called the Little Professor. When the nurse is fearful, guilty or ashamed it is called the Adapted Child (The International Transactional Analysis Association 2007). There are many examples in the data of Child ego states, for example the use of humour, during times of advocacy and conflict. The nurses frequently used creativity in problem-solving. There are many negative connotations surrounding the Child (The International Transactional Analysis Association 2007), yet the child is seen as important for creativity and recreation. The Child state helps renew the nurses' psyche to prevent compassion fatigue and burnout.

It can be assumed that the majority of time when they are caring for extremely premature babies, the nurses are in the Adult state. It is possible that when they experience ethical dilemmas, the nurses' hostility, anger and frustration immediately moves them to the Parent or Child state. Ethical dilemmas and not being involved in discussion and decision making provoke emotions, which could preclude rational and objective behaviour. The desperation of the nurses was palpable at times, and desperation is not associated with rationality. The hostility and anger in the nurse could provoke the controlling Adult in the medical staff. Alternatively, the nurturing Adult could be provoked if the medical staff were also experiencing an ethical dilemma. At times the nurses assumed the position of the Child in response to being denied their voice or opinion.

When considering communication it is important to see and feel what is being said, because only seven percent of meaning is in the words spoken, 38% of meaning is in the tone and way the words are said, and 55% of the meaning is in facial expression and body language (Mehrabian 1971). A transaction is the smallest unit of social interaction (Bailey & Baillie 1996, p. 40). Berne (1961, p.28) identified three types of transaction that people use in their everyday lives. Communication occurs from the alter ego states of Parent, Adult or Child. The individual's feelings will determine which one is used, and something can trigger a shift in states. At the core of Berne's (1961) theory is that effective transactions in the form of successful communications must be complementary. The communication must go back from the receiving ego state to the sending ego state.

Complementary transactions occur when the ego states of those interacting complement each other. Communication flows back and forth in a consistent manner, and occurs without conflict such as Adult to Adult. If the stimulus is Parent to Child, the response must be Child to Parent, or the transaction is 'crossed', and there will be a problem between sender and receiver. Crossed transaction is where the ego state that is addressed is not the one that responds. When a transaction is crossed communication is ineffective, leading to one or both people becoming upset. Crossed transaction is where the ego state that is addressed is not the one that responds. Crossed transactions result in conflict and stress for either one or both parties, for example Child to Parent (Berne 2007). Ulterior transactions are those where the surface message is different from the hidden message. The transaction might appear Adult to Adult, yet one party is in the Parent state. Ulterior transactions contain both overt and covert meanings, resulting in the transaction feeling negative (Bailey & Baillie 1996, p. 40). The situation can be rescued with the complementary transaction; however there are times when the relationship can be irreparably damaged. For a balanced approach to life, Adult to Adult is generally recommended.

When nurses communicate with doctors, parents or colleagues, ego states can conflict, and communication can break down. The other could be labelled as unco-operative or bad. Nurses would find it empowering to identify the ego states of those with whom they are communicating, and respond in a complementary manner, rather than crossing transactions and evoking conflict. Conflict can occur when the other person changes ego states and the nurse fails to shift ego state to maintain complementary transactions (Bailey & Baillie 1996, p.42).

The traditional role of the nurse within the hospital system encouraged a Parent-Child relationship, with the student nurse the Child. The training of nurses emphasised discipline and inculcated subservience. The relationship was autocratic, punitive and controlling. Parent behaviour is autocratic in nature. Both the Parent and Child states are heavily laden with emotion. Contemporary nurses are freeing themselves from the subservient role and the white, male, middle class culture that has dominated hospital care

for the past century. It seemed that the nurses wanted to be Adults; however doctors might not be prepared to relinquish the Parent role and adopt an Adult role, giving nurses the role of equal in the team. What has probably made the most difference is the level of education of nurses. All the nurses in this study were Registered Nurses; most had midwifery and NIC qualifications. Most, too, held Bachelors Degrees, some had Masters Degrees. These nurses were highly educated and had extensive experience with babies of extreme prematurity, so it is not hard to understand why they would resist and be unhappy in the Child and handmaiden role.

The nurses experienced much frustration and anger; however when anger predominates reason, the Child is in control. If the nurses were able to adopt the Adult ego they might not take their lack of involvement in decision making personally. Maintaining the Adult role is about rationality in the present. The nurses need to recognise that medical staff may not want input from others if they see themselves as responsible for decision-making. This is not ideally how a team works, however, some medical staff still cling to outdated notions of patriarchy. The traditional relationship between doctor and patient can also be understood as Parent-Child. Changes in the status of doctors, public airings of their fallibility, and an increase in the public's medical knowledge through the internet, has made doctors much more accountable for their actions (Fagin & Garelick 2004, p.280). The public is demanding a different role with their doctor. It could take many years before parents or nurses will be considered as equal members of the team.

There were clearly communication problems between the nurses, parents and doctors in this study. There were times when it seemed that both nurses and doctors engaged in inappropriate Parent-Child interactions when communicating with parents. Parents lament the lack of appropriate communication with health professionals that precludes their ability to be involved in decision making (Ward 2005, p. 26). The problem is that the need for information and a role in decision making are two different entities, and while parents who want more information generally want to be involved in decision making (Sobo 2003, p. 255), this cannot be assumed. Staff and parents differ in their perception on what is appropriate communication (Ward 2005, p. 31), and staff should

not assume that all parents desire the same amount of information. Nurses have been found to underestimate parents' desire for information (Sobo 2003, p. 261), while medical staff have been found to decide how much parents should know and to try and protect parents from the harsh realities of decision making (Ward 2005, p. 30). In this situation the nurturing and controlling Parent could merge into one.

The concepts with TA could be used by the nurses for personal growth and personal change. It could assist the nurses to analyse and understand all forms of verbal and non-verbal interactions behaviours, thus providing insight into the process. TA is a language within a language. It is a language of meaning, feeling, emotions and motive. It gives nurses the opportunity to choose which ego states to adopt, which signals to send, and where to send them (Berne 2007), thus enabling the nurses to make the most of communication, thus creating and maintaining better relationships. TA can help the nurses to think and reason in the Adult manner and develop awareness of when their arguments are emotive, rather than rational and objective (Bailey & Baillie 1996, p.42).

The premise of TA is that people are capable of deciding what they want for their lives. TA can help the nurses understand how people give and receive positive and negative strokes. To receive positive strokes, the nurses also need to give them, and recognise a job well done in others. Harris's (1967) "I'm OK - You're OK" establishes and reinforces the notion of the value and worth of every person. People are regarded as capable of change, growth and healthy interactions. TA has some organizational benefits. Clearly, at times the NICU seemed a toxic environment, in need of therapy. TA could be used to help the institutional climate and culture, the developmental and educational needs of the staff, self esteem building, staff motivation and behaviour management (The International Transactional Analysis Association 2007).

### **10.2.2 Summary**

The neonatal nurses wanted to be involved in discussions and decision making about the ethical areas of their practice with extremely premature babies. The historical relationship

between doctors and nurses could still be impinging on the nurses' inability to be accepted as full members of the team, making involvement impossible. Berne's (1961) Parent, Adult, Child ego concepts have illustrated theoretically what can happen when the nurses were denied a voice and retreated into Child mode. Nurses are more likely to gain acceptance in teams when they remain in Adult mode. Adult behaviour is reality orientated, questioning and analytical, rather than the emotional and demanding Child state. In this theoretical exploration the concepts of TA can be shown to explain behaviours and reactions as they have been described by the nurses in this study. Such explanations open up the possibility of understanding the nurses' behaviour and developing different ways to communicate and interact with others.

### **10.3 Dealing with awfulness**

There were times in carrying out care the nurses inflicted pain on the extremely premature baby. The hope for a good recovery meant the nurses could cope with inflicting pain, however, when hope was no longer an option, the nurses began to view themselves as torturers. Inflicting physical and psychological pain on human beings is antithetical to nursing (Laborde 1989, p. 31).

There were times when the nurses could not accept what they had to do to the baby in the name of treatment. When they believed the baby was being kept alive without consideration of its humanity, the nurses came to believe that continuing to care would take an emotional and physical toll on them as thinking, feeling human beings. The nurses learnt to protect themselves from ethically troubling situations.

#### **10.3.1 Inflicting pain**

The nurses experienced difficulties when their nursing care inflicted pain on extremely premature babies. At times they could not reconcile hurting and caring. Lantos (1999, p. 238) sums it up when he writes, "...there is nothing morally neutral about a NICU. NICUs are horrible, wonderful places. They are the best and the worst of pediatrics. They save

many lives and they cause much pain and suffering". The nurses believed there were times when their acts were tantamount to torturing an extremely premature baby. Torture can be defined as the intentional infliction of severe physical pain or mental anguish as punishment (Collins Concise Dictionary, 2001, p. 1593). There came a time when the nurses could no longer care for a baby, especially if they believed they were inflicting unnecessary pain or causing the baby to suffer. Gustaitis and Young (1986, p. 57) suggest nurses and medical staff have different roles and ways of relating to the baby.

"How often have I heard a neonatologist say, 'I have to give this kid a chance to live. I have to give him an opportunity. The baby will decide for us'. A nurse, on the other hand, is more likely to say 'I cannot stand to see this pain any longer. I cannot, in light of my own integrity, continue to inflict pain, deny this baby the dignity of a human being in the process of dying'." (Gustaitis and Young 1986, p. 57)

The boundary between healer and torturer can blur, or even vanish for nurses (Whittier 1999, p. 224). Analogies can be drawn between common acts of torture and common acts of nursing, however there is usually a differentiation between nursing acts and torture (Schroeder 1992, p. 212). Although the nurses believed themselves to be torturing the baby, there was never a suggestion that they intentionally inflicted pain on the baby. A comparison can be drawn between torture methods and what happens as part of treatment in the NICU. The infliction of pain and suffering is unintentional, yet it nevertheless occurs. Burns can occur from the technology used to measure oxygen tension or saturation in the blood. There is exposure to bright lights, sensory overload and deprivation of social contact. The placement of breathing tubes and intravenous cannulas to administer fluids all compound to give the impression that the baby is part of a futuristic experiment. The following quote from Harris Williams (1994, p. xvii) considers treatment from the premature baby's perspective.

The morning after the night when I was prematurely ejected from my mother's womb during a violent tempest...I awoke to find myself in many pieces, pinioned to the incubator floor, with my several senses

separately trapped in distinct forms of torture: my eyes shut against the insufferable brightness, my mouth scorched by dryness, my skin scratched by roughness, the sensitive mucosae of my nose crudely pierced by foreign tubes....Only pain made any link between my senses so that I could recognise they were all functions of myself, me.

(The Ugly Duckling, Harris Williams 1994, p. xvii)

Nurses learnt to distance themselves from ethically troubling situations. Historically, the good nurse was the one who had the ability to hide emotional reactions and to cultivate an air of detachment, or professional distance. The good nurse was the one who could give and receive pain stoically (Lawler 1991, p. 126). Nurses use different techniques to help them endure what they had to do to the patient. These strategies include nurses distancing themselves from the patient's pain, engaging with the patient's pain, seeking social support, and finally reconstructing their role as carer (Nagy 1999, p. 1427). Distancing is an attempt to place a physical distance between the nurse and the patient's pain. For the nurses in Nagy's (1999, p. 1431) study, this included taking time out, having a brief or extended break from the unit, having a break from carrying out painful procedures, having another nurse look after the patient, having a tea break, going home at the end of the shift, and having a holiday.

Distancing helps nurses continue working, and not face physical and emotional burnout. The distancing strategies used by the nurses in Nagy's (1999, p. 1427) study included emotional detachment by switching off, tuning out, not dwelling on the pain, accepting the inevitability of pain, deliberately not trying to think of the patient as a person, or focusing attention on the procedure rather than the patient and his/her pain. Distancing was effective when the nurse could focus his/her attention on the long-term benefits of the procedure to the patient (Nagy 1999, p. 1431). Structuring the painful procedure, so that nurse could maintain the control, was seen as another way of distancing. This strategy prevented the nurse from being overwhelmed by the patient's pain.

Engaging with the patient's pain is an effective method of coping with inflicting pain for nurses (Nagy, 1999, p. 1427). The nurses in the current study came to a stage with a

particular extremely premature baby where they could no longer engage with the baby's pain. Distancing oneself as the nurse from the patient's pain has its costs. Constant exposure to patients in pain contributes to nurses becoming less sensitive to the patient's pain, and also less sensitive to the patient's need for pain relief (Nagy 1999, p. 1428). There was no evidence in the current study that the nurses were becoming less concerned about inflicting pain. The reverse seemed to be true and they displayed anger at inflicting pain. Nagy (1998, p. 337) found neonatal nurses' feelings about pain alleviation were tied with personal responsibility. When the nurses in the current study were unable to fulfil their expectations of themselves at relieving the baby's pain, their disappointment in themselves was evident.

The nurses in the current study did not experience disembodiment. Disembodiment could prevent the nurses becoming overwhelmed by what was happening to the baby.

Embodiment refers to the idea that nurses are fully present to the patients and their situations. Alternatively, disembodiment is the dissociating of one's consciousness from one's body. To disembody is where nurses separate themselves from their body while inflicting pain (Schroeder 1992, p. 217). During disembodiment one cannot be truly aware, or present to the suffering of others (Maeve 1998, p. 1137). As many nursing procedures require nurses to participate in acts that inflict pain and suffering they frequently disembody so that they will not suffer while their patients are suffering. The ability to disembody in this context is necessary for nurses to be able to tolerate the realities of what is happening with their patients (Schroeder 1992, p. 211).

Disembodiment can be problematic. Disembodiment by nurses serves to more easily deny the pain and suffering of others (Schroeder 1992). It also allows the pain and suffering of patients to be less real than if the nurses were vulnerable to the same pain and suffering. While disembodiment can be a powerful protector for nurses, patients are at their most embodied when they are in pain and suffering (Maeve p. 1137). It is difficult to know whether this concept of embodiment applies to extremely premature babies. They can feel pain, however, the total experience of pain within the lived body is still being debated. To justify the aggressive treatment required to save the extremely premature babies life, and the infliction of pain, Whittier (1999, p. 224) suggests nurses

must consider the non-likeness of the infant to self, and use a compensatory hyper-personification of the baby as 'another'. There was evidence of depersonalisation in the nurses' accounts though not when the baby was in pain and suffering.

Schroeder (1992) suggests that only the nurses' conscious attempts to maintain embodiment makes the infliction of pain part of caring, which is differentiated from an act of torture. Disembodiment can serve to stifle the moral conscience of the nurse (Schroeder 1992). Embodied nurses recognise and associate wholly the experience of others (Maeve 1998, p. 1136). Remaining embodied is more likely to make the nurse consider the purpose and need for continuing painful procedures, and whether the outcome is congruent with the means. The nurses in the current study remained embodied, were attuned to the baby's pain and demonstrated critical thinking in relation to their actions.

Nurses perceive their role as relieving pain, not inflicting it. Nurses, whose attempts at cure also entail potentially painful procedures, have to come to terms with what they do to their patients. A 'burns' nurse in Tisdale's study (1986, p. 122) stated, "I never get bored.....but what I get tired of is causing pain". Another 'burns' nurse in Tisdale (1986, p. 123) stated, "...your helplessness is palpable. Your job is to cause more pain." Maeve (1998) explored how nurses learnt to live with patients who were suffering and dying. Nurses were accustomed to being asked, "How can you do that"? and they often asked themselves the same question. All meaningful relationships are ordeals, and being in a relationship with a patient, no matter how old or how small, results in the nurse sharing each of their patient's experience. This sharing includes the pain and suffering (Maeve 1998, p. 1136).

Core role reconstruction is aimed at reconciling the incompatibility between a nurse's core image of self as a reliever of pain, and the necessity of inflicting pain. For the nurses in Nagy's study (1999), core role reconstruction was a coping attempt, which allowed the nurse to view nursing as not exclusively concerned with relieving the pain of their patients. The nurses who were effective in doing this reached the conclusion that,

“...caring for patients sometimes meant hurting them and that hurting patients was so much a part of being a nurse that there was no alternative but to work out ways of coming to terms with it” (Nagy 1999, p. 1433). As Dind (1989, p. 81) stated, ‘...hurting is part of the job’. It is unclear if the nurses in the current study achieved core role reconstruction, because they seemed unable to reconcile care with hurt. On the other hand, the nurses saw themselves as other than an inflictor of pain.

### **10.3.2 Summary**

The nurses expressed their concern at what they had to do to the baby in order to save life. They described themselves at times as torturers, or what they did to the baby as torture, but there was never the intentional infliction of pain. The nurses used distancing to avoid situations they considered ethically troubling. In order for the nurses to stay productive in the NICU they need to come to terms with the nature of nursing care that it involved.

### **10.4 Reflecting on the outcome**

Not knowing exactly what will happen, or not being able to accurately predict, causes concern for those who require assistance from health care professionals. The understanding of uncertainty in illness has been greatly advanced by the work of Mishel (1984, 1990, 1997) who suggests that uncertainty regarding an illness has been identified as the greatest psychological stressor for patients with acute life threatening illness (Mishel 1997, p. 57). There is however, no research that addresses how neonatal nurses manage the uncertainty related to extremely premature babies. Neonatal nurses come to learn to deal with uncertainty if they are to remain productive in the NICU. As there is little research that addresses what uncertainty means for nurses, an attempt to extrapolate from a theoretical exploration based on models of uncertainty in illness is undertaken in order to suggest how neonatal nurses and parents manage the uncertainty associated with extreme prematurity.

### **10.4.1 Dealing with uncertainty**

One certainty in life is that there will always be uncertainty. Uncertainty is a dynamic and ever-changing cognitive state, not a static and rigid one. Uncertainty is experienced in the present, but is affected by past experiences and individual coping mechanisms, that can, in turn, impact on the future. Historically, the things that have contributed to uncertainty have changed over time, however, the ability to predict the future is still one of humankind's unfulfilled desires (Cohen 1993a, p. 78). Uncertainty exists when caring for the extremely premature baby. Neonatal care has not developed directly from ignorance to enlightenment, uncertainty has always existed.

While many would argue they choose certain aspects of their lives, uncertainty will always prevail. Uncertainty implies discomfort. Characteristics of uncertainty include vagueness, ambiguity, inconsistency, unpredictability and unfamiliarity (McCormick 2002, p. 127). Penrod (2001, p. 239) defines uncertainty as "...a dynamic state in which there is a perception of being unable to assign probabilities for outcomes that prompts a discomforting sensation that may be affected (reduced or escalated) through cognitive, emotive or behavioural reactions, or by the passage of time and changes in the perception of circumstances. The experience of uncertainty is pervasive in human existence and is mediated by feelings of confidence and control that may be highly specific (event focused) or more global (a world view)".

Uncertainty, as it relates to health and illness, can be defined as the "...inability to determine the meaning of illness-related events" (Mishel 1988, p. 225). Studies of uncertainty in patients and their families have revealed four major areas where uncertainty is likely to arise. These include symptoms, which can come and go; hospital routines which are unfamiliar; treatment decisions which produce variable outcomes; and communication with health professionals, with the messages frequently being unclear, ambiguous; or where information is not forthcoming (Wurzbach 1992, p. 29).

Uncertainty is not always a negative experience. Uncertainty has the effect of producing positive effects, as hope is linked to uncertainty. Absolute certainty often means there is little room for hope. Certainty can lead to boredom, depression and a sense of helplessness, as the outcome is inevitable (Wurzbach 1992, p. 29). Certainty and uncertainty can have the positive effect of mobilising coping resources. Uncertainty varies in magnitude and intensity, and can have the effect of making one question his/her every day life, and even such existential questions as life and death. Internal uncertainty can make people question the beliefs and values they base their lives on; it can also challenge or strengthen religious faith. Uncertainty can exist for a short period of time, or it can persist for an indefinite period of time. It can be experienced as a major stressor or a welcome challenge (Cohen 1993a, p. 79).

Neonatal nurses are required to manage the uncertainty associated with caring for premature babies. If uncertainty is the norm for families who endure the waiting, then to extrapolate, nurses also feel the effects of uncertainty. Uncertainty has the potential to alter the parents' and nurses' moods. Nurses in the NICU should be accustomed to uncertainty. Neonatal nurses and the parents of the extremely premature baby are possibly managing not just uncertainty, but "sustained uncertainty" (Cohen 1993a, p. 77). If considering Wurzbach's (1992) work, there would probably only be one major issue in relation to uncertainty that could be problematic for neonatal nurses. Uncertainty, for neonatal nurses, would focus on the prognosis and outcomes for the baby, because they understand the patients' symptomatology; they are familiar with the hospital routines; and for them, communication issues do not generally present a problem, as they have access to all level of communications surrounding the baby. Uncertainty about all aspects of the prognosis and outcome cause the nurses concern, and is confirmed in the results of the current study.

Parents of sick and hospitalised babies and children have to endure many stressful events during hospitalisation. Mishel (1983, p. 324) found that predictability of events influenced parents' ability to cope with their child's illness and hospitalisation. Unplanned hospitalisation was worse than planned hospitalisation for the parents

(Gulseth Schepp 1991, p. 44). The birth of an extremely premature baby is a crisis situation; it is generally not planned; it is an emergency. The possibility of stopping the premature labour, even in the short term, and showing the parents the NICU, could diminish some uncertainty. Mothers in a study by Gulseth Schepp (1991, p. 45), who knew what to expect, experienced less anxiety and used less energy to cope with stressful events during their child's hospitalisation.

When a woman enters premature labour at 24 weeks gestation the uncertainty begins, or as Cohen (1993a, p. 84) states "uncertainty comes to be experienced as intruding and receding in a wave-like pattern". If the extremely premature baby is born and is resilient enough to be admitted to the NICU, one hurdle is completed, but many more are to follow. The condition of the baby can have a significant impact on the parent's emotional state. While the effects of certainty or uncertainty on parents' moods remains unclear, the nurses in the study believed their clinical experience led them to the understanding that the ups and downs of the baby's condition mirror the ups and downs of the parents' emotions. The ups and downs led to more uncertainty. Early uncertainty about whether the baby would survive was replaced by uncertainty about the baby's outcome. Certainty and uncertainty can be viewed as being at different ends of the spectrum, and may be inevitable during illness. For parents of extremely premature babies, this uncertainty can present difficulties as they grapple with the realities of the present. In having to consider the future for their baby, uncertainty adds to the stress and confusion they experience.

Parents with a baby in the NICU enter a foreign world, one which with the help of neonatal nurses, they slowly learn to navigate. It is unlikely that they ever feel comfortable in this foreign place but they learn to adjust. With adjustment comes adaptation. Familiar routines and familiar faces at least make the NICU bearable. Parents desire some control over an otherwise uncontrollable situation and learn the basics about the monitoring devices. Some parents watch the nurses so frequently they learn to ascertain what numbers on the monitors are acceptable. They do not know the clinical significance of the numbers, however it gives them some knowledge, and as knowledge relates to power, or at least control, this makes parents more comfortable. Parents may

gain some knowledge and some control, however they lack predictability or the ability to predict or foresee the future.

Uncertainty can be problematic for neonatal nurses. Clinicians are unable to accurately predict the outcome for tiny babies and parents and nurses are left in a kind of limbo waiting for positive or negative signs. High resolution ultrasound images can show the brain and any damage, yet some babies will always defy prediction. While ultrasound technology requires a skilled and experienced clinician to interpret the results, there are times when the ultrasound results leave clinicians with more questions than answers. This factor contributes to the uncertainty.

Parents of extremely premature babies usually take an active role to play in decision-making for their baby. It is difficult for parents to make reasonable decisions when the situation is surrounded by uncertainty and doubt. Information from medical staff is the cornerstone in helping parents make decisions, however, even with modern technology, there can be substantial room for doubt. Parents are informed about extreme prematurity in a way that stresses risk and doubt (Vermeulen 2004, p. 2083). Leaving the parents with uncertainty may be a purposive strategy on the part of the medical staff, designed to prevent the parents from becoming too optimistic about their tiny baby's chances, and thus preparing the parents for the worst case scenario. There can never be certainty about whether the baby will live or die, and this uncertainty can remain for weeks or possibly months. The risk of brain damage is great, but not certain, so any discussions with parents will always involve some uncertainty (Vermeulen 2004, p. 2077). Dealing with doubt, for these parents, is one of the complexities of dealing with uncertainty. Parents have to deal with uncertainty and the insecurity that accompanies doubt. They have to learn to interpret the medical facts, because they need to weigh up all medical knowledge and contribute to the decision-making. Participating in decision making will be difficult for parents, and as stated by Penrod (2001, p. 240), uncertainty is related to "...the perception of being able to assign probabilities for outcomes". Parents are unable to estimate probability because they lack the information and possibly the education required to consider the relevant variables. The nurses help the parents by deciphering medical

information and statistics, recommending reputable internet sites and talking about the extremely premature babies they have cared for in the past.

Parents find it difficult to make decisions. This is related to the uncertainty about what to choose, possibly because of the inherent complexity of the choice. It would be difficult for parents to decide between benefits, harms and scientific uncertainties. The parents could have inadequate knowledge and not enough support to make decisions (O'Connor, Legare & Stacey 2003, p. 737). Shared decision-making is difficult, and it cannot be shared without understanding the risks. There is evidence that shared decision-making rarely happens, and Godolphin (2003, p. 693) suggests that patients', or, in the case of this thesis, parents', understanding of information and role are rarely explored. Parents have been reported having difficulty asking the medical staff questions. They feel intimidated or fear assertiveness will jeopardise rapport (Godolphin 2003, p. 693). The involvement of neonatal nurses could help ameliorate this problem, or in the very least they could support in their decision making.

The communication between medical staff and parents can become awkward when uncertainty prevails. Lerner (2002, p. 2) suggests medical staff do not deal well with uncertainty. Silverman (1987, p. 411) explains that "...uncertainty is inescapable; it arises from the messy vagaries encountered at every turn in medical study and from the glossy fact that there are simply no criteria to judge when we are in possession of a complete set of facts about phenomena". Parents and doctors experience diagnostic uncertainty dissimilarly (Cohen 1993a, p. 83). Diagnostic certainty provides the doctor with a clear direction for decisions and actions, while the parents are left with their child's diagnosis, but they need to make sense of what that diagnosis entails without clear rules and guidelines (Cohen 1993b, p. 139). What parents generally want to know is what extreme prematurity means for the baby's survival and quality of life, or the amount of time until death. Unfortunately, these things are not known and the questions can only be answered with generalisations and references to statistical probabilities (Cohen 1993b, p. 139), which leave the parents with an uncertain prognosis and outcome for their child. Uncertainty has the potential to erode parents' trust in health professionals, as one father

in Vermeulen (2004, p. 2079) stated “...you become distrustful, suspicious and insecure”. The nurses emphasised that trust was a vital component between the parents and health professionals. The nurses recognised the uncertainty and attempted to help the parents understand it, which helped maintain trust in the health care team.

Risk refers to the probability or likelihood of an event occurring, combined with the magnitude of losses or gains that would ensue. Currently, risk refers to negative outcomes (Jacobs 2000, p. 12). The concept of risk and uncertainty are closely correlated. The concept of risk is directly related to the uncertainty surrounding the applications of scientific knowledge into clinical practice (Jacobs 2000, p. 14). Risk communication is the basis for informed consent. Risk communication is crucial for decision-making. It is difficult to know how parents assess risk. Godolphin (2003, p. 692) suggests that, “...risk communication is risky”. Medical staff are prone to biases in the judgement of risk and the use of available information, because there are few medical problems where risk information is available, and risk outcomes rarely include psychosocial outcomes (Godolphin 2003, p. 693). The nurses were familiar with the long term outcomes related to extreme prematurity, however, they might over estimate the risk of poor outcomes (Streiner et al. 2001, p. 152) leaving the parents to believe the outcomes were worse than they might actually be.

There is little evidence that knowledge of risk influences the way in which the public perceives and responds to risks (Alaszewski & Horlick-Jones 2003, p. 728). Currently, the approach to risk assumes that the public will rationally review evidence to identify and choose the best course of action. Interventions that try to put generalised risk into specific context can be effective (Gigerenzer & Edwards 2003, p. 741). In the case of the extremely premature baby, the risk of death and disability (minimal and severe) in the context of everyday life, is what the parents need in order to make decisions. This becomes problematic because individuals are more likely to be sensitive to, and over assess, the likelihood of low probability or high consequence risks (ie killed in train crash), and underestimate the risk of harm from more common causes (smoking) (Gigerenzer & Edwards 2003, p. 742). In the case of the extremely premature baby, the

parents may over-assess the risk of severe disability, and under-assess the risk of long-term morbidities. Bogardus, Holmboe and Jekel (1999, p. 1039) emphasise that some unwanted outcomes may be permanent (disability) or transient (pain). The timing of risk is important. In the case of the extremely premature baby, the outcome may not be seen for months or even years. Parents are required to balance present benefit with future risk, or decide to accept significant present risk for possible future benefit (Bogardus et al p. 1039). Parents will rate adverse outcomes differently, and what one person sees as catastrophic could be seen by another as acceptable quality of life. This subjective badness makes it difficult to know exactly what risks should be revealed to the parents, however risks of death, disability and disfigurement should always be discussed. Parents of extremely premature babies should be reminded that all treatment is associated with risk. Risk has come to represent a combination of probability and something that is hazardous (Jacobs 2000, p. 12). Paling (2003, p. 746) suggests that medical staff should avoid explaining risks in such terms as “low risk” but instead use numbers. They should avoid using descriptive terms because they reflect the speaker’s perspective, therefore the parents understand risks in a different order of magnitude. Both positive and negative outcomes should be presented (Paling 2003, p. 746). It is important to avoid words such as probable, unlikely, rare because they convey elastic concepts. A rare outcome can have different meanings to different people (Edwards, Elwyn & Mulley 2002, p. 827). Health professionals need to be careful of the language they use as their language can be very persuasive, and might impinge of parental informed consent.

What is probably underplayed is that the media play an important part in shaping risks for extremely premature babies. In this situation, individuals give precedence to media accounts of miracle babies, without recognising that the accounts may be fictional or not accurate. Perception of risk by the public originates from social and cultural factors. The response to life’s gambles is a result of family and ethnic traditions. The problem is that misleading personal experiences can cause the denial of uncertainty; risks to be misjudged and unwarranted confidence in unproven facts (Jacobs 2000, p. 15). The nurses were disturbed by the miracle baby stories, believing they led to unrealistic expectations in the community. Conversely, it could be the uncertainty that engenders

parents to hope for a miracle, as Mishel, Padilla, Grant and Sorenson (1991, p. 240) suggest that when a person's strength is depleted through uncertainty the person may become reliant on interpersonal states like faith. The nurses encountered parents who the nurses believed, put unrealistic faith in the hope for a miracle. It is difficult to know if both certainty and uncertainty prompt belief in miracles by desperate families.

When communicating with families, neonatologists and nurses often use exemplars of babies that have been cared for in their NICU. They include examples of exemplary children who defied the odds, despite contradictory brain ultrasound images. To give a complete picture, the children who did worse than expected should also be presented, because the children who survive the odds are rarities. The nurses vividly remembered the children who did poorly, and as Vermeulen (2004, p. 2080) suggests these babies are used as a deterring reference, or a metaphor in times of doubt about the wisdom of saving other babies. Uncertainty is not only about looking back on previous babies, but it involves the future prediction of quality and quantity of life. All the nurses told stories about exemplars, the positive, the negative and when uncertainty prevailed. The babies that defy explanation for the nurses could be an example of what Cohen (1993a, p. 80) sees as "...an experience that challenges our assumptive world". The assumptive world for the neonatal nurses is their clinical knowledge, values, beliefs and expectations (Cohen 1993a, p. 80) about extremely premature babies. The challenge of the nurses' beliefs about extremely premature babies and the uncertainty involved, makes the nurses want the staff see the baby at birth and its response to treatment, rather than having blanket rules designed to save babies from a certain gestation.

A critical thinking approach would lead nurses to question whether they are inadvertently conspiring with the medical staff to maintain the parents in a place of uncertainty. If nurses temper the parents' hope with reality, as they believe they do, then uncertainty may not be an onerous place for the parents to be. For the parents to be positive that their child will survive, particularly during the early honeymoon phase when nothing is certain, is difficult for the nurses. Allowing for uncertainty in the parents is one way in which the nurses prepare the parents for all eventualities. While there might be hope with

uncertainty, uncertainty can be a difficult place for parents. During times of uncertainty when their baby is sick, parents shift worlds and "...move from the secure world of the known, the familiar, and the unpredictable to a norm less world of the ambiguous boundaries, unclear rules, probabilistic predictions, and sinister probabilities" (Cohen 1993a, p. 83). Helping parents take one day at a time is an approach nurses are able to offer. This slow progression is important because, for the parents, "...thinking about the future seems to invite the threat of loss" (Cohen 1993a, p. 83).

Uncertainty was difficult for nurses. While there was uncertainty there was hope, the hope for what they saw as a positive outcome for the baby. Certainty is where the fate of the baby is known. The ethical dilemmas seemed to be more pronounced and were experienced when the prognosis and outcome were closer to certain or considered to be poor. Ethical dilemmas could be more likely to be experienced during times of certainty and not unexperienced during uncertainty. Uncertainty keeps the nurses transfixed with the hope for a good outcome but in a state of unease and stress.

#### **10.4.2 Summary**

This section has sought to explore how neonatal nurses and parents live with the uncertainty associated with extremely premature babies. There seems to be no other conclusion than research is required in this field in order to establish how neonatal nurses and parents deal with the uncertainty of extreme prematurity. For the nurses uncertainty has both positive and negative aspects because, while ever there is uncertainty, there seems to be room for hope.

#### **10.4.3 Disability as a burden**

The neonatal nurses believed that extremely premature babies who survived with severe disabilities could be a burden on the family and society. Where these beliefs have originated, is another discussion, however nurses have been socialised like other members of the public. A stereotypical view that the disabled are burdens has probably

pervaded Australian culture. The nurses will have received education about disability, the needs of disabled people and how to include them in mainstream society. They, however, genuinely believed treatment should be withdrawn on some babies if a severely disabled child would be the outcome of treatment. These nurses were not indifferent to the needs of the disabled. They knew in keeping with recent research how devastating the disabilities associated with prematurity, particularly neurological disabilities (Woods et al 2000, p. 378), are in comparison with other disabilities.

Approximately 10% of the population are considered to be disabled (Northway, 1997, p. 136). Nurses who work in general hospital and acute care wards may have limited contact with disabled people, and only see them when illness occurs (Conway 1996, p. 121). Northway (1997, p. 736) suggests that disabled people view nurses as part of their problems of oppression, disadvantage and injustice, rather than part of the solution. Nurses have been exposed to the prevailing social views about disability in the same way as the public. The public does not understand about disability. Negative attitudes towards people with disabilities have not changed significantly in recent years (Davis 2002, p. 20). Cultural beliefs affect the way all people are viewed. The attitudes of people towards disability are experienced individually, however, their attitudes are socially constructed. The beliefs and attitudes of a society to disability reflect the dominant culture. While there has been a growing recognition of the needs of the disabled within the community, these views are not shared universally.

The media can be a source of misleading stereotypes. In an analysis of the media, the images of the disabled are either missing totally or they are portrayed as tragic victims or super heroes who overcome their hardships (Northway 1997, p. 740). Popular culture has portrayed the disabled as helpless and childlike and in need of care, like Dicken's (1843) Tiny Tim in *A Christmas Carol*. Another portrayal of the disabled is one of the villain who is sinister or morally flawed. Consider the hunchback of *Notre Dame* (Hugo 1862), Captain Hook in *The Adventures of Peter Pan* (Barrie 1928), *The Elephant Man* (Gould & Pyle 1896) who was profoundly disfigured, Captain Ahab in *Moby Dick* (Melville 1851) who lost a leg and was portrayed as vengeful, or Shakespeare's (1591) Richard III

who was given a hump on his back when none existed on the real king (Shapiro 1994, p. 31). All the nurses in the current study claimed to have read widely, so they could have internalised these representations of the disabled.

Unwanted infants, both normal and defective, have been killed or allowed to die since the beginning of recorded history (Fost, 1986, p. 149). The 1982 case of Baby Doe in Bloomington Indiana, in the USA, sent a message to the world that disabled babies were to be treated the same as their non-disabled counterparts. Baby Doe was born with Down Syndrome; however, he also had oesophageal atresia where the oesophagus and stomach were not connected. His parents refused consent for surgery, and the state court upheld the parent's decision. The Baby Doe case sparked an outcry from Right to Life groups, and legislative changes were made in the USA to Child Abuse Laws. The nurses spoke about how it was no longer acceptable to leave babies with Down Syndrome to die. They all emphasised they believed the child with Down Syndrome would have a better life than the profoundly impaired child born prematurely.

It is interesting that the idea of humanely ending the lives of the disabled, including babies, has never really gone away. A controversial book titled 'Should the baby live: The problem of handicapped infants' (Kuhse & Singer 1985, p. IV) states, "...we think that some infants with severe disabilities should be killed". Kuhse and Singer (1985) argue that it is acceptable to kill a deformed or handicapped newborn before it has the chance to develop a history; however, once the parents have decided that the child should live, then all steps should be taken to provide the type of nurturing that a baby needs. In their defence Kuhse and Singer (1985) suggest, "...it is one thing to say, before a life has properly begun, that such a life should not be lived; it is quite different to say that, once a life is being lived, we need not do our best to improve it. We are sometimes prepared to say the former: we are never prepared to say the latter" (Kuhse & Singer 1985) p. IV).

How can the next generation obtain a positive view of the disabled? Children need to be exposed to disabled children at school. The segregation of the disabled in separate schools seemed to do little for acceptance and understanding. The nurses' generation did

not have disabled children at their school, however if they had been exposed to disabled children at school they might have developed positive attitudes about the disabled (Roberts & Lindsell 1997, p. 133; Weiserbs & Gottlieb 2000, p. 345; Tamm & Prellwitz, 2001, p. 223). The nurses' generation would have seen physically and cognitively disabled children being driven around in special transportation. These disabled children and their bus became objects of derision and fun for the able-bodied children. Children could be heard calling out names as the bus passed. Lack of exposure could equate with lack of understanding. Children learn about disabilities from being exposed to children with disabilities. Inclusion of disabled children in mainstream education will increase the contact between children with disabilities, and those without disabilities (Magiati, Dockell & Logotheti, 2002, p. 410). Understanding plays an important role in underpinning belief structures and patterns of behaviour (Magiati et al, 2002 p. 411). The nurses' beliefs could have been shaped by their schooling and their peers.

It is difficult to know whether health professionals' views of disability have changed since Baby Doe, and the implementation of the Americans with Disabilities Act, or the Australian Disability Discrimination Act (Australian Government 1992). Health professionals still seem to have negative attitudes towards those with disabilities, even with previous experience with the disabled. Medical students in a study by Tervo, Azuma, Palmer and Redinius (2002, p. 1537) held negative attitudes towards people with disabilities. Perhaps it is because, among medical staff, disability is seen as incompatible with their ideal of healer and curer (Tervo et al 2002, p. 1541). Nursing education includes clinical time caring for those with developmental disabilities. Conway (1996, p. 122) has suggested that nurses who care for disabled patients are more likely to have positive attitudes towards the disabled.

The neonatal nurses in this study emphasised that it was those babies with profound disabilities or those considered to be almost in a vegetative state that caused them concern. Many nurses spoke of caring for profoundly impaired adults during their general nursing training. It seems this experience, although not negative at the time, could have influenced their beliefs about the profoundly impaired. The numbers of profoundly

impaired children and adults would be small in relation to the whole of the disability population. It could be that working in an environment where heroic rescue and 'saving' babies who are normal is seen as success, and all else is considered to be failure. It may also be assumed that neonatologists influenced the neonatal nurses' attitudes about disability, though there seems to be no evidence of this in the nurses' accounts.

The nurses were convinced that profoundly disabled babies would be burdens on their families. Those with profound impairment require complex and specialised around-the-clock care, and it is usually the mother who meets the child's needs (Brett 2002, p. 826). When a person is perceived a burden it implies someone who receives but never contributes to relationships, finances and responsibilities. Being viewed as a burden could bring harm to the psyche and the soul, and diminish the disabled persons' quality of life (Asch 1998, p. 79). In holding these views the nurses were clear that this did not refer to disabled people in general. Their view concerned the devastating disabilities associated with extreme prematurity, those that are profound. In relation to the outcomes of extreme prematurity the nurses had come to believe there were babies whose interests were not served by being alive.

When the nurses spoke of withdrawal of treatment on a baby who was deemed to have no future, these were the babies who would ultimately be so cognitively and physically disabled that they might not experience their lives. The nurses opened up questions about whether it was easier to withdraw treatment on a baby who would be profoundly damaged before it has the chance to develop a personal history. They questioned whether babies were of lesser value, therefore expendable. They wondered whether it would be harder for parents to lose a baby, or a child who has developed a character of its own. Perhaps the issue lies in seeing the profoundly disabled person, and projecting oneself and attempting to live the life of another. It could be that the nurses saw the profoundly disabled as suffering, or they believe that if it was them, they would suffer.

The neonatal nurses believed that profoundly disabled babies and children would suffer. Suffering appears to be multidimensional (Read 2003). Suffering is when people

experience something they would not ordinarily choose to endure. It has a time component, involves a perceived threat to the individual and engenders beliefs and feelings related to the event itself (Read 2003, p. 10 & 11). Suffering is a personal phenomenon, because while most know suffering, one cannot compare the suffering of oneself with the suffering of others. There are four themes to suffering, and these include isolation, hopelessness, vulnerability and loss (Read 2003, p. 13 & 14). Isolation is the loss of contact with their loved ones, or perceive themselves to be disconnected from their normal world. The neonatal nurses spoke of profoundly disabled babies being abandoned and placed in an institution. The nurses expressed their distress when this happened. They projected themselves into the baby's situation and imagined the hopelessness of the situation. The nurse's experience led them to believe that the lives of the profoundly impaired would be hopeless, and that the profoundly disabled were vulnerable and susceptible to harm. They had seen developmentally disabled people taken advantage of and abused, and this led them to this conclusion. The nurses have seen and experienced the vulnerability of disabled people, particularly women, and feared it happening again. They saw the profoundly disabled baby as having lost opportunities for a worthwhile life. The suffering associated with loss also extended to the family, who having lost their ideal child, had to come to terms with life with a disabled child. While it cannot be known how profoundly disabled children feel, the neonatal nurses firmly believed that these children suffered, or, more importantly, they believed they would suffer if they were the child in question.

The nurses were troubled that parents were expected to take on the burden of care for their child. There is evidence that some parents accept this role, other parents see their caring role as "...tinged with bitterness" (Forbat, 2002, p. 759). One mother in a study by Brett (2002, p. 833) felt coerced that she was suddenly expected to perform the high level of care that her profoundly impaired child needed on a 24 hour day basis. Another mother spoke of her terror of going to bed and waking up to find that the equipment had malfunctioned and her child had died (Brett 2002, p. 833). The nurses thought, in many instances, that a disabled child was an unacceptable burden on the parents.

There is a hierarchy of disability with cognitive disabilities listed as being the worst. The nurses spoke of cognitive disabilities as being worse than physical disabilities. Charlton (2000, p. 97) suggests that people with mental disabilities have the most difficult lives, while those with physical disabilities and visual disabilities have greater social, political and economic opportunities. This hierarchy of disability can also affect the way in which the non-disabled relate to those with disabilities. Differences in attitudes to the different types of disability have been reported, and Karnilowicz, Sparrow and Shrinkfield (1994, p. 65) found that adolescents had more favourable attitudes to the physically disabled than to the cognitively disabled person. In the current study it was found that neonatal nurses who work with babies of 24 weeks gestation and less in perinatal centres were more optimistic than nurses from surgical centres. A possible explanation is that only babies requiring surgery will be transported to a surgical centre. The reason for the surgery will be an indicator of the nurses' optimism, for example hydrocephalus requiring surgical intervention. The potential for brain injury in the extremely premature baby is very real, and a link exists between the baby's brain and the nurse's optimism.

Prenatal screening can influence the way the disabled are viewed by society. An assumption exists that prenatal screening reduces the incidence of disability, and therefore increases quality of life (Saxton 1987, p. 217). The underlying subtext related to prenatal diagnosis seems to be that it is better not to exist, than to exist with a disability. Prenatal screening is concerned with the existence or avoidance of disability in individual and society (Kaplan 1993, p. 64). Prenatal screening raises ethical, social and psychological issues. Prenatal diagnosis has the potential to discriminate against the unborn.

Not all women who undergo prenatal diagnosis want to know if their baby will be abnormal, and not all women will seek to terminate a pregnancy if an abnormality is detected (McFadyen, Gledhill, Whitlow & Economides 1998, p. 695). The use of prenatal diagnosis can impact on the way parents are viewed by nurses. The nurses in the current study were surprised that parents given a diagnosis that their child would have a genetic defect or major malformation, did not take the opportunity to terminate the pregnancy.

They showed their surprise, yet respected the parent's right to decide. Parents in a study by Maijala, Astedt-Kurki, Paavilainen and Vaisanen (2003), experienced negativity from medical and nursing staff when they decided to continue with the pregnancy, when they were expecting a malformed child. Shapiro (1994, p. 279) believes that legalised termination of pregnancy has played upon the parents' fear of giving birth to a child with defects. The use of "...exaggerated pity talk" (Shapiro 1997, p. 279), gives parents the idea that their child will have no future. Fear that the handicapped child will be a burden seems to be the prominent issue when deciding to terminate a pregnancy (Saxton 1987, p. 220). Whether the neonatal nurses had internalised this "tragedy talk" (Avery 1999, cited in Brett 2002, p. 829), "tragedy repertoire" and "labor repertoire" (Vehkakoski 2007, p.291), they believed they had an understanding of the difficulties the disabled faced. It is not surprising that the nurses would be concerned about parents who chose to bring a child into the world who will ultimately be disabled.

Would the disabled choose to be non-disabled if they had a choice? Disabled people have argued they did not want to be cured, because they believed they were disabled by society, not by their bodies (Shakespeare 2003). Hahn and Beaulaurier (2001, p. 40) found the disabled in their study were ambivalent about whether they would take a "magic pill" to cure their disability. It is clear from the current research that the neonatal nurses would have difficulty accepting the idea that disability was a preferred state. Mothers of disabled children, have, however, indicated that they would change their children if they had the choice. In a study by Landsman (2003, p. 1949) mothers experienced conflict when they spoke about their disabled child, and stated, "I love you as you are, and I would do anything to change you". (p. 1949). It could be suggested that for the neonatal nurses in the current study it is as Scheper-Hughes (1990, cited in Landsman 2003, p. 1947) believes that the physically different infant challenges the delicate and symbolic boundaries between human and non-human.

#### **10.4.4 Summary**

This section has explored where nurses might have obtained their attitudes and beliefs about disability. I suspect that the nurses are a mixture of attitudes and beliefs that are

part of their initial socialisation, but experience has shaped their viewpoints. Culture, like attitudes does not exist in a void and is constantly changing. There came a time when the neonatal nurses began to believe that the profoundly impaired baby would burden his/her parents. A full exploration of the attitudes of neonatal nurses to disability warrants attention, but is not within the scope of this thesis.

### **10.5 Conclusion**

There are many different issues for the neonatal nurses to consider and deal with when they care for extremely premature babies. At times it seemed as though they were caring for a fetus rather than a baby, as the baby's appearance was more fetal than baby. It was important for the nurses to be included in decision making, yet their lack of voice could see them in the role of Berne's (1961) Child, often petulant, hostile and angry. Admission to the NICU and active treatment led the nurses to believe that there were times when they hurt the baby, rather than provide acceptable nursing care. The nurses could not cope at times with giving care, and their ethical dilemmas overwhelmed them. They distanced themselves physically and emotionally to protect themselves. While initial uncertainty of the baby's prognosis and outcome gave the nurses hope, certainty of diagnosis and outcome could take that hope away. Babies who survive in a damaged state are likely to be profoundly disabled. The nurses believed that a baby with a profound disability represented a profound ethical dilemma. They worried about the baby, the parents, and the ramifications of the baby's survival on the family unit. The nurses had a range of ideas about the level of disability which would be acceptable to live life.

The following chapter titled summary, reflections, issues for practice and conclusion will provide a summary of the research, explore the limitations of the study and consider issues for neonatal nursing practice. My reflective analysis on the interviews and dealing with sensitive data will also be discussed, because interviewing nurses on sensitive topics requires personal reflection on the part of the researcher.