

CHAPTER 11: SUMMARY, REFLECTIONS, ISSUES FOR PRACTICE AND CONCLUSION

11.0 Introduction

This study has examined the ethical issues experienced by neonatal nurses concerning the care of babies 24 weeks gestation and less. It has provided knowledge about the neonatal nurses' experience of ethical dilemmas related to the care and management of extremely premature babies. The dilemmas permeate the world of the neonatal nurse, and some leave the profession because they are unable to resolve their dilemmas. This research consisted of a questionnaire, and a qualitative analysis informed by phenomenology. Four hundred and fourteen nurses completed the questionnaire and twenty four neonatal nurses were interviewed in fourteen interviews.

This final chapter presents a summary of the research, presents my reflections on the research experience, including dealing with sensitive data. It explores the limitations and issues for nursing practice, it considers my reflections on caring and ends with some concluding remarks.

11.1 Summary of the research and findings

This study has provided an Australian perspective on the ethical dilemmas experienced by neonatal nurses when caring for babies of extreme prematurity. The study developed from my experience as a neonatal nurse and my formal study in bioethics. The aims of the study were to explore and describe the ethical issues faced by neonatal nurses concerning the care of babies of twenty-four weeks gestation and less.

The first three chapters examined issues related to preterm labour, delivery, extremely premature babies and the ethical complexities associated with the baby's existence. The quantitative and qualitative study methodologies were explored in chapter 4, and questionnaire results presented in chapter 5. The entire questionnaire results are found in

the appendices (Appendix B). In chapters 6-9 the qualitative results are presented. In chapter 10 there was an in-depth exploration of aspects associated with each theme.

The answer to the study question, how are ethical issues experienced by neonatal nurses concerning the care of babies 24 weeks gestation and less, has been revealed in a qualitative description of the nurses' experience as *balancing hope with reality*. Four essential themes have emerged; *It's all about this baby*; *Having a voice*; *Dealing with awfulness* and *Reflecting on the outcome*. These four themes are described in chapters 6-9, and are summarised below. *Balancing hope and reality* is the ultimate finding of the qualitative research and has illuminated how the nurses hope for a baby's survival, yet expect and, are often confronted with, a different reality.

11.1.1 It's all about this baby

It's all about this baby is about the baby as an individual. The nurses believed that each baby should be treated as an individual, and given the opportunity to live if it was vigorous and active at delivery. They recognised that not all babies could live or would survive, but if the baby was resuscitated they wanted it to receive the best available treatment. This would enable those destined to survive to have the best possible outcome, while those destined to die had been given every possible opportunity.

The nurses valued the extremely premature baby. Valuing the baby meant the nurses would do their best to save the baby's life. The baby would decide whether it would live or die. Attributing decision making to these babies allowed the nurses to believe the babies were individuals.

It's all about this baby spoke of the nurse's desire for fairness and equity. The nurses' sense of fairness and justice dictated the baby be given the opportunity to live, if it displayed a willingness to live. The arbitrary rules regarding cut-off points for weight and gestation were inappropriate, and did not take into account individual differences. *It's all about this baby* represents the fair allocation of resources. Caring for tiny babies often

meant the juggling of resources. The allocation of resources caused a great deal of anxiety for the nurses. In many cases the nurses knew the baby would die, yet they believed resources should be available while the baby was alive. The nurses wanted babies to be treated fairly, yet they agonised over a more viable baby being turned away from the NICU. It was emotionally demanding for the nurses to advocate for fair and equitable treatment of tiny babies, when others considered treating tiny babies a waste of money and resources.

The extremely premature baby engendered respect on the part of the nurses. The nurses were able to imagine the life of the baby; empathic imagination played an important role. It was as if standing at the end of the bed and imagining the life the baby would have, influenced whether respect should be associated with keeping the baby alive, or advocating for a peaceful death. Respecting the baby was about honouring the living child, and even mythologising society's written, and unwritten laws about the value of children. It was about the recognition that this baby was part of a family.

It's all about this baby spoke of the nurses' reluctance to have their own baby treated should they go into premature labour. It reflects the nurses' different perspective as they fought hard to save the lives of babies in their care, but freely admit their own baby would not be saved under the same or similar circumstances.

11.1.2 Having a voice

The nurses believed they could participate in the decision making about extremely premature babies, yet they were not allocated a voice. The decision making process left them feeling powerless and helpless at their inability to influence the outcome. The nurses were angry with those who made the decisions, often without consulting them or the parents. They believed they weighed up all options when it came to decision-making. It was as if the nurses took in a vision of the scales of justice, and they attempted to make sense of saving extremely premature babies.

Keeping secrets from the parents was felt as agony for the nurses. Being secretive saw the nurses in a state of withholding. The forced concealment of information from the parents caused them to suffer guilt and shame. Being secretive could have serious deleterious effects on their relationship with the parents. They believed parents knew when staff were not telling them the truth, or were being evasive. The nurses wanted the parents to know the truth, yet they were not allowed to tell them. This meant parents were denied the crucial elements required for decision making. Deceiving the parents brought the nurses to feel guilty. Telling the parents would have meant a breach of professional etiquette. Giving parents information could damage the relationship between the nurses and medical staff.

Honesty was one of the most crucial issues for the nurses. Being upfront represented the nurse's ethical beliefs that parents should be told the truth regarding their baby's condition, prognosis and possible outcome. The nurses wanted to be honourable in all of their interactions with the parents. They wanted to be seen as reliable by the parents. They wanted the parents to know the truth in a sensitive and caring manner, without omissions and without lies.

It was imperative that parents had the information they needed to make decisions about their extremely premature baby. The nurses empowered parents by helping them access information. Accessing the relevant information and understanding its relevance, qualified the parents for their role in decision-making.

The nurses resented exclusion from decision making. It represented a lack of recognition of their experience with tiny babies, and their expertise with caring for families in crisis. The nurses considered themselves well educated, and for them it was unthinkable they should be denied the opportunity to participate. It was important for the nurses to be participants, and not mere spectators. They were disappointed and became discouraged. The nurses became bitter and harboured resentment that they could be totally overlooked. Being resentful for many of these nurses fostered passive aggressive behaviours in them.

The alternate passivity and aggressiveness was expressed as obstruction by the nurses. This type of behaviour had the sole purpose of punishing the medical staff.

11.2.3 Dealing with awfulness

Dealing with awfulness could see the nurses overwhelmed when caring for extremely premature babies. The nurses provided care to a fragile human being who was only slightly bigger than their hands. They provided this care in a highly technological environment where death could be an everyday occurrence. They dealt with distraught parents and relatives who did not know whether to hope or grieve. Knowing what was likely to happen to extremely premature babies made the nurses pessimistic rather than optimistic. Knowing the possible outcome for extremely premature babies kept the nurses hopeful. Hope mediated many of the negative effects of caring for extremely premature babies. Having hope was not enough, because the nurses lacked optimism.

The nurses were anxious and fearful that the baby would die, yet they were anxious and fearful the baby might live in an impaired state. At times they were buried in their own feelings about the devastation caused when things went tragically wrong. They grappled with the complexities of what technology could do, yet wondered should technology be used when the outcomes were anything but positive. Dealing with awfulness saw the nurses submerged in the ethical issues as they sought answers to their dilemmas of care.

Dealing with awfulness was about the nurses feeling powerless and helpless. Powerlessness and helplessness engendered feelings of anger and resentment in the nurses. They were advocates for the baby and family, yet were unable able to fulfil that role. Being powerless meant the nurses came to view their role of advocate sceptically. They came to see themselves as being invisible. Being invisible meant they were like glass, seen through as if they were not present. If one was invisible then he/she was also voiceless. In their powerlessness the nurses saw themselves as being disregarded and ignored by the medical staff.

There were times when the nurses could no longer care for a premature baby and its family. The nurses wanted to take a break from caring, yet felt guilty. Many nurses did not take a break and became enmeshed because at the time they needed the break was when it was believed the baby might die. The nurse's energy levels were depleted by advocacy and anger, and they become mentally, emotionally and physically exhausted. They put aside their feelings, kept going, but finally had to vanish physically and emotionally from the situation.

The nurses spoke of the difficulty of wanting a baby to die so it would be relieved of its pain and suffering, yet they were incapable of ensuring this would happen. The nurses knew themselves paralysed by the law, making it illegal to hasten death. The nurses made meaning from a difficult situation when an extremely premature baby died. They told themselves they had done their best to save the baby, but held onto the idea that death represented a release for the baby. For the nurses, the ethical dilemma was resolved when the baby died. The nurses were touched by sadness. The nurses experienced difficulty reconciling their sadness at the baby's death, with their relief the baby no longer suffered. This paradox about being happy about the death of a baby brought its own set of problems for the nurses.

11.2.4 Reflecting on the outcome

The nurses thought deeply about all aspects of the care associated with extremely premature babies. The nurses considered the future life of the baby, and contemplated whether the baby would thank them for saving its life. The nurses questioned the saving of extremely premature babies. They had seen what they believed were many tragic outcomes. There was a sense of wonderment that technology could save babies so tiny, and they had seen the age of viability slip closer towards 20 weeks gestation. There was pride as they spoke of their efforts at saving babies of greater gestations. Their pride in theirs and others achievements was almost palpable. The pride around saving extremely premature babies was hidden.

The nurses genuinely believed the baby should be given a chance to survive, but they were torn between this and the need for the baby to die in peace. The nurses vacillated between the two points of view. The nurses wanted the parents to know what was likely to happen, yet not dash all their hopes. The nurses were realists. It was agony for them when they found out a baby who they thought would have a good outcome, was impaired. This information seemed to lacerate their hope and optimism.

The nurses struggled with uncertainty, and at times they likened it to winning a lottery. For the extremely premature baby it was a game of chance. For the nurses it was about picking a number, and waiting for it to come up. It was about taking a gamble and, in essence, gambling with the baby's life. It was about babies who defied the odds.

Caring for extremely premature babies challenged the nurses' ideas of normal babies. Not all outcomes are positive and although they were immensely proud of their efforts, they experienced embarrassment and guilt when they were confronted by what they perceived as their failures. For the nurses the increasing number of poor outcomes in babies of 24 weeks and less meant at present the limit of functional viability had been reached.

At times the nurses seemed to carry the weight of responsibility and they perceived themselves as partly responsible for what happened to the baby. This weight of responsibility was seen by the nurses as worrisome, and they experienced sorrow and guilt about the outcome that might have been. The nurses were remorseful, and they apologised to the baby for the pain and suffering they had caused to it and its family.

11.2 Reflection on the research process

When I started on the research journey I was convinced by my supervisors that keeping a journal would be a helpful adjunct to the interview transcriptions. It was believed the journal could help with my creative, professional and personal development. I recognised journals have many purposes, but I decided the journal would be a tool for thinking,

reflecting and articulating using description and narration. When reflecting on the transcripts I documented in the journal what I thought I had missed, should have asked, and would still like to know. The journal has provided me with an opportunity to have the whole experience recorded, and reflect on my process of learning. The following section explores my journey through the research process, including some thoughts about the research, interviewing and how a researcher deals with sensitive data.

11.2.1 Sharing experience – notes from my research journal

We find a comfortable area and we exchange pleasantries. I know most of these nurses. Those I do not know personally, I know by name. NIC is a small specialty, and most experienced nurses know each other, or of each other. I know that these nurses have been caring for extremely premature babies for many years. They have extensive experience. I am grateful they have consented to talk to me. I seek to walk in their shoes. I want to understand what caring for extremely premature babies is like for them.

My experience as a neonatal nurse and a researcher brings me to ask them about their experiences. I have always been interested in the ethical issues surrounding neonatal care, particularly those associated with extreme prematurity. Having studied bioethics, I wanted to formalise my thinking and reading into a scholarly inquiry that could reveal the ethical complexities of caring for extremely premature babies.

I know how to start, but I have no idea how it will finish. This study is large, with a questionnaire and qualitative investigation. Setting limits has been difficult, but essential. I want to know about the experiences of ethical dilemmas with extremely premature babies, from the nurses who have experienced them. It is not common practice to use a questionnaire, interviews and qualitative investigation, but I want the whole story. I tell myself that the study is rigorous and manageable and that in Van Manen's (1990, p. 36) words "...lived experience is the starting point and the end point". The lived experience of the neonatal nurses became central to the research.

I travel, sit, listen, and talk in many different places. I travel across Sydney, to Newcastle and to Canberra. I go to the nurses' own homes, they come to mine. I go to the neonatal nursery of their employment and to NICUs I have not visited before. The nurses are proud of their practice and units. Each NICU is different, each excelling at something. This excellence is what I am shown. The nurses are generous with their time, refreshments, tea and coffee. As they talk they give of themselves. There is nervous energy as they describe the issues that cause them to soul search.

The nurses have completed the questionnaire, and are aware there will only be one interview. I want to know about their experiences of ethical dilemmas when caring for babies of 24 weeks gestation and less, and 24 nurses in 14 interviews agreed to tell me. These nurses are pragmatic; they have to cope in the NICU. They know that participating in interviews about a difficult topic can bring them to revisit distressing incidents. They are prepared for this and say they believe in the importance of the research. No one has ever asked them about their experience before.

11.2.2 Reflections on the interviews - notes from my research journal

I mentally prepare myself for the interviews. I physically prepare the space. It needs to be conducive for talking. I check that the tape recorder is working. I am careful. Batteries are changed before every interview, even though this may not be necessary. I do not want any mishaps with recording. The nurses are informed that the interviews will be audiotaped and that they can discontinue at any time. They sign the consent form. They know I will arrange formal debriefing and counselling for them if necessary. They explain that if they could not cope with all that they have been through, they would have left neonatal nursing. I nod in agreement; this is something that I also know. I will myself not to interrupt, but sometimes clarification is necessary. It is their words which are important, not mine. For much of the interview I am engrossed in their stories. I ask about their ethical dilemmas and their experiences of ethical distress. I put to them the main findings of the questionnaire. Sometimes they are surprised by these findings, or shake their head in agreement, their eyes wide in recognition. Mainly they agree and

smile. I encourage them to talk about their experiences. They seem to make each word count.

I am taken aback with their openness and their bluntness. I am grateful for the rich data. I had not expected such richness. Some stories are extraordinary offered by these ordinary nurses who have been placed in extraordinary situations. I am told that I am getting the full story because as a neonatal nurse I will understand. I wonder how such experiences could allow them to keep going. They do not dilute their experience. I have asked for their experiences, they tell me. For many of them this is an opportunity to tell their story. I wonder how the nurses help the parents in their ordeal, when they themselves are traumatised by their experience. They cope, they say they have to, and ask what choice they have. They are regularly asked if they want to talk to professionals about their experiences. They choose to talk with their colleagues, those who understand, and not those they believe could not understand. For these nurses, those who have experienced similar situations will understand.

The nurses tell me they love caring for sick babies. During the good times they could not imagine doing anything else. In the bad times they would choose another career. They talk about working as a cleaner, check out operator or even a gardener. They admit they do not always enjoy looking after extremely premature babies, because it brings anger, frustration, conflict and anxiety. Knowing what can happen to the babies is draining. Being helpless to prevent it is seen as a torture. Distancing in order to prevent themselves being traumatised is their way of coping. They understand this strategy may not be the best way to deal with the situation, but they cannot help themselves. They need to protect themselves. To come back to the NICU day after day, they need this protection. The nurses believe they are realists, and survival is essential. Todd (1995, p. 3) a neonatal nurse has reflected, "I view our club as one of survivors of an unnamed war, of a war that was never declared because it is ongoing and will never end."

These nurses see tiny babies as miniature human beings with specific needs and wants. The babies are respected by the nurses. They work hard to save lives, and

have hope for positive outcomes. Hope is held until an intracerebral bleed is diagnosed. Hope then diminishes and reality sets in. The nurses want the best for the baby and family. Knowing that death is inevitable, the only option is not something they can talk about freely. It is as if there is secret business in neonatal nurseries when death is likely. It is not something to be shared. They wonder who would understand. All too often the media portrays these babies as miracles, but the nurses may not see them as such. Miracles are not part of these babies' existence, but heartache and suffering are. The nurses' stories are overwhelming at times.

There are experiences that are hard for the nurses to recall. They sigh, they cover their faces with their hands as if to hide and they cry. They apologise and make jokes. They talk of their powerlessness and helplessness. They also talk of power. These nurses are not powerless in the traditional sense. They have power, though most of them do not recognise this. They talk of being embarrassed and avoiding parents who bring a severely impaired baby back to the nursery for a visit. They feel guilty and ashamed when they hide from the parents. They know that survival can mean disability, but this forced acknowledgement is sometimes too much for them. They understand success, but they know that for babies of 24 weeks gestation and less this is often impossible. They talk of feeling guilty about those babies who survived in a damaged state. They hope for success but for some it never comes. Advocacy comes at a price for these nurses. To advocate is to put oneself in a vulnerable position and experience conflict for the benefit of another. Yet they do this time and time again. I wonder at their courage. Most times they think they do a good job. I thank these nurses for their generosity, their time, for allowing me to borrow their experience, and see things as they do. I leave with the thought that very few people will ever know their world.

11.2.3 Dealing with sensitive data

The spoken words of the data have presented some problems. Many times the words of the participants are sensitive and sometimes disturbing. The life and death of extremely

premature babies is a sensitive topic. Sensitive topics have the potential to arouse emotional responses (Cowles 1988, p. 163). Data is considered sensitive if its emergence renders it problematic for the researcher, the researched, or the dissemination of the data (Lee & Renzetti 1993, p. 5). Sensitive data in this story pertains to those statements that could cause people to be hurt or offended if the results were taken out of their context. The context of a research situation becomes important. A literature search looking for clues how researchers manage sensitive data has shown that while sensitive topics are reported extensively in the literature, very few authors have specifically examined these issues, or more importantly, how they are handled (Dickson-Swift, James, Kippen, Liamputtong 2006, p. 853). The work of Lee (1993) and Lee and Renzetti (2003) have been illuminating because most discussions relate to the ethical issues of dealing with sensitive data such as informed consent and confidentiality. Clearly, these matters need to be considered. When researchers, however, enter the private world of participants, evoking strong emotions and pursuing thoughts that may have been hidden (Cowles 1988, p. 163), a practical approach to dealing with emotional responses and decisions about data that might be too personally or professionally sensitive was not to be found. Alty and Rodham (1998, p. 275) call the practical difficulties with dealing with sensitive data “the ouch! Factor”. It is heartening to note that Lowes and Gill (2006, p. 587) found interviews on sensitive topics did not cause distress to the participants, but were a medium through which they could express their thoughts.

The measure of a sensitive topic is not a measure of its social or theoretical significance, yet frequently research on sensitive topics addresses some of society’s most pressing social issues and policy questions (Lee 1993, p. 2). In the case of this research it is a social issue surrounded by taboo; the life and death of the most vulnerable human beings. The sensitive data has created technical problems, problems which cannot be dealt with in any simple way. This thesis is laden with emotions that inspire feelings of sadness and desperation which have been at times been overwhelming for me as a researcher. The purpose of qualitative research is to search for meaning, which meant the first thing I had to do was to step back from the data and ask myself “what was in their hearts when they said...”. If I took the data at face value I would have found the nurses to be uncaring and

callous, therefore it was essential that I expose the layers and uncover the meaning in their words.

The nurses spoke of severely disabled babies as having the capacity to burden their parents and the community. They spoke about withdrawal of life support as an alternative to severe disability. It has been difficult to deal with sensitive information. Even in these times when people with disabilities are understood to have rights and special services, the nurses believed their extensive experience had led them to question medical interventions and its outcomes. These nurses are not uncaring or indifferent to the needs of disabled children. In fact, they spoke passionately about the need for financial and social support for the families of those babies who survived with some impairment.

As a researcher I worry that the nurses' words will be taken out of context. I experience a type of inertia and do not want to continue. I procrastinate, I feel like I am unable to move. There is inner conflict, I worry how the general public and specialist groups will perceive these findings. I consider leaving out the data but I cannot. This is the nurses' story, not mine. I asked them to tell me their innermost thoughts and they did. They trusted me. They have seen so much pain, suffering and tragedy. I am expected to tell their story in an authentic way. Van Manen's (1990, p. 98) words echo, "...participants of the study often invest more than a passing interests in the research process in which they have willingly involved themselves". I am, therefore, the interpreter and conveyer of their experience. I ponder that only qualitative researchers could understand my anxiety. My supervisors are sympathetic but the problem remains mine. It is as if I cannot deal with the answers I should never have posed the questions. I know, however, that the nurses' experience is not to be sanitised to make it more acceptable. I ask myself, how does one report such sensitive data, be faithful to its meaning and yet not intimate that neonatal nurses are insensitive and uncaring. Here is the hardest part and one that I grapple with even at the end.

11.3 Limitations of the study

This study makes an important contribution to the understanding of the experience of neonatal nurses caring for extremely premature babies. It is possible that sampling neonatal nurses who were members of ANNA might have yielded different results from neonatal nurses who were not members of this professional association. The Royal College of Nursing Australia (RCNA), the major nursing organisation in Australia, suggests that professional organisations aim to raise awareness among nurses of the key professional issues affecting nurses in Australia (RCNA 2005). Neonatal nurses who are members of their professional association could be more likely to think about issues related to their clinical practice. For the purpose of this research this could equate to having a captive audience of nurses who were concerned about the ethical issues surrounding their clinical practice. Different results might be expected from neonatal nurses who were not members of ANNA.

Purposeful sampling selects those neonatal nurses who have experience with caring for babies of 24 weeks and less for in-depth study, however, purposeful sampling can be problematic. A number of issues could have potentially undermined the essence of the purposeful sampling. Firstly, sampling decisions are made by others, as most of the participants were not chosen by the researcher (23/24). This ‘gatekeeper bias’ (Tuckett 2004, p.58) meant that the CNCs and CNEs had control of the sample. Secondly, CNCs and CNEs when selecting suitable neonatal nurses, might have recommended neonatal nurses whose beliefs about babies of extreme prematurity were aligned with their own. The limitations in sampling has been countered by using a number of different research strategies and using different methods to collect data (Tuckett 2004, p. 59).

Conducting research amongst my peers made me particularly sensitive to the ethical issues associated with interviewing participants, such as confidentiality. While researching neonatal nurses does not raise distinct ethical issues, collecting data from peers could be problematic. I was concerned that power dynamics might exist between researcher and participants, and this could impact on the data quality. Most nurses (23)

were not chosen by the researcher, however, one nurse was chosen by the researcher because the nurse at that institution who had initially agreed to be interviewed, subsequently declined when it was time to be interviewed.

The neonatal nurse as researcher can present opportunities and dilemmas. The positives include experiential and insider knowledge, and honesty and openness on the part of the participants. The neonatal nurse as researcher also has a sense of the NICU organisational structure, and is in a position to understand the research needs and opportunities. Conversely, the neonatal nurse as researcher could feel that he/she already has the answers, is biased and lacks objectivity. It is hoped that these potential problems have been minimised by building a solid foundation for the research by using both quantitative and qualitative methods. Thoughtful consideration was given to my ability to make meaning from the nurses' stories.

The absence of independent scrutiny of the data could present problems. Full disclosure of the research process, however, has been embraced by the researcher to ensure the credibility of the research. The full results of the questionnaire are included in the appendix and the decision trail is outlined in detail in chapter 4. This will help those who attempt to reproduce, validate or build on the work. It also needs to be remembered that two researchers faced with the same research question will produce different accounts.

The nurses participated in only one interview, because I was not looking for longitudinal change. Over the duration of this study some treatment regimes have changed, but the outcomes of extreme prematurity have remained the same, or improved only slightly. If I had re-interviewed two years after the initial interviews some of the nurse's experiences might have been different.

In retrospect it would have been advantageous to differentiate between the states of Australia in the demographic data. I am now aware that different states have different standards by which they resuscitate and initiate life support in infants. Some states view legal viability as the time at which they must resuscitate, while other states view legal

viability as a guide, and that decisions based on the condition of the baby are more important than gestation alone. While I hope this has not affected the research, it would be interesting to interview neonatal nurses from a state that saves from 20 weeks gestation.

All interview participants were of Anglo-Celtic heritage which limited consideration of whether cultural beliefs impact on perceptions about extreme prematurity. The questionnaire, however, surveyed a larger neonatal nursing population. Information gathered in qualitative research is self report. Its trustworthiness can be affected by the participant's less than accurate recall, the protection of the ego and the ability to rationalise, or discomfort with self-disclosure. While I have no reason to suspect this occurred, I nevertheless acknowledge the possibility.

Research is an investigation into the unknown. The benefit of hindsight is not possible at the outset. It is important for the researcher to reflect on the entire research process. I am directed to the past to consider what I would do differently. I believe I chose a worthy topic, one which could sustain my interest. This research has been a quest to discover the reality about extremely premature babies and the nurses who care for them, yet it takes a while to recognise there are multiple versions of reality. In qualitative research there is no such thing as objective, interpretation free research. The recounting of lived experience is reliable data in this qualitative study informed by phenomenology. The results are founded on my interpretation, and I can only hope that I have reported them in an authentic manner.

As a researcher I was keen to dissect and discover, therefore I delved into the research with high expectations. In hindsight using a questionnaire and a qualitative study was lofty and ambitious, and could have been two separate studies. A partial replication of Armentrout's (1986) work may not have answered the research question. The interviews ensured the originality of this study.

11.4 Issues for practice

Prior to embarking on a selection of issues for practice I believe I need to ensure that some of the findings are seen in perspective against the back drop of the positives associated with caring for babies in the NICU. The world of the neonatal nurse has dark places, but the reality is that I asked the nurses about their ethical dilemmas associated with caring for extremely premature babies. Extreme prematurity is not common, but the impact is huge.

Neonatal nurses experience ethical dilemmas surrounding the care and management of babies of twenty-four weeks and less. Ethical dilemmas surfaced when there was the possibility of poor outcomes. In order for nurses to continue working in this environment, where exposure to tiny babies is a regular occurrence, several issues for practice need to be considered:

11.4.1 Clinical supervision / reflection / discussion of ethical issues

The nurses experienced ethical dilemmas when caring for extremely premature babies. Decreased viability and burgeoning technology have contributed to these dilemmas. Neonatal nurses could benefit from the opportunity to explore their feelings about caring for extremely premature babies and the experience of ethical dilemmas through the provision of clinical supervision. Nurses have been reported to be enthusiastic about the opportunity to reflect on clinical situations which were seen as upsetting, challenging and “sometimes harrowing” (White, Butterworth, Bishop, Carson, Jeacock, Clements 1998, p. 185). The benefits of clinical supervision have been documented as improved clinical competence, increased job satisfaction and confidence (Fowler 1996, p. 472). It is important that clinical supervision be distinguished from therapy. It would be beneficial for the nurses to choose their clinical supervisor (Lyth 2000, p. 725) as self disclosure is involved. It would be preferable that the supervisor was not the nurse’s manager, as the manager already has de facto positional power which could impact on the supervisory relationship (Kilminster & Jolly 2000, p. 835).

It is likely the nurses would benefit from an organisational culture that encouraged reflection and reflective practice. Reflection has been described as an essential component of clinical supervision (Hannigan 2001, p. 280). The idea of reflection comes from the belief that humans have the capacity to introspectively consider their activities and actions, and moderate those actions in the future. Both undergraduate nursing and postgraduate neonatal nursing curricula require revision to ensure that formal reflection is embedded in the curriculum, not just as a core aim and philosophy. Reflective material could be used for assessment purposes. Diaries and journals are used widely in undergraduate curriculums for reflection. Postgraduate students might derive more benefit from the use of critical incident techniques which helps the nurse identify behaviours deemed to be helpful or unhelpful in a given situation (Hannigan 2001, p. 281).

The nurses believed they did not have the opportunity to discuss their issues of concern about caring for extremely premature babies. Neonatal nurses might value the opportunity to participate in discussions at a ward, hospital and community level, about the ethical issues associated with their nursing practice. It is not enough for others to speak on behalf of nurses. These nurses are capable of articulating the nursing perspective. This public profile could help to dispel the myths of the 'miracle baby'. A case could be made for institutions to provide an ethics committee forum where clinicians could discuss and debate their dilemmas of practice.

11.4.2 Open dialogue between the professions surrounding extreme prematurity

The nurses were convinced that the present level of viability was 23 to 24 weeks gestation. They were aware that even with the available technologies there had not been an appreciable improvement in the outcomes of tiny babies (Markestad et al. 2005, p. 1289). It would be helpful if all of those who care for extremely premature babies in Australia (obstetricians, neonatologists, midwives and neonatal nurses) examine the issues surrounding the birth, resuscitation, management and care of extremely premature babies. The nurses were emphatic that guidelines, not laws, would be helpful to prevent

the indiscriminate resuscitation of babies considered too immature to survive. Good ethics requires good medicine. Good medicine is where current evidence-based data is used to help with decision-making (Hartline 2001, p. 248). The nurses believed that medical staff should consider their motives for saving the lives of tiny babies. Experimenting on humans who were unable to give consent was a cause for concern for the nurses. The nurses were passionate that decisions to resuscitate, institute life support and discontinue life support be made on an individual basis for each baby, as each situation is unique. They emphasised the best interest of the baby should be at the heart of all decision-making.

11.4.3 Education for practice

11.4.3.1 Ethics education

The majority of nurses had not received formal education in ethics, yet they considered ethics education would be beneficial. Neonatal nurses could benefit from education in ethics (theoretical, philosophical and clinical) to help them deal with the complex issues related to caregiving. Neonatal nursing course curricula need revision to ensure that nurses are adequately prepared to face ethical dilemmas. It is difficult to point to a superior method of teaching ethics to nurses, however the use of debates, so that nurses can articulate their ethical stance, is seen as effective (Webb & Warwick 1999, p. 155). The curriculum would need to be creative and critical, because nurses tend to reason and behave in a conformist or conventional manner when faced with ethical dilemmas (de Casterle, Caerlens & Derwael 1998, p. 460). The opportunity to have their values challenged in a creative format that allows them the safety to disclose could be of benefit to neonatal nurses.

The nurses have been exposed to some very difficult caregiving situations. Education could help neonatal nurses deal with ethically troubling situations. Education is necessary if neonatal nurses are to remain productive members of the healthcare team. The reality is that difficult situations are part of their job. Swanson (1990, p. 63) suggests that “to

evaluate the reality of caring for preterm infants is a lofty, challenging, theoretic and philosophic dilemma". The nurses recognised there was likely to be the occasional situation that was tremendously difficult for the staff. The majority of cases are more straightforward. The difficult cases could make the staff feel as if they are held hostage by the technological imperative (Hefferman & Heilig 1999, p. 173). There will probably always be parents for whom the survival of their child is paramount, regardless of the ethical distress it causes the staff.

11.4.3.2 Research education

The nurses emphasised the value of nursing research, yet few of them had formal research skills. Neonatal nurses could benefit from education on research methods and practical skills to help them become involved in researching the ethical issues surrounding their practice. It is not enough that others write about nurses' experiences, because there is evidence (Green 1995, p. 115) that neonatal nurses are unlikely to share fully their experiences with those who are considered to be outsiders. The nurses have been exposed to situations they would prefer not be made public. It is this experiential knowledge, or special knowledge (Mitchell 1984, p. 9) that is difficult for neonatal nurses to discuss with those who have little understanding of their world. Neonatal nurses might be more likely to speak to researchers who are themselves neonatal nurses, or have an understanding of their world, because during the interview "people talk as fellow members of the same professional group" (Lawler 1991, p. 17). I am not suggesting that only neonatal nurses should research neonatal nurses, what I am suggesting is that the neonatal nurse researcher's perspective would add a different dimension. As a researcher I also recognise that the insider perspective might have meant that I was too close to the situation and was not able to see the issues with fresh eyes.

11.4.3.3 Education about the legal aspects of extreme prematurity

The nurses emphasised that the law surrounding viability and resuscitation of extremely premature babies was confusing. Neonatal nurses might benefit from education about the

law as it relates to extreme prematurity. The application of the law remains a grey area, however, education could help the nurses understand the legal implications of withholding and withdrawing life treatment. Currently there are no laws that require the resuscitation of extremely premature babies, but the born alive rule does exist, which contributes to the nurse's confusion. Law and ethics could be seen by the nurses as existing at opposite ends of the spectrum, where the law ignores ethical principles, claiming that the law is more important (Newnham 1998, p. 42).

11.4.3.4 Conflict management strategies

The nurses experienced conflict with all aspects of providing care for the extremely premature baby and its parents. Neonatal nurses could benefit from education sessions that address conflict and conflict resolution strategies. This education could help neonatal nurses deal with conflict effectively. There were two different types of distress experienced by the nurses; initial and reactive. Initial distress was where feelings of frustration, anger and anxiety were experienced when the nurse was faced with obstacles and conflict with the values of other staff. Reactive distress occurred when nurses did not act on their initial distress (Jameton 1993, p. 542), or may have avoided the situation. Such avoidance is not in the best interests of the NICU, or the nurse. It is possible that poor resolution of conflict could be one reason why neonatal nurses leave the NICU and/or the nursing profession. Education might help the nurses understand that conflict in the NICU could be inevitable, as nurses and physicians operate under a different frame of reference, despite their similar value systems (Caswell & Cryer 1995, p. 30). Greenall (2001, p. 112) suggests the conflict arises because doctors see the babies as "primarily objects, nurses see them as people, despite their prematurity". Differences of opinions and values will be commonplace, but they need not always result in conflict. Neonatal nurses should be provided with the opportunity to discuss those issues that cause them to experience conflict. Not all conflict can be considered a negative experience. In NICUs there is less stress when everybody agrees, and conversely there is more stress when there is little or no agreement. Agreement, however, does not necessarily reflect correctness of knowledge, attitudes (Lantos 2007, p. 201) and ethical

decision making. Janvier, Nadeau, Deschenes, Couture and Barrington (2007, p. 207) found that staff reported fewer ethical dilemmas when they were less knowledgeable about the outcomes for tiny babies. A lack of ethical controversy does not mean that practices are ethically appropriate, conversely the presence of ethical conflict does not mean the practices are less ethically appropriate (Janvier et al. 2007, p. 206). Conflict might be inevitable for the nurses. Lantos (2007, p. 202) suggests that moral distress and confrontation “might be a sign of progress, rather than a sign of problems.”

The nurses acknowledged they did not deal well with conflict. Dealing with conflict and anger effectively requires emotional intelligence. Neonatal nurses could benefit from education on emotional intelligence. Emotional intelligence is the ability to regulate the emotions of self and others (Reeves 2005, p. 173). The skills required for emotional intelligence are self awareness, self management, social awareness and relationship management (Kooker, Shoultz & Codier 2004, p. 31). It is considered acceptable for nurses to show their emotions and thus their humanity, however education could provide nurses with some practical skills to help them manage their emotions. With emotional intelligence the emotions are not suppressed or ignored but are acknowledged. Education on emotional intelligence could help neonatal nurses recognise and identify their feelings and emotions, thereby allowing them to function without being controlled by their emotions. Individuals with higher levels of emotional intelligence engage in collaborative conflict resolution (Jordan & Troth 2002, p.98). Education on emotional intelligence might help neonatal nurses understand how they can simultaneously feel anger and compassion (Jordan & Troth 2002, p. 95) when dealing with extremely premature babies. Currently the best way to provide this education has not been ascertained (McQueen 2004, p. 106).

11.4.3.5 Managing anger in themselves and others

The nurses experienced high levels of frustration and anger when caring for extremely premature babies. Neonatal nurses could benefit from education and practical skills on frustration and anger management. The education to manage frustration and anger could

include acting on the anger triggers, or alternatively finding healthy ways to discharge the physiological arousal associated with anger (Thomas 2003, p.108). Anger is a complex emotion and Thomas (2004, p. ix) states anger “eats away at us inside and takes its toll”. There are positives associated with anger as it can promote advocacy for patients. The problem with anger is that for the nurses it can become destructive, especially when it becomes “too frequent, too intense, too prolonged, too punishing – to ourselves as well as others” (Thomas 2004, p. 6). The nurses recognised they did not manage their anger well. This is consistent with Thomas (2003, p. 107) who suggests that nurses’ anger is mismanaged. Nurses have been reported as feeling ashamed of losing control (Thomas 2004, p. 29). It would be less than helpful to recommend that nurses do not become angry. What can be recommended is that the anger needs to be channelled into constructive actions.

The nurses were distressed when the parents of babies in their care displayed anger and aggression. Neonatal nurses could benefit from education to help them minimise parental aggression. This education could help nurses develop skills to deal with anger from parents. It is ironic that the people who the nurses are trying to help become the perpetrators of abuse and aggression. Angry parents challenge nurses; they do not know how to respond to the anger. Education and support could help the nurses deal effectively with parental anger, as well as provide understanding and support to the parents (Griffin 2003, p. 212). It is important for nurses to be able to deal with parental anger, however an educational program could address the common sources of parental anger. Education could help nurses feel they are adequately prepared when anger escalates to violence, and when to seek help from security.

It is essential that neonatal nurses receive help to manage parental anger and aggression because of the negative consequences for the nurse and organisation. Organisations need to acknowledge that the health industry is the most violent industry in Australia (Deans 2004, p. 32). Nurses who have been the victims of abuse or aggression should be provided with professional counselling, as aggression can be interpreted by the nurse as a significant physical and emotional trauma (Deans 2004, p. 32). The nurse’s physical and

psychological wounds can linger and interfere with work and leisure for months and even years after the aggressive episode (Needham, Abderhalden, Halfens, Fischer & Dassen 2005, p. 284). The nurses had resolved to spend the rest of their careers in the NICU, therefore it is essential they have their mental health protected.

11.4.3.6 Stress management techniques

The nurses recognised that caring for extremely premature babies was stressful. Neonatal nurses could benefit from stress reduction and stress management techniques. The nurses are carrying vicarious stress. This is the stress that results when people take on the burdens of other people (Thomas 2004, p. 218). In this case it is the experience carried by the baby and family. This stress is not new. Menzies (1960) acknowledged the inherent and unavoidable stress associated with the realities of caring. What is new is the level of involvement, because historically there has been a change from detachment and distancing to intimacy, commitment and involvement (Williams 2001, p. 660). The nurses were convinced that caring was the ethical ideal, but they experienced stress when they were unable to reach the levels espoused by the theorists. Carrying vicarious stress could lead to psychological overload and a chronic impotent anger because nurses are unable to solve problems (Thomas 2004, p. 218). Detachment from the situation is sometimes necessary, however stress reduction and management techniques could help neonatal nurses achieve a balance between engagement and detachment.

11.4.3.7 Professional distancing

Neonatal nurses could benefit from some education about the realities of caring. Education might help them understand that human need is infinite, and they can only give their best. The education could benefit the nurses if it focused on professional distancing, because distancing as a strategy is associated with better mental health for nurses (Chang, Daly, Hancock, Bidewell, Johnson, Lambert & Lambert 2006, p. 35). Undergraduate nursing curricula need revision to ensure nurses are adequately prepared for the physical

and emotional realities of caregiving. It would be useful if the neonatal nurses gave themselves permission to care for themselves with as much intensity as they care for others. In order to give to others they need to nurture themselves in ways that replenish their hope and optimism.

11.4.3.8 Communication skills

The nurses identified communication problems in the NICU. It would be beneficial for neonatal nurses to have education and practical skills about communicating with parents and professionals. Education could help neonatal nurses become skilled communicators, and ensure they were as proficient in their communication skills as they are in their clinical nursing skills (Thornby 2006, p. 267). Clearly, a culture change is needed, as a neonatal work culture that accepts poor communication among the staff and parents causes harm to the babies and their families. It is clear that there are difficult situations between nurses, doctors and parents. Education could help neonatal nurses understand that during difficult situations, emotions may overwhelm their thinking. During difficult situations it is only natural that nurses would hope that others would change their behaviour, but the nurse can only control or change himself/herself. Thoughts and feelings influence actions and words, and the negative thoughts could be reframed to create more positive and empowering thoughts (Thornby 2006, p. 271). The negative thoughts could make neonatal nurses feel irritated, annoyed and unappreciated.

11.4.3.9 Innovative approaches to nursing care

The nurses were emphatic that if tiny babies were to survive, they required the best nursing care available. Neonatal nurses would benefit from education that addresses innovative approaches to caring for the extremely premature baby. Bredemeyer, Presker-Smith, Osborn, Reid and Evans (2001, p. 10) introduced a skin care policy because of staff concerns that the current skin care policies were not adequate to meet the needs of such fragile premature babies. The facilitation of parental attachment through the use of kangaroo care (skin to skin) is a way for nurses to enhance the relationship between

mother and baby (Affonso, Bosque, Wahlberg & Brady, 1993, p. 25; Gale, Franck & Lund 1993, p. 4). The nurses were aware that the psychological impact of preterm birth may have a significant impact on the mother (Kavanaugh 1988, p. 61; Goldson 1992, p. 32; Maroney 1994, p. 131; Layne, 1996, p. 629; Padden & Glenn 1997, p. 122; Davis, Edwards, Mohay & Wollin 2003, p. 1). They also understood the relationship between mother and baby was essential if the baby was to survive, thrive and not be a victim of child abuse.

11.4.4 Implementation of the neonatal individualised developmental care and assessment program (NIDCAP).

The nurses were convinced that if extremely premature babies survived the first week, then neurodevelopmental care became a major issue. The nurses emphasised that the baby needed to be cared for in an environment that fostered its development in order to reach its full potential. One promising aspect is the implementation of Neonatal Individualised Developmental Care and Assessment Program (NIDCAP). NIDCAP is a care-giving program that uses repeated systematic observations of the baby's behaviour to devise individualised care plans. NIDCAP helps premature babies cope with the overwhelming NICU environment. Strategies which have been adopted include adjustment of the NICU environment by reducing the levels of noise and light, encouraging flexion through the use of "nests" understanding of cues, and interaction with the baby when they signal readiness, as well as helping parents to understand their baby's signals. Australian NICUs, nurses and babies could benefit from having at least one NIDCAP trained nurse on staff. The USA based NIDCAP training is costly, (US \$2750 per person plus airfare or US \$1200 per day plus airfare for USA NIDCAP trainer to teach the program in Australia) (Personal communication Dr Joy Browne Director Colorado NIDCAP Centre and Master NIDCAP trainer, 2007a & 2007b), therefore NICUs might be reluctant to fund NIDCAP training. Studies have revealed that babies who have more supportive nursing care and who have been nursed in a less stressful environment had fewer medical complications, and required less sedation (Heller, Constantinou, Vandenberg, Benitz & Fleisher 1997, p. 107). Perhaps more importantly, Buehler, Als, Duffy, McAnulty and Liederman (1995, p. 923) found that in low risk

premature babies NIDCAP could prevent the attentional difficulties, which cause the behavioural and scholastic problems, which are seen in premature babies. As yet there is no evidence that extremely premature babies will benefit from this, however research is continuing and looks promising. There is evidence that early intervention programs can alter the outcomes for premature babies of greater gestation; however for the extremely low birth weight baby this has not yet been found to be noticeably effective (Bennett & Scott 1997, p. 190)

11.4.5 Involvement in decision making

The nurses were emphatic they wanted to be involved in decisions related to the continuation or the withdrawal of treatment in extremely premature babies. They recognised the medical staff were responsible for decision making, but they believed they could contribute to the discussions. The nurses were very knowledgeable about extreme prematurity. Neonatal nurses with extensive experience could value the opportunity of involvement, as experienced nurses can offer much to these discussions (National Association of Neonatal Nurses, position statement #3015). Previously, the nurse was at the bedside coping with the aftermath of the medical staff decisions (Moulsdale & Johnston-Canjar 1993, p. 15); however when nurses are involved they are a valuable support person for the parents.

The nurses were passionate that parents have a legitimate place in the decision making team. They emphasised that when an extremely premature baby was born, parents need to be empowered to make decisions for their baby. It was clear to the nurses that parents have the legal responsibility for their children, but they need information to be able to exercise this legal responsibility. Catlin (2005, p. 169) discusses the use of an advanced directive to help parents make decisions in these difficult situations.

The nurses believed parental involvement could only happen if staff dealt honestly and openly with them. This is good in theory, however, there were definite problems in the communication between parents, medical staff and the nurses in this study. Neonatal

nurses would benefit from education about communicating with families. Education could help nurses support parental decisions, even if the nurse believed it was the wrong decision. The nurses supported decisions to withdraw treatment, therefore they need to develop strategies to help them support the parents' decision not to withdraw support. It is, after all, the parent's right to make that decision.

11.4.6 Support groups

The nurses have chosen who they rely on for support when dealing with ethical dilemmas and difficult situations. It might be beneficial for neonatal nurses to have a ward based support group, while recognising the effectiveness of structured support groups is inconclusive (Tyson et al. 1984, p. 901; Oehler, Peter & Seyler, 1989, p. 21). The nurses derive support from their colleagues (Rosenthal et al. 1989, p. 22). Teasdale et al (2001, p. 216) found that nurses receiving clinical supervision continued to use their informal networks for support. Simone (1984, p. 34) stated "there can be a special closeness among staff involved in helping families through what may be the most stressful experience of their lives". If support groups were implemented it would be preferable if they were facilitated by someone familiar with the ethical dilemmas encountered by the nurses (Jacobson 1978, p. 150). Story-telling is one way that nurses can share their experiences (Small, Engler & Rushton 1991, p. 104). Debriefing after traumatic events can be recommended because an inability to debrief is associated with diminished internal coping skills (Abendroth & Flannery 2006, p. 354).

11.4.7 Recognising their own limitations and level of responsibility

The neonatal nurses believed they were responsible for the outcomes of tiny babies. This responsibility does not seem to be socially construed within the NICU, but could be part of the nursing profession. Comments such as "nurses are born not made" and "nursing is a vocation" emphasise responsibility (Menzie's 1960, p. 107). Nursing evokes a strong sense of responsibility in nurses (Menzie's 1960, p. 104). Nurses are believed to have

conflicting inner voices about the nature of their obligations, with one voice urging the limitation of responsibility, while another voice urges the nurse to rise to the challenge and accept the responsibility (Jameton 1993, p. 545). The nurses in this study wanted to be acknowledged as professionals who were accountable and responsible for their nursing practice. Registered Nurses are accountable for their nursing decisions and actions, however, the nurses were not personally responsible for the long term outcomes of tiny babies. Menzies (1960, p. 104) suggests that for nurses “the burden of responsibility is difficult to bear consistently”. Believing they were responsible for neonatal outcomes seemed to burden the nurses. It is probably not important to find where the responsibility emanated, what is important is the professional survival of the nurses. In this situation it would be useful for neonatal nurses to acknowledge they gave their best and move on. Their survival as nurses depends on it.

11.4.8 Learning to manage uncertainty

Uncertainty prevails in the NICU and is a constant companion of these nurses. This uncertainty seemed to affect the nurses. It would be useful for neonatal nurses to develop strategies that help them manage the uncertainty surrounding the prognosis and outcomes of extremely premature babies. There is some event-familiarity for the nurses, which represented the degree to which the situation was repetitive or had recognisable cues (Mishel & Braden 1988, p. 99). When events are familiar, less uncertainty exists, however, event-familiarity develops over time. The nurses believed they could predict which babies would live or die in the short term, therefore the uncertainty is related to the outcome of the baby who survived. Hope is associated with uncertainty. It was difficult for the nurses to hold on to hope when their experiences have led them to a different conclusion. Developing a philosophy that includes giving the best possible care to extremely premature babies, but recognising that uncertainty exists might be helpful for neonatal nurses.

11.4.9 Professional counselling

The nurses recognised the inherent stresses in caring for extremely premature babies, yet they were convinced they did not need professional help. At times the nurses seemed to vacillate between vicarious traumatisation, compassion fatigue and burnout. The nurses emphasised wanting to be understanding and empathic to the baby and parents' situation, but they became drained by constant giving. It is clear to me that at times the nurses were depleted of empathy. They were functioning in the workplace but were not attuned to their emotional needs.

Neonatal nurses could be offered the opportunity to discuss the difficult situations they faced with professional counsellors. It is unrealistic to expect nurses to repeatedly provide care to babies and their families without eventually being affected by caregiving. While similar in effects, vicarious traumatisation, compassion fatigue and burnout all affect health workers who deal directly with people experiencing life threatening events. The effects can be extensive and have implications for the nurse's personal and professional life and the organisation.

The organisation has a responsibility to offer neonatal nurses the opportunity of professional counselling. Professional counselling could help nurses understand that vicarious or indirect trauma is the cumulative effect of working with families during traumatic events. Nurses cannot be protected from this indirect trauma and its negative effects (Maytum et al. 2004, p. 172), however counselling might help nurses recognise it, acknowledge it, and develop support networks to ameliorate its effects. If left unaddressed vicarious stress can lead to post traumatic stress disorder (Sherman 2004, p. 54). The difficult situations confronting the nurses has resulted in vicarious trauma and counselling might help neonatal nurses recognise trauma development. Repeated connection to, and caring for, extremely premature babies and their families has made the nurses vulnerable (White 2006, p. 343). This empathic vulnerability has disrupted the nurses mental and emotional wellbeing, and at times has insinuated itself into their

private lives (Clark & Gioro 1998, p. 86). When the nurses experience strong emotional reactions they disengage from the situation, and avoid the baby's parents. This avoidance is a consequence of vicarious traumatisation (White 2006, p. 342).

A professional counsellor could help neonatal nurses understand that compassion fatigue is a natural consequence of working with people who have experienced extremely stressful events (White 2006, p. 342). Compassion fatigue is precipitated by the emotional demands of working with those who are traumatised (Maytum et al. 2004, p. 174). It has been suggested that nursing as a profession sets nurses up for compassion fatigue (Johnson 1992, p. 116), as compassion is an expected component of nursing (Maytum et al. 2004, p. 178). For the neonatal nurses it was constant exposure to situations requiring empathy which has made them vulnerable to compassion fatigue, because empathy is the critical component in the helping relationship (Sabo 2006, p. 140). The empathic nurse perceives the world of another, is non-judgemental and understands other's feelings, and can communicate this understanding (Sabo 2006, p.137).

Professional counselling could help neonatal nurses recognise the signs of burnout. Burnout is where the nurse is caught in a state of mental fatigue and drained of all energy (Espeland 2006, p. 178). Nurses who are burnt out are likely to experience frustration, feel emotionally drained, and be less productive. The nurse who is experiencing burnout will lose interest in others, make derogatory statements, engage in inappropriate humour and experience conflict at work and home (Sherman 2004, p. 51). At times this described the neonatal nurses in this study. Nurses in a study by Maytum et al (2004, p. 175) stated the most common triggers for burnout were "seeing too many painful procedures done to children, too much sadness, and too much death". The same could apply to the neonatal nurses in the current study.

Burnout is born of good intention, and personal variables such as perfectionism influence the nurse's stress (Sherman 2004, p. 51). The nurses demonstrated perfectionist tendencies. Counselling could help neonatal nurses set realistic goals, and relinquish perfectionism. Resilience, hardiness and social support seem to afford protection against burnout (Sabo 2006, p. 140). Changing employment may be necessary to prevent burnout.

Organisations need to take a proactive stance and recognise the deleterious effects that working with people in crisis have on the staff. Employees experiencing vicarious stress, compassion fatigue and burnout will not be functioning at optimal levels. There will be increased sick time, staff turnover and low morale. This can impact on the organisation and the quality of service it provides. Organisations have the responsibility to provide counselling services, education and opportunities to discuss ethical dilemmas associated with caregiving. These opportunities could reflect positively on sick time, staff morale and staff turnover, thus saving the institution money.

11.4.10 Exploration of the issues surrounding disability

The fear of a baby surviving with disabilities often seemed overwhelming for the nurses. This is consistent with Campbell and McHaffie (1995, p. 340) who suggest that the legacy that parents fear most is brain damage, and the ramifications for their child. The nurses' fears arose from seeing surviving premature babies in institutions. It is likely that neonatal nurses would benefit from the opportunity to explore their feelings, attitudes and beliefs about babies and children with disabilities. It might also be beneficial for neonatal nurses to see disabled babies and children in the community, rather than in institutions.

Some might see the issue of disabled babies as part of the personhood debate, and whether or not the seriously damaged baby is a person and worthy of the rights and respect afforded to persons. This is a discussion that needs to be had, but is far too large for the scope of this thesis. There is no doubt that with proper care these children can live

into adulthood. The difficulty for the nurses is that these children are a stark reminder of the contrast between what they consider a life worth living, and the kind of life they believe lies ahead for this child (Elliott 2003, p. 20).

11.4.11 The availability of funds to discover more about the causes of extremely preterm labour

It was the belief of the nurses that greater attention needs to be paid to premature birth by governments. They suggested that more of the health budget needed to be diverted to antenatal care to detect, and hopefully prevent premature birth. It has been shown that women who have received regular antenatal care have a decreased risk of premature delivery (Berkowitz & Papiernik 1993, p. 414; Wheeler 1994, p. 66S). Despite improvements in antenatal care the proportion of preterm births has not changed. This suggests that too much effort has been concentrated on treating preterm babies and not enough on the causal pathways to preterm birth (Stanley 2001).

11.4.12 Education for expectant parents and the community

The nurses were convinced that expectant parents did not understand about prematurity and what would happen if they delivered a premature baby. The nurses believed pregnant women and their partners would benefit from the provision of information that addressed the risks of prematurity. A study by Freda, Damus and Merkatz (1991, p. 143) found that 50% of women did not know what constituted a normal length of pregnancy, and that babies born prematurely could have problems. The nurses emphasised there should be an honest appraisal of the situation without brutalising the expectant parents with information. It was the belief of the nurses that antenatal tours do not address prematurity in any depth, and therefore require realism. The nurses suggested that midwives might be the most appropriate personnel to conduct antenatal tours. Discussions during antenatal preparation classes should contain disclosure of adverse pregnancy outcomes, newborn intensive care, and the resulting ethical dilemmas (Harrison 1986, p. 173). Such discussions might ensure that expectant parents do not face the crisis situation of extreme prematurity totally unprepared. The nurses suggested that antenatal preparation might

offer educational opportunities. The antenatal clinic waiting room could be utilised to deliver prematurity prevention education and psychological support to expectant mothers (Tiedje 2004, p. 373). The best way to provide this type of education has not been ascertained, however Gupton and Heaman (1994, p. 118) suggest a learning assessment needs to be carried out on pregnant women at risk of preterm birth, and information should be presented in a way that can be readily used and understood.

The nurses were convinced that the public did not understand that prematurity could pose a serious health threat to mother and baby. It would be useful for the public to be educated about prematurity and premature birth. Prematurity is not considered a serious threat because of the belief that all babies can be saved (Tiedje 2004, p. 375). A study by Masset, Greenup, Ryan, Staples, Green and Maibach (2003, p. 121) found that adults in the USA did not consider prematurity to be a serious public health problem. They also largely blamed the mother's prenatal behaviour for the prematurity, even though the aetiology of 50% of the cases cannot be identified (Masset et al. 2003, p. 121). This is despite evidence that prematurity is by far the most important problem in relation to infant mortality and morbidity (Hernandez et al. 1986, p. 461). The nurses suggested that parents might feel better supported by their family and friends if they were knowledgeable about prematurity. Parents in a study by Kavanaugh (1997, p. 47), whose baby of marginal viability died, felt overwhelmed by inappropriate, unsolicited comments from family members and friends, who criticised the parents on their health care choices. It is these misperceptions that with education could be identified and rectified.

11.4.13 Community resources for families with disabled children

The nurses were passionate that the families of children who survive required ongoing support services. They were convinced that if extremely premature babies were going to be saved, the onus should be on the community to provide the resources that parents needed for their children. The nurses emphasised that while society acknowledged that a duty existed to save babies, it tended to overlook the ongoing needs of the baby and family once the intensive care phase was over. Families are left with providing for the

needs of these children (Nolan 1987, p. 5). The nurses did not want the parents to feel that the system had abandoned their child.

11.5 My reflections on hope and reality

Using phenomenology as a research method is a reflective experience. Reflexivity requires that I as the researcher am aware of my contribution to the construction of meanings throughout the research process. It involves reflecting upon how my own values and experiences have shaped the research, and how the research has affected and possibly changed me, as a person and as a researcher.

Van Manen (2002e) suggests that the phenomenologist is like an artist and an author who attempts to use words to evoke some aspect of human existence in a linguistic image. As the researcher is not separate from the research in phenomenological inquiry, I will recount an experience that I had caring for an extremely premature baby. This experience could be as Van Manen (2002f) suggests my momentary gaze through the crevices. The narrative is a memory and presents an experiential window on which my reflection is possible and meaning can be found. Experience, knowledge and wisdom are gleaned from memory. I look back and am able to re-live the experience.

Not long ago I was given the opportunity to care for a 24 week gestation baby who I will refer to as Daisy. Daisy was eight days old when she was referred to the surgical NICU where I work. On day six Daisy suffered a grade IV IVH which had extended into her ventricles. The continuation notes stated this had happened rapidly, so she was referred to the neurosurgeons for possible surgical management. Daisy was on full intensive care support. Following the MRI the full extent of the damage was realised; there was very little brain tissue to be seen. Daisy's parents had been given the news, and had opted for withdrawal of treatment the next morning. I was assured by the nurse present at this meeting that the information was given with sensitivity and compassion. Withdrawing treatment the next day would give friends and relatives time to arrive to support the parents. Daisy would also be christened at that time.

The unit I work in is purely a surgical NICU attached to the major Children's Hospital in Sydney. The admission of an extremely premature baby so young is a rare event. During the course of the evening I came to know the parents who were both in their late thirties. They had two other children, all children had been conceived using IVF technologies. The parents were philosophical and, although they were incredibly sad, they indicated they had started grieving her loss following the initial haemorrhage as they had been told to prepare for the worst. As family members started arriving around six pm I did not see much of them for the rest of the evening.

Daisy was tiny at 550 grams. She was nursed in an incubator. It was not difficult to provide care for her even though she was so small. What was difficult was providing care to a baby who was non-responsive. Daisy was unconscious so did not open her eyes or interact in any way. I did not even see her eyes, and she made no spontaneous limb movements like stretching. When I picked her up to change her position she seemed limp and lifeless. I made sure she was comfortable and her morphine infusion made her pain free. I hoped it made her pain free as many indicators used in neonatal pain scores are negated when the baby is unconscious. I dressed her in a tiny colourful dress. In the unit a group of volunteers make beautiful christening gowns for babies who will be christened in the NICU. The gown is given to the family as a memento. I managed to find a gown for Daisy, but as it was sized to fit a 1000 gram baby, I knew it would be a bit big.

Caring for Daisy was not an ethical challenge. The reality is that I believed withdrawing treatment was the right thing to do. I reflected that I would have experienced an ethical dilemma if treatment was not to be withdrawn. I imagined her lying in the incubator in an unresponsive state, and imagined a better future for her.

I didn't feel so sad for Daisy, but I felt sad for her parents to be denied a future with Daisy. I admired their bravery at making this hard decision. It was hard not giving parents hope, because I think that buoying parents with hope is what neonatal nurses do well. Giving hope helps keep parents going. The only hope I could offer them was a peaceful death. As I watched Daisy I thought of some of the nurse's stories about their

caregiving dilemmas, and I think I got off lightly. I am told by the nurse who was with the family when support was withdrawn that Daisy died in her mother's arms.

11.6 Conclusion

The improved survival of extremely premature babies comes at a price. For the nurses in this study the historical changes in the way extremely low birth weight babies are resuscitated and cared for was at the heart of their ethical dilemmas. What has been gained through lowered viability, has been lost when babies are resuscitated who, the nurses believed, should have been allowed to die in peace and with dignity. Working in an environment where viability has been lowered meant that the nurses were required come to terms with caring for sick and injured babies. The day-to-day working existence of the nurses was one of highs and lows.

Technology has given endless possibilities to save tinier and tinier babies; however, now it is time to live up to the responsibility of using the technology wisely. We have the ability to save the life of extremely premature babies, but questions surrounding whether we should do it are more pertinent than ever. It is no longer enough to push the envelope of viability, just because it is possible to do so, without thinking of the ramifications of the survival of the child on the family and society. In the wake of extremely premature birth it could be impossible for families to understand or comprehend the statistics, and that their child, may have in fact, become a statistic. Categorising tiny babies as 'little miracles' and the publication of miracle baby stories is the cause of concern for the nurses. The reality is that babies of extreme prematurity suffer from their premature births. Families need help and support to ensure the family unit is able to deal with the ongoing problems of prematurity.

Conflict was expected and experienced by the nurses in all aspects of caring for babies of extreme prematurity, however, conflict was not always seen as serious or detrimental to their professional wellbeing. Conflict, at times, energised the nurses and contributed to

their creativity, helping them seek answers to their problems and dilemmas. Conversely, conflict in the workplace could impact on nurse retention and needs to be addressed by the NICU and organisation.

A great deal is known about the outcomes of extreme prematurity, however, much of the outcomes are uncertain. Uncertainty was difficult for the nurses. The uncertainty in the NICU is summed up by Morris (1999, p. 23) who states that, "...in this unpredictable job, where the common saying is 'one day at a time'. I am always aware that I have neither all the answers nor the control, and a greater presence is holding the strings". This uncertainty can be a source of torment for the neonatal nurses.

Balancing hope and reality is the qualitative description of the nurses' experience of the ethical dilemmas in caring for babies of 24 weeks gestation and less, and is the ultimate finding of this research. When the life and death of an extremely premature baby hangs in the balance, the nurses hope for the best and expect the worst. They focussed equally on hope and reality, balancing between these two emotional states. The nurses dealt with the ups and downs of the family's emotions during this difficult time. Their main function was to help the parents maintain hope while preparing them for reality. The parents could experience hope as an emotion, experience or need. It is only natural that the parents would hope for a positive outcome for their baby, however, false hope or the hope based around an unlikely outcome, was not seen as helpful by the nurses. The nurses strove to ensure that parents understood the possible reality and to prevent reality blindness. The nurses in being professionally aware, compassionate and highly competent practitioners continued to seek the balance between hope and reality.

11.7 Postscript

Two events have occurred in the time of writing this thesis that have added to this ongoing field of human interest and have generated much discussion.

On the 6th October 2006 Amillia Sonja Taylor was born in Miami Florida (USA). She is considered to be the world's most premature baby born at 21 weeks and 6 days. She weighed 284.0 grams with a length of 23.0cm. On the February 21st 2007 Amillia was discharged from hospital (Sydney Morning Herald 2007a; Sydney Morning Herald 2007a). I have a strong interest and commitment to the welfare of extremely premature babies, and wait to see the long term outcome of this baby.

In November 2006 NSW neonatologists released a consensus statement that declared there is a "grey zone between 23 weeks' and 25 weeks and 6 days' gestation. While there is an increasing obligation to treat with increasing length of gestation, it is acceptable medical practice not to initiate intensive care during this period if parents so wish, after appropriate counselling" (Lui et al. 2006a).