

CHAPTER 5: THE RESULTS

5.0 Introduction

In this chapter the findings of the questionnaire are reported. The questionnaire was used to explore the neonatal nurses' dilemmas associated with caring for extremely premature babies. The results of the questions that were taken to the interviews, and the initial qualitative analysis are presented in this chapter. Balancing hope with reality as thesis title and the final description of the phenomenon of the ethical issues experienced by neonatal nurses caring for babies of 24 weeks gestation, will also be explored.

5.1 Selected results of the questionnaire

The questionnaire consisted of 62-point Likert-type questions, with 4 self-reporting questions, making it a large questionnaire. Rather than present the results of all questionnaire items, the questions (23) with a response of 48-50% or greater, plus one that made a distinction between extremely premature infants and full term infants are presented. The full results of the questionnaire are located in the appendix (Appendix B)

5.1.1

Q16:3 Caring for babies 24 weeks and less makes me feel challenged

Most of the nurses (70% N=232) almost always felt challenged when caring for babies of 24 weeks gestation and less. Challenged could have been construed as both positive and negative by the nurses, because a challenge is a demanding or stimulating situation that tests one's abilities. The intention of the question was about the demands of the situation, however the interview response to this item confirm the nurses were more likely to read the question as being stimulated by the situation.

Response	Frequency	Percent
Never	17	5.2
Seldom	21	6.4
Occasionally	60	18.1
Almost Always	232	70.0
Total	330	100

5.1.2

Q16:4 Caring for babies 24 weeks and less makes me feel concerned

Most of the nurses (87.3% N=290) almost always felt concerned when caring for babies of 24 weeks gestation and less. The nurses expressed their concern at what was required to save the baby's life. Given the poor outcomes for babies of this gestation, it is surprising that one nurse stated he/she was never concerned when caring for these babies. Many of the nurses wrote in the comments section of their future concern for the baby and family when the baby was discharged home.

Response	Frequency	Percent
Never	1	.3
Seldom	6	1.8
Occasionally	35	10.6
Almost Always	290	87.3
Total	332	100

5.1.3

Q16:7 Caring for babies 24 weeks and less makes me feel discouraged

Over half of the nurses (58.9% N=194) occasionally felt discouraged when caring for babies of 24 weeks gestation and less, while 24.2% (N=80) almost always felt discouraged. To be discouraged meant that the nurses lacked enthusiasm for treating the extremely premature baby and were thus deprived of hope for a positive outcome.

Response	Frequency	Percent
Never	12	3.6
Seldom	43	13.1
Occasionally	194	58.9
Almost Always	80	24.2
Total	329	100.0

5.1.4

Q16:8 Caring for babies 24 weeks and less makes me feel depressed

Over half of the nurses (53.7% N=177) were occasionally depressed when caring for babies of 24 weeks gestation and less, while 12.5% (N=41) almost always felt depressed. Several nurses commented that they were not depressed to the point of illness, but their mood was low, and they expressed sadness about what was happening to the baby. Several used the word 'gloomy' to describe their mood. Providing a definition of the 'felt depressed' could have minimised the confusion.

Response	Frequency	Percent
Never	44	13.4
Seldom	67	20.4
Occasionally	177	53.7
Almost Always	41	12.5
Total	329	100

5.1.5

Q17:3 If resuscitated these tiny infants should be ventilated with minimal support for the first 24 hours to determine if they will live or die

The neonatal nurses were not sure whether or not infants of 24 weeks gestation and less should have minimal support for the first 24 hours. Nearly half of the nurses (48% N=186) disagreed with this statement. Many commented that because these babies could be damaged through lack of treatment, an all or nothing approach should be adopted. They spoke of intensive treatment until it was proved that the baby was not responding to treatment or had suffered complications necessitating withdrawal of treatment.

Response	Frequency	Percent
Disagree	186	48.0
Agree	144	37.3
Neutral	57	14.7
Total	387	100.0

5.1.6

Q17:4 Full disclosure of the potential prognosis and the results of the outcome studies should be conveyed to the parents prior to the delivery of infants less than 24 weeks gestation and less

The majority of the nurses (96.5% N=380) agreed that parents needed to be given information prior to delivery of an infant of 24 weeks gestation and less. Many nurses mentioned the difficulty of giving information to a woman who was in labour, though they emphasised that giving information was important for informed consent. Several nurses mentioned that expectant parents might need to be spared some information, because they would be frightened if they were told the likely outcomes for their baby.

Response	Frequency	Percent
Disagree	6	1.5
Agree	380	96.5
Neutral	8	2.0
Total	394	100.0

5.1.7

Q17:5 Treatment should not be instituted in infants of 24 weeks and less if the parents request non-intervention

It was clear that the nurses were convinced the parents should be part of the decision making team. Most of the nurses (89.6% N=350) agreed that treatment should not be instituted in infants of 24 weeks gestation and less if the parents request non-intervention. In the comments section many nurses stressed that this decision should be an informed one. They believed that the outcomes for these babies were so poor that the parents' decisions should be respected. Conversely, they also emphasised that babies of greater gestations would need to be resuscitated.

Response	Frequency	Percent
Disagree	15	3.8
Agree	352	89.6
Neutral	26	6.6
Total	393	100.0

5.1.8

Q17:6 Treatment should be instituted in infants of 24 weeks and less regardless of parental wishes

The nurses generally believed that parents' decisions should not be overridden. Most nurses (87.5% N=343) believed that parental wishes were paramount, however, they also reported their past experiences and made suggestions as to why medical staff overrode parental decisions. In the comments section many emphasised that refusal of consent must be informed and parents should understand the ramifications of their decisions.

Response	Frequency	Percent
Disagree	343	87.5
Agree	13	3.3
Neutral	36	9.2
Total	392	100.0

5.1.9

Q17:7 Survival, even with handicap, is better than death

Most of the nurses (80.6% N=312) did not believe that survival, even with handicap was better than death. In the comments section many stated they did not believe in life at all costs. Several stated they did not see death as a failure, but were clear that if the baby survived the quality of life of the baby and family needed consideration.

Response	Frequency	Percent
Disagree	312	80.6
Agree	14	3.7
Neutral	61	15.7
Total	387	100.0

5.1.10

Q17:8 Tiny infants with a poor neurological prognosis would be better off dead

Over half of the nurses (60.7% N=231) believed that tiny infants with a poor neurological prognosis would be better off dead. In the comments section they spoke about the damage to the still developing brain during the course of treatment. For these nurses it was clear that the amount of damage was likely to be significant. The nurses made frequent mention that the other problems of severe prematurity coupled with the brain damage would make it impossible for the extremely premature baby to have a life that they considered worth living.

Response	Frequency	Percent
Disagree	57	15.0
Agree	231	60.7
Neutral	92	24.3
Total	380	100.0

5.1.11

Q17:9 All infants with a poor neurological prognosis would be better off dead

Although more nurses agreed (43.1% N=163) that all infants with a poor neurological prognosis would be better off dead, there was no consensus. This result suggests that the nurses perceived a difference between extremely premature infants and term infants with neurological damage. In the comments section the nurses explained that the brain of full term infants when damaged might have the ability to regenerate to a certain extent because the brain was fully mature.

Response	Frequency	Percent
Disagree	101	26.8
Agree	163	43.1
Neutral	114	30.1
Total	378	100.0

5.1.12

Q18:1 The costs of funding newborn intensive care should not be an issue

Over half of the nurses (54.3% N=220) agreed that the costs of NIC should not be an issue. Many stated that they understood how expensive NIC was, however they emphasised that it was offensive to think that money would be used as the criterion for whether or not the life of a tiny baby should be saved. Medical and clinical decision making based solely on economics was not seen by the nurses as beneficial to society.

Response	Frequency	Percent
Disagree	144	35.6
Agree	220	54.3
Neutral	41	10.1
Total	405	100.0

5.1.13

Q18:7 The value of human life should not be measured in dollars and cents

The majority of nurses (77.0% N=310) believed that human life was more important than money and that money should be available to save tiny babies. This question was a cost/benefit calculation, and asked whether the nurses considered the life of an extremely premature baby to be equal to the amount of money that had been spent on them, or would be spent of them. The nurses were to consider the money spent on the baby with the baby's future potential expected earnings. The nurses recognised the problems inherent in cost/benefit calculations as linked to justice and fairness, considering it immoral to equate human life with dollars and cents.

Response	Frequency	Percent
Disagree	41	10.1
Agree	310	77.0
Neutral	52	12.9
Total	403	100.0

5.1.14

Q18:12 Family disruption / dysfunction occurs frequently with babies of 24 weeks gestation and less

The majority of the nurses (90.6% N=368) believed that family dysfunction and disruption occurred with babies of 24 weeks gestation and less. Several nurses identified premature birth as a crisis for parents, with ongoing stressors that cause continued disruption for the family for the period of the baby's hospitalisation. The intense and prolonged nature of the stress for the parents was singled out by several nurses, who were not surprised that families experienced difficulties. Many nurses commented seeing marriages and relationships dissolve when the baby was still hospitalised or later when the baby went home.

Response	Frequency	Percent
Disagree	9	2.2
Agree	368	90.6
Neutral	29	7.2
Total	406	100.0

5.1.15

Q19:1 Laws are required which will allow the withdrawal of treatment in infants of 24 weeks gestation and less

The majority of nurses (63.0% N=249) believed that laws were needed to allow the withdrawal of treatment in infants of 24 weeks gestation and less. The nurses commented that problems have emerged in relation to technology, and how technology is being used to keep babies alive who they believe would benefit from withdrawal of treatment. They stated that there is a widening gap between the law and neonatal medical practice. This gap means that the best ethical decisions are often in conflict with the law.

Response	Frequency	Percent
Disagree	85	21.4
Agree	249	63.0
Neutral	62	15.6
Total	396	100.0

5.1.16

Q19:2 The law should require initiation of treatment in infants of 24 weeks and less regardless of the circumstances

The majority of nurses (80.3% N=318) did not agree that the law should be involved in whether or not infants of 24 weeks gestation and less were treated. This is interesting given the nurses wanted laws for withdrawal of treatment in the previous question. In the comments section many emphasised that these treatment decisions should be made on an individual basis and not directed by the law. The law was considered by the nurses to be too prescriptive, and they feared the indiscriminate resuscitation of tiny babies that would come with rules and directives.

Response	Frequency	Percent
Disagree	318	80.3
Agree	31	7.8
Neutral	47	11.9
Total	396	100.0

5.1.17

Q19:3 Hospitals should have policies governing the management of infants of 24 weeks gestation and less

The majority of nurses (83.0% N=332) were convinced that hospitals should have policies governing the management of extremely premature infants. Some nurses were concerned and commented that hospital policies are not laws and could be designed to protect the institution rather than the clinicians. Several other nurses commented that hospital policies were not laws, and implementing them could be problematic.

Response	Frequency	Percent
Disagree	38	9.5
Agree	332	83.0
Neutral	30	7.5
Total	400	100.00

5.1.18

Q19:4 Decisions regarding treatment of infants 24 weeks gestation and less should be left to the medical staff

The majority of nurses (74.0% N=293) did not believe that treatment decisions should be left to the medical staff. Many nurses commented that it was unacceptable for medical staff to usurp parental responsibility by making unilateral decisions, especially as it was the parents who lived with the consequences of those medical decisions.

Response	Frequency	Percent
Disagree	293	74.0
Agree	76	19.2
Neutral	27	6.8
Total	396	100.0

5.1.19

Q19:5 Decisions regarding treatment of infants 24 weeks gestation and less should be left to the parents

The majority of nurses (60.0% N=236) did not believe that decisions related to treatment should be left to the parents. In the comments section many proposed that decisions related to treatment should be made by doctors, parents and neonatal nurses. Several nurses commented that parents could be traumatised by deciding the outcome for their baby, yet others emphasised the important role of parents in decision making.

Response	Frequency	Percent
Disagree	236	60.0
Agree	118	30.0
Neutral	39	10.0
Total	393	100.0

5.1.20

Q19:9 Neonatal nurses should be involved in decisions related to the continuation or discontinuation of care for infants of 24 weeks gestation and less

Most nurses (91.0% N=365) agreed that neonatal nurses should be involved in decisions about continuation of care for extremely premature infants. Many nurses made comments about how neonatal nurses could help the parents through this difficult time. Other nurses emphasised that even when the nurses were not involved with decision making, parents frequently sought their opinions.

Response	Frequency	Percent
Disagree	25	6.2
Agree	365	91.0
Neutral	11	2.8
Total	401	100.0

5.1.21

Q19:10 The development of ethical guidelines would make these difficult treatment decisions much easier

The majority of nurses (77.6% N=311) accepted that the development of ethical guidelines would make difficult treatment decisions easier. Many commented that although ethical guidelines were important, they were guidelines not law, therefore not enforceable, and could be problematic for clinicians. Other commented that decisions related to babies of extreme prematurity were never easy, and should never be easy.

Response	Frequency	Percent
Disagree	41	10.2
Agree	311	77.6
Neutral	49	12.2
Total	401	100.0

5.1.22

Q19:11 An ethics committee should monitor decisions concerning treatment of infants of 24 weeks gestation and less

The majority of nurses (76.1% N=303) considered that an ethics committee should monitor decisions concerning treatment of extremely premature infants. Several nurses reported their experience with ethics committees, some were positive, while others were negative. Others made reference to the difficulty of those not involved in NIC being asked to deliberate on the life of an extremely premature baby. Difficulties were reported by several nurses of getting an ethics consultation in the middle of the night.

Response	Frequency	Percent
Disagree	47	11.8
Agree	303	76.1
Neutral	48	12.1
Total	398	100.0

5.1.23

Q19:12 When making decisions for infants of 24 weeks gestation and less, quality of life must be a critical factor to be considered

Nearly all the nurses (93.5% N=374) were convinced that quality of life (QOL) is a critical factor to be considered when making decisions about infants of 24 weeks gestation and less. There was much comment from the nurses about QOL, what constituted it and how it could be used to help decision making. Even nurses who agreed that QOL should be used, commented that caution should be exercised to ensure that it was not used to make determinations about the value of the baby.

Response	Frequency	Percent
Disagree	8	2.0
Agree	374	93.5
Neutral	18	4.5
Total	400	100.0

5.1.24

Q20:2 Future technology will only add to our dilemmas in relation to infants of 24 weeks gestation and less

The majority of nurses (77.3% N=313) anticipated that future technology would add to the dilemmas in relation to extremely premature infants. Many nurses made comments about what they envisioned the future for neonatology would be like, and included technology to gestate fetuses in fluid. Several nurses spoke of their retirement from the nursing profession when they were expected to care for fetuses underwater.

Response	Frequency	Percent
Disagree	46	11.3
Agree	313	77.3
Neutral	46	11.4
Total	405	100.0

5.1.25 Summary

The questionnaire was used to explore the neonatal nurses' dilemmas associated with caring for extremely premature infants. The results provided valuable feedback and insight into the nurses' issues of concern. The questionnaire results have been used to develop the qualitative procedures.

5.2 The findings of the qualitative component

In interviews, the everyday experiences of the neonatal nurses as they cared for extremely premature infants were explored. Analysis included thematic analysis and the construction of themes. The nurses' stories were examined, meaning was extracted and structures in the form of themes were constructed.

There are four themes, which make up the description of the phenomenon of the nurses' experiences of the ethical issues associated with caring for babies 24 weeks gestation and less. They are:

It's all about this baby
Having a voice
Dealing with awfulness
Reflecting on the outcome

The themes contain a description of the nature of the experience for the nurses, and what it is to be the nurse who experiences ethical dilemmas when caring for extremely premature babies. Each of the themes has several dimensions. The themes will be explored in detail in the following four chapters (6-9).

5.3 Balancing hope with reality

The final description of the phenomenon of the ethical issues experienced by neonatal nurses caring for babies of 24 weeks gestation is given as *Balancing hope with reality*, and is the title of the thesis. Balancing hope with reality illuminated the phenomenon, and was rigorously grounded in the text. Balancing hope with reality is not a theme, it is the final description that encapsulates the meaning of the neonatal nurses' experiences as they grappled with the difficulties and complexities associated with caring for extremely premature babies, whose survival could not be assured. Balancing hope with reality was found to be the final description and was present in each aspect of the nurse's experience of the phenomenon.

5.3.1 Discovering balancing hope with reality

Following the interviews the audiotapes were transcribed. The spoken word was transformed into text. In seeking to identify themes a reflective analysis of the text was undertaken. The analytical question "What is it to be the neonatal nurse who experiences ethical dilemmas when caring for babies of 24 weeks gestation and less?" was posed. Following this the question "What is the nature of the experience of the neonatal nurse with ethical dilemmas when caring for babies of 24 weeks gestation and less?" was posed. Concepts of hope and reality as central descriptions emerged. The understanding

that with each extremely premature baby the nurses carried hope for a good outcome, and yet recognised that this might not be reality brought clarity to the phenomenon. In balancing hope with reality the nurses managed the ethical dilemmas at the heart of their practice and offered an authentic description of the phenomenon under investigation.

It could be claimed that balancing hope and reality is not only for the nurses. The nurses were cautious with hope, and sometimes they simply 'hoped for the best'. Such hope for the best does not necessarily refer to survival of the baby. The nurses recognised there were widely divergent views of reality and that hope exists in the presence of reality. It is not a romantic, idealistic hope. Parental hope may not be so in touch with reality. The nurses did not want the parents to cling to a false hope, but understood they would hope against hope for the survival of their child. The nurses wanted parental hope to include a vision of a future that was grounded in reality. They, however, were not sure that this was possible.

In speaking about their experience of hope, the nurses said they were hopeful, but not optimistic, for the survival and outcome of extremely premature babies. I wondered if the concept of hope was to be found only in the interview transcripts. I went back to the questionnaires and could see that hope appeared in the comments section. Some examples of the nurses' hope include:

"To balance giving them [parents] hope and taking away all hope is hard". (Q/A 141)

"Who am I to deny hope?". (Q/A 163)

"I live with hope". (Q/A 328)

"I guess I try to live in hope". (328)

"The positive outcome of some infants gives me a glimmer of hope". (317)

5.4 Conclusion

The results of this study show that the neonatal nurses experienced ethical dilemmas with the care and management of babies of 24 weeks gestation and less. Such dilemmas were consuming as the nurses grappled with life and death issues, the potential for profound disability, and what the future will hold for the baby and family should the baby survive. Twenty four (24) nurses participated in fourteen interviews. Interviewing the nurses on the sensitive topic of extremely premature babies was a challenge. Their stories have shown them to be deeply concerned about the care and management of tiny babies and the ethical dilemmas surrounding the life and death of these babies.

The following chapter is the first of the four qualitative chapters that examines each theme separately. The first theme, *It's all about this baby*, explores issues related to the individual nature of extremely premature babies and the nurses experience of caring for them.