APPENDIX A:

THE QUESTIONNAIRE

An exploration of the ethical issues faced by neonatal nurses concerning the care of babies less than twenty-four (24) weeks gestation

Would you please indicate with a √ your answers to the following questions.

<u>Demographic data</u>:

1. Your gender
M [ ] (1)
F [ ] (2)

2. Your present age
21-25 [ ] (1)
26-30 [ ] (2)
31-35 [ ] (3)
36-40 [ ] (4)
41-45 [ ] (5)
46-60 [ ] (6)

3. Your religion Optional ______________________

4. Do your religious beliefs have an influence on your ethical decision-making?
None [ ] (1)
Minor [ ] (2)
Major [ ] (3)

5. Your present working role
Enrolled Nurse [ ] (1)
Registered Nurse [ ] (2)
Clinical Nurse Specialist [ ] (3)
Nurse Unit Manager [ ] (4)
Nurse Manager [ ] (5)
Clinical Nurse Consultant [ ] (6)
Clinical Educator [ ] (7)
Nurse Educator [ ] (8)
Nurse Academic [ ] (9)
Research Officer [ ] (10)
Other (please specify) [ ] ________________

6. Your educational qualifications (Hospital-based)

Enrolled Nurse Qualification [ ] (1)
Hospital Registration Certificate [ ] (2)
Midwifery Certificate [ ] (3)
Neonatal Intensive Care Certificate [ ] (4)
Other qualifications (please specify) [ ] ______________

7. Your educational qualifications (College/University)

Diploma [ ] (1)
Bachelor Degree [ ] (2)
Post Graduate Diploma [ ] (3)
Masters Degree [ ] (4)
PhD [ ] (5)
(Please specify field of study) ______________

8. Have you had any formal education in ethics?

Yes [ ] (1) please specify__________________________
No [ ] (2)

9. How many years have you been employed as a nurse ______________

10. How many years have you been employed in neonatal nursing ______________

11. Your current employment

Not employed in nursing [ ] (1)
Employed in the neonatal area [ ] (2)
Employed outside the neonatal area [ ] (3)
Employed in an educational institution [ ] (4)

12. Your current neonatal nursing employment

Employed in neonatal nursing - full time [ ] (1)
Employed in neonatal nursing - part time [ ] (2)
Employed in neonatal nursing – casual [ ] (3)
Not applicable [ ] (4)

13. Level of Nursery in which currently employed

Level I [ ] (1)
Level II [ ] (2)
Level III [ ] (3)
Level IV (surgical centre) [ ] (4)

14. How much experience have you had with caring for babies of 24 weeks gestation and less?

None [ ] (1)
0-1 years [ ] (2)
2-5 years [ ] (3)
5-10 years [ ] (4)
10-15 years [ ] (5)

15. Please summarise your experience (if any) with babies of 24 weeks gestation and less.

After reading this part of the questionnaire, please indicate with an √ your answers to the following questions.
Please feel free to make comments in any of the spaces provided.

If you <u>have</u> cared for babies less than 24 weeks gestation please commence with <u>Q.16</u>.
If you <u>have not</u> cared for babies less than 24 weeks gestation please commence with <u>Q.17</u>.

Q.16.	**Almost always (1)**	**Occasionally (2)**	**Seldom (3)**	**Never (4)**	**COMMENTS**
1. Caring for infants of 24 weeks gestation and less makes me feel hopeful					
2. Caring for infants of 24 weeks gestation and less makes me feel rewarded					
3. Caring for infants of 24 weeks gestation and less makes me feel challenged					
4. Caring for infants of 24 weeks gestation and less makes me feel concerned					
5. Caring for infants of 24 weeks gestation and less makes me feel satisfied					
6. Caring for infants of 24 weeks gestation and less makes me feel positive					
7. Caring for infants of 24 weeks gestation and less makes me feel discouraged					
8. Caring for infants of 24 weeks gestation and less makes me feel depressed					
9. Caring for infants of 24 weeks gestation and less makes me feel angry					
10. Caring for infants of 24 weeks gestation and less makes me feel ambivalent					
11. Caring for infants of 24 weeks gestation and less makes me feel dissatisfied					
12. Caring for infants of 24 weeks gestation and less makes me feel negative					

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Any overall comments on this section?

Q. 17	**Strongly agree (1)**	**Agree (2)**	**Neutral (3)**	**Disagree (4)**	**Strongly disagree (5)**	**COMMENTS**
1. The definition of viability is confusing.						
2. Allowing infants of 24 weeks gestation and less to die, rather than resuscitate them should be accepted neonatal medical practice.						
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.						
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 infant less than 24 weeks gestation and less.						
5. Treatment should not be instituted in infants of 24 weeks and less if the parents request non-intervention.						
6. Treatment should be instituted in infants of 24 weeks and less regardless of parental wishes.						
7. Survival, even with handicap, is better than death.						
8. Tiny infants with a poor neurological prognosis would be better off dead.						
9. All infants with a poor neurological prognosis would be better off dead.						
10. All infants of 24 weeks gestation and less should receive the same medical treatment, regardless of any differing circumstances.						
11. Life in and of itself is of supreme value.						
12. Treatment should not be instituted in infants of 24 weeks gestation and less if the probability of severe impairment is high.						
13. No one has the right to define what constitutes meaningful life for another human.						
14. There is no moral difference between not instituting life support and withdrawing life support.						
15. Continued existence with physical pain and psychological suffering would outweigh any positive experiences for infants of 24 weeks gestation and less.						
16. A full term infant dying concerns me more than an infant of 24 weeks gestation and less dying.						

Any overall comments on this section?

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Q. 18	**Strongly agree (1)**	**Agree (2)**	**Neutral (3)**	**Disagree (4)**	**Strongly disagree (5)**	**COMMENTS**
1. The costs of funding newborn intensive care units should not be an issue.						
2. Society cannot afford the costs of life-support measures for infants of 24 weeks gestation and less.						
3. A disproportionate amount of time, money and energy is expended on the care of infants of 24 weeks gestation and less.						
4. Economic factors should not be a consideration in decisions to care for infants of 24 weeks gestation or less.						
5. Society is obligated to provide adequate continuing care for infants of 24 weeks gestation and less who survive.						
6. The high cost of life-long care required by infants of 24 weeks gestation and less does not justify life support measures at birth.						
7. The value of human life should not be measured in dollars and cents.						
8. The contributions to society by healthy infant survivors of 24 weeks gestation or less outweigh the burdens imposed by survivors with major handicaps.						
9. Medicare should pay for all the costs of care for infants of 24 weeks gestation and less.						
10. For economic reasons society needs to determine a cut-off point in relation to gestation.						
11. Parents who choose to continue life support on infants of 24 weeks and less when the prognosis is extremely poor should pay some of the NICU costs.						
12. Family disruption / dysfunction occurs frequently with babies of 24 weeks gestation and less.						

Any overall comments on this section?

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Q. 19	**Strongly agree (1)**	**Agree (2)**	**Neutral (3)**	**Disagree (4)**	**Strongly disagree (5)**	**COMMENTS**
1. Laws are required which will allow the withdrawal of treatment in infants of 24 weeks gestation and less.						
2. The law should require initiation of treatment in infants of 24 weeks and less regardless of the circumstances.						
3. Hospitals should have policies governing the management of infants of 24 weeks gestation or less.						
4. Decisions regarding treatment of infants 24 weeks gestation and less should be left to the medical staff.						
5. Decisions regarding treatment of infants 24 weeks gestation and less should be left to the parents.						
6. The law should not be involved in issues related to infants of 24 weeks gestation and less.						
7. The government should provide guidelines for the care and management of infants of 24 weeks gestation and less.						
8. Society needs to set priorities as to who to keep alive.						
9. Neonatal nurses should be involved in decisions related to the continuation/discontinuation of care for infants of 24 weeks gestation and less.						
10. The development of ethical guidelines would make these difficult treatment decisions much easier						
11. An ethics committee should monitor decisions concerning treatment of infants of 24 weeks gestation or less.						
12. When making decisions for infants of 24 weeks gestation and less, quality of life must be a critical factor to be considered.						
13. Uncertainty about neurological prognosis and outcome makes me conservative in my opinions about what should happen to infants of 24 weeks gestation and less.						

Any overall comments on this section?

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Q.20	**Strongly agree (1)**	**Agree (2)**	**Neutral (3)**	**Disagree (4)**	**Strongly disagree (5)**	**COMMENTS**
1. We can rely on future technology to solve the morbidity factors experienced by infants of 24 weeks gestation and less.						
2. Future technology will only add to our dilemmas in relation to infants of 24 weeks gestation and less.						
3. We have the technology so we must use it to save infants of 24 weeks gestation and less.						
4. Sending long term survivors home on technology (ie ventilated) should be an option						
5. As more neonatal intensive care beds are filled by infants of 24 weeks gestation and less, there will not be adequate room for the more viable infants.						
6. Biologic limitations to extra-uterine survival exist that cannot be overcome.						
7. Increasing numbers of infants of 24 weeks gestation and less have increased the number of infants with serious handicaps.						
8. Neonatal intensive care units do more harm than good in treating infants of 24 weeks gestation and less.						
9. It is not the neonatal intensive care which causes harm to these tiny babies, it is the decisions which are made.						

Any overall comments on this section?

21. How would you define quality of life?

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22. How would you determine what was in the best interest of babies of 24 weeks gestation and less?

23. Are there specific ethical issues that concern you about the care of babies of 24 weeks gestation and less?

24. Do you have specific concerns about the long term outcomes for babies of 24 weeks gestation and less?

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25. Do you have any further comments?

Thank you for your time and thought in completing this questionnaire.

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APPENDIX B:
THE QUESTIONNAIRE RESULTS

The questions which were used from the original work of Armentrout (1986) with permission, and the questions which were taken into the interviews are shown though out the results.

THE RESULTS

Q.1: Gender

	Frequency	Percent
Male	11	2.7
Female	**400**	**96.6**
Total	411	100.0

Q.2: Age of nurse

	Frequency	Percent
21-25	7	1.7
26-30	28	6.8
31-35	**64**	**15.6**
36-40	**96**	**23.4**
41-45	**90**	**21.9**
46-60	**125**	**30.5**
Total	410	100.0

Q.3: Religious beliefs of nurse

	Frequency	Percent
No religious affiliation	**35**	**8.5**
Jewish	2	.5
Buddhist	3	.7
Salvation army	1	.2
Church of Scotland	1	.2
Hindu	1	.2
Greek orthodox	3	.7
Seventh day Adventist	2	.5
Eckankar	1	.2
Jehovah's Witness	1	.2
Roman Catholic	**90**	**21.7**
Brethren	1	.2
Church of England	**88**	**21.3**
Presbyterian	11	2.7

Lutheran	12	2.9
Baptist	7	1.7
Christian	**36**	**8.7**
Methodist	3	.7
Uniting	**31**	**7.5**
Total	329	79.5
Missing	**85**	**20.5**
	414	100.0

Q.4: Do religious beliefs have an impact on ethical decision making?

	Frequency	**Percent**
None	**228**	**56.7**
Minor	132	32.7
Major	43	10.6
Total	403	100.0

Q.5: Present working role

	Frequency	**Percent**
Enrolled Nurse	3	.7
Research Officer	4	1.0
Midwife	15	3.6
Clinical nursing co-ordinator	1	.24
Clinical Nurse Specialist & Research Nurse	1	.24
Lactation consultant	1	.24
Nurse clinician	2	.5
Child Health Nurse	1	.24
Registered Nurse	**168**	**41.0**
Clinical Nurse Specialist	**127**	**31.0**
Nurse Unit Manager	25	6.0
Nurse Manager	9	2.2
Clinical Nurse Consultant	18	4.3
Clinical Educator	17	4.1
Nurse Educator	15	3.6
Nurse Academic	2	.5
Total	409	100.0

Q.6: Educational qualifications (hospital-based)

	Frequency	Percent
Enrolled Nurse certificate (EN)	2	.5
Registered Nurse certificate (RN)	7	1.7
Midwifery certificate	5	1.2
Neonatal Intensive Care (NIC) certificate	22	5.3
EN, RN, Midwifery certificate, NIC certificate	6	1.4
RN, Midwifery certificate, NIC Certificate	**197**	**49.7**
RN, Midwifery certificate, NIC certificate, Child & Family Health certificate	17	4.1
RN, Midwifery certificate	49	11.8
RN, Midwifery certificate, Paediatric certificate	8	1.9
RN, NIC certificate	24	5.8
RN, Midwifery, NIC certificate, Adult Intensive Care certificate	5	1.2
RN, Midwifery certificate, Paediatric certificate, Child & Family Health certificate	7	1.7
RN, Midwifery certificate, Child & Family Heath certificate	7	1.7
RN, Midwifery certificate, NIC certificate, Child & Family Health certificate	8	1.9
Midwifery certificate, NIC certificate	20	4.8
RN, Paediatric certificate	3	.7
RN, Midwifery certificate, Paediatric Intensive Care certificate	2	.5
RN, Paediatric Intensive Care certificate	1	.2
Paediatric certificate, Child & Family Health certificate	1	.2
RN, Midwifery cert, NIC certificate, Paediatric Intensive Care certificate	2	.5
Paediatric certificate	1	.2
RN, Midwifery certificate, Developmental Disability certificate	1	.2

RN, NIC certificate, Paediatric certificate	1	.2
Total	396	100.0

Q.7: Educational qualifications (College / University)

	Frequency	Percent
Diploma	24	5.8
Bachelor degree	**120**	**29.0**
PG Diploma	43	10.4
Masters Degree	**38**	**9.2**
PhD	**1**	**.2**
Bachelor degree & PG Diploma	40	9.7
Diploma & PG Diploma	5	1.2
Total	271	65.5
None	**143**	**34.5**
	414	100.0

Q.8: Formal ethics education

	Frequency	Percent
Yes	148	36.6
No	**256**	**63.4**
Total	404	100.0

Q.9: No of years as a nurse

	Frequency	Percent
1-3 years	2	.5
4-8 years	27	6.7
9-12 years	24	6.0
13-20 years	**154**	**38.3**
Greater than 20 years	**195**	**48.5**
Total	402	100

Q10: No of years as neonatal nurse

	Frequency	Percent
1-3 years	37	9.3
4-8 years	**107**	**27.0**
9-12 years	**98**	**24.7**
13-16 years	65	16.4
17-20 years	59	15.0
Greater than 20 years	30	7.6
Total	396	100.0

Q.11: Current employment

	Frequency	Percent
Not employed in nursing	8	2.0
Employed in neonatal area	**358**	**87.8**
Employed outside the neonatal area	37	9.0
Employed in educational institution	4	1.0
Employed in neonatal area and an educational institution	1	.2
Total	408	100.0

Q.12: Current neonatal employment

	Frequency	Percent
Neonatal nursing full time	**197**	**49.0**
Neonatal nursing part time	**151**	**37.6**
Neonatal nursing casual	14	3.5
Not applicable	40	9.9
Total	402	100.0

Q.13: Level of nursery employed

	Frequency	Percent
Level I	11	2.9
Level II	**113**	**29.9**
Level III	**191**	**50.6**
Level IV	**63**	**16.6**
Total	378	100.0

Q.14: No of years of experience with caring for 24 weekers and less

	Frequency	Percent
None	53	13.2
0-1 years	65	16.2
2-5 years	**101**	**25.1**
5-10 years	**95**	**23.7**
10-15 years	**88**	**21.8**
Total	402	100.0

Q.15: A summary of the nurses' experience with babies of 24 weeks gestation and less

- **Selected comments from the nurses**

"Babies of this gestation who make it with good quality of life are the exception more than the norm… every baby is an individual and so must be given a chance". (1)
"I have rarely seen a baby under 24 weeks survive, and in our unit we would be unlikely to treat a baby under 24 weeks these days….in consultation with the parents of course". (11)

"As technology has advanced so has the survival rate of tiny babies…looking after babies and families has posed many questions and I personally don't think that gestation matters it is the baby who matters". (21)

"…problems as staff know the inevitable, but parents unable or don't want to make decision to withdraw." (33)

"It's worth it for science but is it worth it for parents, siblings and society?". (59)

"I find it challenging, wondering if we are really doing the right thing by treating them. Hopeful occasionally that they may do well, but still wondering whether we are playing God in the extreme". (63)

"Those babies that have been resuscitated have a torrid time…most die and those closer to 25 weeks that do survive are not intact. Most of the parents have no understanding of the future of these babies. I like neonatology not 'fetology'". (75)

"Traumatic, emotional and stressful". (162)

"Sometimes I was glad when they died, other times I was saddened at the distress they caused my colleagues, yet I found the work interesting". (163)

"Sad, depressing, uselessness…..I find they fight so hard and suffer so much, many fighting a losing battle….Parents don't realise the consequences as they see a pink, breathing baby and don't realise the abnormalities that could be present". (187)

"I have seen many families struggle with life and death decisions. I have seen many parents go through hell and back, some with good outcomes and some with bad. I have seen so many procedures performed on these tiny babies, and have to wonder how much suffering is being inflicted". (212)

"Challenging, rewarding, devastating at times,…memorable". (218)

"I am more disturbed with each year passing....I am also very worried about infants being subjected to multiple and repeated invasive and painful procedures during the course of their treatment". (288)

"Poor outcome for many with substantial disabilities if survival. Mostly they die. The fight for the life of these extremely prem babies is exhausting both mentally and physically. Often feel that these babies are used as guinea pigs. We are playing God and really not considering the best outcomes for these babies". (292)

"Nursing babies of 24 weeks gestation and less is a challenge to the neonatal nurse on all levels. Good communication skills when interacting with the family are essential and the neonatal nurse must provide them with emotional support whilst caring for an infant requiring skilled and careful management. These circumstances culminate in a high level of physical/ mental and emotional stress for the neonatal nurse". (320)

"Experimental, challenging, frustrating, mentally and physically very demanding…can be emotionally traumatic…a relief when they survive without handicap…a relief when they die if handicapped". (335)

"Usually sad and I always wonder about their future and the future ahead for their families". (374)

"It is both physically and mentally draining as you give ultimate care to a baby who in my belief has little chance of survival. At the same time helping parents with the conflict of their feelings as the realisation of "the perfect birth" is not and they try to digest what has been told to them, either with acceptance or rejection". (381)

"The longer time I spend working with neonates, the more "grey", rather than black and white decision making becomes". (401)

Section 16

Q16:1 Caring for babies 24 weeks and less makes me feel Hopeful

* Used with permission (Armentrout 1984)

	Frequency	**Percent**
Never	35	10.6
Seldom	**120**	**36.5**
Occasionally	**147**	**44.6**
Almost Always	27	8.3
Total	**329**	**100**

Q16:2 Caring for babies 24 weeks and less makes me feel Rewarded

* Used with permission (Armentrout 1984)

	Frequency	Percent
Never	27	8.1
Seldom	**97**	**29.5**
Occasionally	**159**	**48.2**
Almost Always	47	14.2
Total	330	100

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

* Question taken to interview

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

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

* Question taken to interview

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

Q16:5 Caring for babies 24 weeks and less makes me feel Satisfied

* Used with permission (Armentrout 1984)

	Frequency	Percent
Never	26	7.8
Seldom	113	34.2
Occasionally	**152**	**46.0**
Almost Always	39	11.8
Total	330	100

Q16:6 Caring for babies 24 weeks and less makes me feel Positive

	Frequency	**Percent**
Never	40	12.1
Seldom	**136**	**41.1**
Occasionally	**130**	**39.3**
Almost Always	25	7.5
Total	331	100.0

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

* Used with permission (Armentrout 1984)
* Question taken to interview

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

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

* Used with permission (Armentrout 1984)
* Question taken to interview

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

Q16:9 Caring for babies 24 weeks and less makes me feel Angry

* Used with permission (Armentrout 1984)

	Frequency	**Percent**
Never	84	25.4
Seldom	**87**	**26.4**
Occasionally	**131**	**39.7**
Almost Always	28	8.5
Total	330	100.0

Q16:10 Caring for babies 24 weeks and less makes me feel Ambivalent

	Frequency	**Percent**
Never	**93**	**29**
Seldom	**92**	**28.8**
Occasionally	**93**	**29**
Almost Always	42	13.1
Total	320	100.0

Q16:11 Caring for babies 24 weeks and less makes me feel Dissatisfied

	Frequency	**Percent**
Never	64	19.5
Seldom	**96**	**29.3**
Occasionally	**134**	**40.8**
Almost Always	34	10.4
Total	328	100.0

Q16:12 Caring for babies 24 weeks and less makes me feel Negative

	Frequency	**Percent**
Never	64	19.5
Seldom	86	26.1
Occasionally	**137**	**41.2**
Almost Always	42	12.8
Total	329	100

- **Content analysis of the nurse's comments on their feelings, attitudes and beliefs**

Outcomes and concern for the future / ongoing problems

Frequency	**Percent**
57	43.8

The expression of negative emotions

Frequency	**Percent**
46	35.4

Impact on the family

Frequency	**Percent**
39	30.0

Expression of positive emotions

Frequency	Percent
34	26.2

Philosophical questions

Frequency	Percent
29	22.3

What am I doing / why am I doing this?

Frequency	Percent
23	17.7

Difficult to generalise / feelings change with individual babies

Frequency	Percent
18	13.8

Doing the job / no time to think about

Frequency	Percent
11	8.5

Given a chance / right to life

Frequency	Percent
9	6.9

Condition at birth

Frequency	Percent
8	6.2

Realistic about chance of survival

Frequency	Percent
7	5.4

Concern for pain and suffering

Frequency	Percent
7	5.4

Extremely premature babies are the only hope for some couples

Frequency	Percent
4	3.1

When care is felt to be compromised by inexperience or poor allocation of staff

Frequency	Percent
3	2.3

- ***Selected comments from this section***

"Feelings depend on the condition of the infant when born". (2)

"Enjoy the challenge of nursing the babies, realistic about their chance of survival, rewarding when they make it, at least they were given a fair chance". (11)

"Rewarded with success stories and infants return for visit. Angry when parents wishes are not respected, depressed in empathy with the parents". (15)

"Angry if infant suffering". (18)

"Deserve same chance of life as other prem babies. Time will tell if treatment needs to be terminated". (20)

"Experience I found devastating at the end". (27)

"Angry when inexperienced medical and nursing staff handle the infant". (37)

"Always left angry. Depressed after nursing these babies only for them to die 6-10 days from infection. Dreadful way to die, awful for the parents to watch this. Concerned about the pain and suffering of the infant and family". (41)

"Depressed when care is prolonged when no longer required". (45)

"Dependant on the condition at birth and the number of problems in the first week. See the worst as transferred for surgical management". (50)

"If the infants does well I feel rewarded. I enjoy caring for them. I worry for the parents day to day". (58)

"I dread looking after infants less than 24 weeks gestation". (64)

"There should be less concern about death and let there be dignity with death; its part of the life cycle". (75)

"I do not think I feel depressed just sad for all concerned". (102)

"The greatest challenges from smaller sicker babies comes with the immediacy and urgency of the situation of care required. I often do not even consider morbidity, mortality possibilities other than getting the baby through that 8 hour shift. If I reflected too long about prognoses whilst at the cot side care could be potentially compromised and my role as objective clinician". (103)

"The most difficult issue…not the day to day management, but knowing the path that many of these babies will travel down……Dealing with parents in the early days of their baby's life, knowing this is the life in front of many is very difficult. To balance giving them hope and taking away all hope is hard". (141)

"This was my job, how I earned my pay. I was here because I didn't want to be anywhere else. So I did my job. My thoughts I either kept to myself or did not think about my work". (163)

"I think my attitude has changed with increased knowledge and experience". (184)

"Of course there will be the very occasional infant that will survive intact to make us feel a little better than devastated". (196)

"You always know these babies will have a stormy course. Can't help but feel sorry for the baby with all the handling, pain and problems it will inevitably encounter. It is hard to stay positive for the parents. Sometimes it just all seems too hard". (197)

"I am usually concerned that the long term implications are not generally appreciated or considered and less so by the family unit at the time. Have actually had a parent say to me about 26/40 who survived multisystem problems 'You never told me things would be this hard still at 18/12 old'". (215)

"This area is an ethical nightmare. After quite a few years of working in this area I think it is very disempowering when you find yourself caring for 24 weekers. The parents are given false hopes. The outcomes are seldom as they imagine". (241)

"Because the babies seem so vulnerable and the treatment so very invasive it could be quite distressing caring for them in the first few". (316)

"After many years of nursing 24 weekers I could not nurse them if I hadn't come to some personal resolve about them – ethically/morally. I believe as we are only human, we are learning all the time. It's not about right or wrong for me, it's about what's fair and just. I believe we're pushing the limits at 24/40 and less. The limits physically, emotionally and financially. Maybe its time to draw a line, cut off point at 25/40. It's a very difficult thing but we must be responsible for our actions and with knowledge create a more reasonable practice". (335)

"There are highs and lows for these precious tiny scraps of humanity and to say there are not many rewards would be lying, but there are also times when you ask yourself why?.

Why put them through all that they must go through to make it? And yet you do and they make it and it all seems worthwhile". (339)

"Of more concern to me than the actual gestation is the road that these babies take to either home or heaven. The ones who do relatively and consistently well are OK, but others who do poorly and have one set back after another make me think we need to (seriously consider) standardise when treatment should stop being too intensive". (358)

"Angry; not at the baby, but at the circumstances – life is not fair. I just wish it felt more positive". (368)

"I am seldom enthusiastic about being allocated to admit an infant of 24/40 or less. If they suffer an IVH this is when I think the whole exercise is futile. Being a mother I would not want a child with any degree of handicap. If you are called to the resus you are obliged to resuscitate even if futile". (379)

Section 17

Q17:1 The definition of viability is confusing

	Frequency	**Percent**
Disagree	77	20.2
Agree	**255**	**66.7**
Neutral	50	13.1
Total	382	100.0

Q17:2 Allowing infants of 24 weeks and less to die, rather than resuscitate them should be accepted neonatal medical practice

* Used with permission (Armentrout 1984)

	Frequency	**Percent**
Disagree	**182**	**47.0**
Agree	98	25.3
Neutral	107	27.7
Total	387	100

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

* Question taken to interview

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

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

* Question taken to interview

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

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

* Question taken to interview

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

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

* Question taken to interview

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

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

* Used with permission (Armentrout 1984)
* Question taken to interview

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

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

* Question taken to interview

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

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

* Question taken to interview

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

Q17:10 All infant of 24 weeks gestation and less should receive the same Medical treatment, regardless of any differing circumstances

* Used with permission (Armentrout 1984)

	Frequency	Percent
Disagree	**213**	**55.0**
Agree	119	30.8
Neutral	55	14.2
Total	387	100.0

Q17:11 Life in and of itself is of supreme value

* Used with permission (Armentrout 1984)

	Frequency	Percent
Disagree	**149**	**39.7**
Agree	136	36.3
Neutral	90	24.0
Total	375	100.0

Q17:12 Treatment should not be instituted in infants of 24 weeks gestation and less if the probability of severe impairment is high

* Used with permission (Armentrout 1984)

	Frequency	Percent
Disagree	55	14.2
Agree	**263**	**67.9**
Neutral	69	17.9
Total	387	100.0

Q17:13 No one has the right to define what constitutes meaningful life for another human

* Used with permission (Armentrout 1984)

	Frequency	Percent
Disagree	109	28.0
Agree	**209**	**53.7**
Neutral	71	18.3
Total	389	100.0

Q17:14 There is no moral difference between not instituting life support and withdrawing life support

	Frequency	Percent
Disagree	**203**	**52.5**
Agree	122	31.7
Neutral	61	15.8
Total	386	100.0

Q17:15 Continued existence with physical pain and psychological suffering would outweigh any positive experiences for infants of 24 weeks gestation and less

	Frequency	**Percent**
Disagree	67	17.6
Agree	**229**	**60.1**
Neutral	85	22.3
Total	381	100.0

Q17:16 A full term infant dying concerns me more than an infant of 24 weeks gestation and less dying

	Frequency	**Percent**
Disagree	153	39.4
Agree	**210**	**54.2**
Neutral	25	6.4
Total	388	100.0

- **Selected comments from this section**

"If you are going to treat then you must do so 100%".(16)

"It is easier to start treatment than terminate. In my earlier nursing days we placed 24 weekers into a steel receiver and placed in the clean up room after delivery and allowed to die. This always seemed so cruel and one could not bear to stay in that room long at all. Now these same babies are being resuscitated". (20)

"These babies have no choice with the life they end up with. It would obviously make decision making very simple if the crystal ball came with them". (28)

"One never sees the "right to life" people doing anything practical to help families of severely disabled babies". (60)

"If survival meant constant persistent pain then nature should takes its course". (66)

"Death is not a failure". (75)

"Many 24 and less infants have confounded prognosis and survived with little or no disabilities. I feel if an infant is born and makes an effort to breathe and heart rate it should be resuscitated". (99)

"To define meaningful life is a politically correct football… perhaps the person who has to maintain the continued care should make the decision". (109)

"This is a very emotive time for parents. No matter how grim you portray outcome most are not going to let their baby die without help". (141)

"I have seen a 23-24 weeker given full resuscitation and full treatment at parents insistence when baby was obviously in very poor condition, appeared to be suffering greatly, only to die on the ventilator at 4 hours of age. This situation distressed me greatly". (199)

"Public opinion and pressure seems to dictate practice. They should be much more aware of reality "V" miracle stories (240)

"I wouldn't want my 20-24 weeker worked on… place them in my arms so I can say hello and goodbye". (243)

"A mother who has had repeated miscarriages will accept a baby of low gestation with problems if it is her only chances of a live infant". (285)

"Confronting; a reminder of just how difficult an area this is to explore!" (320)

"I found this a difficult grey area as care of 24 weeker may have a reasonable outcome in certain circumstances whereas infants less than 24 weeks if they survive their quality of life is significantly more questionable". (322)

"Some families would be devastated to hear that their baby may 'need assistance to walk or have learning difficulties'. These are the people that have to live with the results for the rest of their lives even though it may be clinically an excellent outcome for a 23/40…what Dr's see as a good outcome for 23/40 is not always best for the family". (340)

"It is difficult to be dogmatic in approach to these infants. Most have seen the 'miracle baby' who does survive non-handicapped however, they are the exception. I believe each infant deserves a chance, but dependant on their birth, apgars, and response to treatment". (362)

Section 18

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

* Used with permission (Armentrout 1984)
* Question taken to interview

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

Q18:2 Society cannot afford the costs of life-support measures for infants of 24 weeks gestation and less

* Used with permission (Armentrout 1984)

	Frequency	Percent
Disagree	**150**	**37.0**
Agree	123	30.2
Neutral	133	32.8
Total	406	100.0

Q18:3 A disproportionate amount of time, money and energy is expended on the care of infants of 24 weeks gestation and less

* Used with permission (Armentrout 1984)

	Frequency	Percent
Disagree	110	27.1
Agree	**178**	**43.8**
Neutral	118	29.1
Total	406	100.0

Q18:4 Economic factors should not be a consideration in decisions to care for infants of 24 weeks gestation and less

* Used with permission (Armentrout 1984)

	Frequency	Percent
Disagree	118	29.1
Agree	**220**	**54.2**
Neutral	68	16.7
Total	406	100.0

Q18:5 Society is obligated to provide adequate continuing care for infants of 24 weeks gestation and less who survive

* Used with permission (Armentrout 1984)

	Frequency	Percent
Disagree	61	15.1
Agree	**279**	**68.9**
Neutral	65	16.0
Total	405	100.0

Q18:6 The high cost of life-long care required by infants of 24 weeks gestation and less does not justify life support measures at birth

* Used with permission (Armentrout 1984)

	Frequency	Percent
Disagree	**188**	**47.5**
Agree	106	26.8
Neutral	102	25.7
Total	396	100.0

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

* Question taken to interview

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

Q18:8 The contribution to society by healthy infant survivors of 24 weeks gestation and less outweigh the burdens imposed by survivors with major handicaps

* Used with permission (Armentrout 1984)

	Frequency	Percent
Disagree	131	32.8
Agree	104	26.1
Neutral	**164**	**41.1**
Total	399	100.0

Q18:9 Medicare should pay for all the costs of care for infants of 24 weeks gestation and less

	Frequency	Percent
Disagree	121	30.0
Agree	**175**	**43.3**
Neutral	108	26.7
Total	404	100.0

Q18:10 For economic reasons society needs to determine a cut-off point in relation to gestation

	Frequency	Percent
Disagree	**167**	**41.3**
Agree	158	39.2
Neutral	79	19.5
Total	404	100.0

Q18:11 Parents who choose to continue with life support on infants of 24 weeks and less when the prognosis is extremely poor should pay some of the NICU costs

	Frequency	Percent
Disagree	**167**	**41.3**
Agree	161	39.9
Neutral	76	18.8
Total	404	100.0

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

* Question taken to interview

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

- **Selected comments from this section**

"I agree that a phenomenal amount of money goes into the care of prem babies but it should not be a determining factor in whether or not to treat. Economic factors should not determine who should live and who should die in any area of medicine". (11)

"As a parent of disabled children the economic costs to parents are hardly ever considered. People are only concerned with economic costs to health care and units". (14)

"What is the price of life?". (20)

"Unfortunately our health budget is finite so huge economic imports of very low weight infant care must be weighed up against spending for the greater good". (28)

"It is not a bottomless pit of funding…only the cute stories make it. Tell all the tragic tales, families torn apart, stress, guilt, hopelessness…it is torture for parents". (52)

"Sadly these babies are often born to low socioeconomic families, with little or no financial means to parents who are all often poorly educated and even intellectually challenged. These families have no insight into the costs in financial and human terms of keeping these babies alive, and even insight into the potential handicaps and suffering those babies may experience". (63)

Ideally economists should be able to balance the budget in order to provide care for the human commodity. Unfortunately, the ideal situation does not exist… the caring professions cannot bow to monetary restrictions placed upon us by economists who have, undoubtedly yet to get sick". (91)

"Unfortunately cost and economics is a real issue in the real world". (130)

"Society pays for a lot worse things (ie abortions, prostitution, space travel) than trying to save peoples precious children". (146)

"Health funding is finite. The ethical issues need wider debate by medics, nurses, academics, religious and government ministers and researchers".(158)

"A whole lot of factors are there. I personally think under 24 weekers have a poor prognosis, and cost society a lot, but I am not about to declare "withdraw". A few years ago handicapped children were forgotten, but they turned into a growth industry requiring special training for carers, which meant more jobs etc. And some of these people it turned out had intelligence. Who am I to deny hope?" (163)

"I agree that in society the high cost of care of these infants should be considered. But who can make this decision? – not me". (200)

"Even though economics drives the health care system, it would be a shame to determine survival by this criterion". (218)

"Babies and cost are always emotive. If we accept that babies of less than 24 weeks are not resuscitated and babied of 24 weeks are given 24-48 hours to prove themselves then the decisions made would be lessened. Thus costs, time and energy would be decreased". (292)

"Society can afford millions for fireworks!" (362)

"Nurseries are 'full' of tiny babies that most probably will not be 'normal' but once 'we' the clever practitioners save them and send them home 'we' have to take some responsibility for the burden it then creates on the families. Unfortunately all less than 24 weekers are not born to highly intelligent, rich, married people who have family support, jobs and common sense". (368)

"Statistics have not improved for 23 – 24 week gestation infants. We should be concentrating more on the ones who will survive and be normal". (376)

Section 19

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

* Question taken to interview

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

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

* Question taken to interview

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

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

* Question taken to interview

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

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

* Question taken to interview

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

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

* Question taken to interview

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

Q19:6 The law should not be involved in issues related to infants of 24 weeks gestation and less

* Used with permission (Armentrout 1984)

	Frequency	Percent
Disagree	**181**	**45.8**
Agree	130	32.8
Neutral	85	21.4
Total	396	100.0

Q19:7 The government should provide guidelines for the care and management of infants of 24 weeks gestation and less

* Used with permission (Armentrout 1984)

	Frequency	**Percent**
Disagree	162	41.2
Agree	**171**	**43.6**
Neutral	60	15.2
Total	393	100.0

Q19:8 Society needs to set priorities as to who to keep alive

	Frequency	**Percent**
Disagree	**202**	**51.2**
Agree	102	25.9
Neutral	90	22.9
Total	394	100.0

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

* Question taken to interview

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

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

* Question taken to interview

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

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

* Used with permission (Armentrout 1984)
* Question taken to interview

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

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

* Question taken to interview

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

Q19:13 Uncertainty about neurological prognosis and outcome makes me conservative in my opinions about what should happen to infants of 24 weeks gestation and less

	Frequency	Percent
Disagree	64	16.0
Agree	**298**	**74.7**
Neutral	37	9.3
Total	399	100.0

- *Selected comments from this section*

*"*I have seen vigorous 24 week neonates as well as not so vigorous 24 weekers who manage to defy the odds and grow up into strong healthy children and adults. Even those with some disability are thus a joy to their family, are capable of finding value in their existence. This is not an issue that can be addressed by any government agency or ethics committee. I have yet to see medical and nursing staff in conjunction with parents allow undue suffering continue in a hopeless situation". (37)

“Society is unaware of the problems occurring with very prem infants. We need to educate people on the long term outcomes and the consequences… what most people read about very prem infants is what they read in the woman’s weekly”. (40)

“An integrated multidisciplinary approach should be the key in making treatment decisions for these infants in consultation with the family and a spiritual and religious representative and a psychologist”. (48)

“Sometimes laws make a situation worse. Would be difficult to make a law”. (50)

“Society has no idea… most don’t even know what a prem baby looks like, let alone what it costs emotionally and financially”. (52)

“Decisions of this sort need a collaborative approach between medical staff and parents (fully informed of consequences and prognosis) with a combination of laws and ethics providing the framework to ensure objectivity in the decision making process”. (82)

“Laws are not flexible and are not designed to meet the needs of the individual”. (91)

“I am hazy about the aspects of laws and government and societal involvement in decision making from the outset…if we told parents we do not have the capabilities of treating less than 24 weekers they would probably accept it, like when people were told they couldn’t save less than 28 weekers”. (92)

“I don’t believe parents should have to carry the burden of the decision”. (142)

“Life is sacred but not at the expense of a meaningful life for not only the infant but the family. I don’t propose a system of eugenics “you are defective, therefore we will dispense with you”, but given a voice would that profoundly neurologically, physically impaired 24 weeker say thank-you for saving my life at age 20 years??. Having worked with severely disabled adults I don’t think so”. (155)

“This is not a black and white area. Shades of grey do exist and therefore guidelines (not) laws are required for the intervention and management of 24 weekers and less”. (160)

“I would think it very hard to set in law who should live and die. Each case should be taken individually looking at each variable / re decisions; decision should involve all care givers”. (171)

“Laws and policies may aid decision-making. However I’m not sure if they help in the delivery of care. There are always exceptions to the rules. Although I do believe a team of people (including parents) should be involved in decision making concerning each individual baby”. (189)

“So much is unknown. Babies with really bad head scans sometimes do OK. Nobody knows for sure exactly how they will end up. I have a real problem with people who sit on ethics committees who probably have no idea at all regarding NICU care. I really think NICU nurses should be very active in neonatal ethical dilemmas”. (197)

“Power should not be with one person, particularly if it’s not the parents. I think if parents want to discontinue or not initiate treatment then that is their right if they have been informed of potential outcomes”. (208)

“Usually hospital ethics committees are made up of all sorts of people…not only neonatal. I don’t think these groups are necessarily the correct people to be making decisions about the uniquely different 24 weeks population”. (237)

“Parents often have a very unrealistic viewpoint. They want to take a baby home and often voice that they don’t care what the infant is like. They fail often to realise that their child will often remain just that a child”. (241)

“Legal issues (even though they sometimes do) should never be held as gun to the medical consultants head…If laws are tightened to reduce/stop withdrawal of life support, perhaps some neonatologists and NICU nurses may find the confines too strict, and leave the neonatal field”. (245)

“If the hospitals have policies then this becomes a black and white issue, which does not exist in nursing and medicine”. (292)

“Medical staff and parents should have the ultimate responsibility for decisions about
these tiny babies which will affect their survival. Some legal parameters are required to guide decision making, however there must be room for each case to be
considered individually”. (320)

“Nothing is ever black or white, always a grey zone”. (379)

Section 20

Q20:1 We can rely on future technology to solve the morbidity factors experienced by infants of 24 weeks gestation and less

* Used with permission (Armentrout 1984)

	Frequency	**Percent**
Disagree	**233**	**57.7**
Agree	66	16.3
Neutral	105	26.0
Total	404	100.0

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

* Question taken to interview

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

Q20:3 We have the technology so we must use it to save infants of 24 weeks gestation and less

	Frequency	Percent
Disagree	**260**	**64.2**
Agree	55	13.6
Neutral	90	22.2
Total	405	100.0

Q20:4 Sending long term survivors home on technology (ie ventilated) should be an option

	Frequency	Percent
Disagree	**232**	**57.6**
Agree	80	19.8
Neutral	91	22.6
Total	403	100.0

Q20:5 As more neonatal intensive care beds are filled by infants of 24 weeks gestation and less, there will not be adequate room for the more viable infants

* Used with permission (Armentrout 1984)

	Frequency	Percent
Disagree	136	33.7
Agree	**182**	**45.2**
Neutral	85	21.1
Total	403	100.0

Q20:6 Biologic limitations to extra-uterine survival exist that cannot be overcome

* Used with permission (Armentrout 1984)

	Frequency	*Percent*
Disagree	47	11.9
Agree	**264**	**67.0**
Neutral	83	21.1
Total	394	100.0

Q20:7 Increasing numbers of infants of 24 weeks gestation and less have increased the number of infants with serious handicaps

* Used with permission (Armentrout 1984)

	Frequency	**Percent**
Disagree	50	12.5
Agree	**245**	**61.2**
Neutral	105	26.3
Total	400	100.0

Q20:8 Neonatal intensive care units do more harm than good in treating infants of 24 weeks gestation and less

* Used with permission (Armentrout 1984)

	Frequency	**Percent**
Disagree	**196**	**48.6**
Agree	77	19.1
Neutral	130	32.3
Total	403	100.0

Q20:9 It is not the neonatal intensive care which causes harm to these tiny babies, it is the decisions which are made

	Frequency	**Percent**
Disagree	68	17.0
Agree	**211**	**52.8**
Neutral	121	30.2
Total	400	100.0

- *Selected comments from this section*

"We must be approaching the limits of human endurance. Technology and research based on overcoming the seemingly biological limits of extreme prematurity should be subjected to more rigorous ethical and economic review". (15)

"The more viable should be given preference, but does that mean that you turn off one ventilator to save another". (24)

"I believe in the human capacity to develop even more advanced technology that will place no limitations on fetal survival. An artificial placenta comes to mind here". (37)

"Technology can never solve immaturity of body systems". (50)

"It worries me that viable gestation may decrease as technology improves, however I feel we have too much needed doing to improve the care of 24 week and more gestation infants. Nature set limits which have been overcome, but we should not go too far. Sometimes we do more harm than good with the technology available". (64)

"Technology cannot take the human element out of the situation. We can hope that it will make lives more bearable though". (91)

"Technology is far from perfect". (155)

"There is no substitute for a womb". (171)

"Depending on which neonatologist is on I feel the parents are given an unrealistic or optimistic view of prognosis and outcomes". (212)

"Life in the womb needs to be preserved. Technology is enabling many of theses infants to survive at this gestation, but at what cost?". (220)

"I think parents should be made aware of the pain they inflict on their child if they choose to prolong that child's life". (241)

"I feel sometimes technology is advancing at a rate far greater than we can cope with. This technology does not seem to extend into the long term care of the surviving babies, who I feel would benefit in more research and money directed to them". (317)

"Technology can't make an immature baby mature". (320)

"The damage is caused by people who don't know when to stop". (340)

"Technology is a major factor in the survival of all infants, but this must not cloud our management". (381)

"Society can't even look after the people who require increased care at present. Sending babies home ventilated would put a huge stress on outlying carers and the family. The government is cutting back on supports not increasing money to them". (410)

Section 21

21: The nurses definition of quality of life.

- **Content analysis of the nurse's statements**

Ability to use one's brain

Frequency	Percent
139	39.7

To be independent

Frequency	Percent
130	37.1

Life which is fulfilling to the individual

Frequency	Percent
121	34.6

Able to interact with others

Frequency	Percent
96	27.4

To be happy

Frequency	Percent
71	20.3

To live life without pain

Frequency	Percent
54	15.4

Able to contribute to society

Frequency	Percent
53	15.1

When the nurses believed it was difficult to define

Frequency	Percent
30	8.6

To love and be loved

Frequency	Percent
28	8.0

To be healthy

Frequency	Percent
28	8.0

Not to be a burden on their family or society

Frequency	Percent
27	7.7

As the parents define it for their child

Frequency	Percent
24	6.9

To be valued

Frequency	Percent
20	5.7

Absence of or minimal handicap

Frequency	Percent
13	3.7

Life is sacred above all

Frequency	Percent
7	2.0

Quality of the life lived was important not the quantity or time lived

Frequency	Percent
4	1.1

- *Selected comments from this section*

"Someone who has a functioning brain. Able to think and respond to others". (1)

"Life that can support a high degree of independence and sustain physical, psychosocial and psychological growth". (3)

"Fulfilling. Self motivated. Self directed". (4)

"Live a dignified and fulfilled life without major impairment". (5)

"Content with yourself. Not be frustrated with what you cannot do, but be contented with what you can do. Show love and be loved. Be needed and useful". (6)

"Mobility, ability to communicate, gain enjoyment from life, reasonable intellectual capacity, use of senses". (11)

"Experience the full potential life can afford for the length of time on earth". (17)

"Enjoy life without major technological requirements, make independent decisions, happy, healthy". (19)

"Contribute positively to society, pain free, aware of oneself and others". (20)

"Capable functioning member of the community. Independence". (25)

"Have all bodily functions, feel emotions, respond to things, feel wanted, have purpose in life". (27)

"Communicate with others, participate in community and social life. Not left in bed or bean bag". (33)

"Perceive stimuli and respond to it. Dignity. Pain free". (49)

"Intellectual, emotional and motor faculties to pursue an independency and fulfilling life". (57)

"Happy, healthy, productive, enjoy relationships with others". (62)

"Independent, face challenges without pain and suffering". (63)

"Participate in day to day life, minimal limitations, live independently, relationships with other people". (89)

"Meet basic daily functions, intellectual development, enjoy pleasures of life without impediment or reliance on others". (93)

"Interact with other people, free of pain and suffering, aware of surroundings, happy, free to live life as you wish". (141)

"What I consider quality may be different to a couple who have tried for 10 years to conceive and are now sitting beside their 24 weeker". (265)

"Ability to be able to contribute, and reap the benefits of interaction with other living things, learn and develop, aspire to greater things and deeds. To be able to feel achievement and fulfillment when reaching your goals / able to carry on an intelligent conversation with someone and know difference between right and wrong. Know you have made an impression in this life to better things". (301)

"The ability of an individual to experience pleasure in being alive. Ability to respond to others, have meaningful relationships, develop ones potential. To be able to be involved in decision making with maturity". (323)

"Hard question.! Recognition and interaction of some kind to people. However, I would not feel, at this time, whether I could care for a baby who was severely brain damaged. But I must say that I have no children, so if that time came, I still don't know what I would do". (359)

"A life that has an intact brain, or one that has only a very mild deficit. A life that does not require around the clock nursing. A life that is useful and happy. Too many small infants leave hospital with severe handicaps. A life long job for parents. One must look at quality of life, not quantity". (370)

"Quality of life is a very personal thing. Enables a human being to participate in relationships, to enjoy life without undue suffering or pain, to experience all of life's cycles ie happiness, sadness, pleasure, success, failure and to learn from them all". (371)

"Quality of life comes in degrees. I believe that quality of life encompasses not only what we (as health professionals) perceive as 'quality' but what that person (ex 24 weeker now 10 years for example) perceives of him/herself". (382)

Section 22

22: How would the nurse determine what was in the best interest of babies of 24 weeks gestation and less?

- **Content analysis of the nurse's statements**

The outcome / prognosis of the baby

Frequency	Percent
92	27.5

Parents need to make an informed decision

Frequency	Percent
91	27.2

The baby's response to treatment

Frequency	Percent
90	26.9

It is the parents choice

Frequency	Percent
85	25.4

The family situation

Frequency	Percent
78	23.4

Condition of baby at birth

Frequency	Percent
61	18.3

Neurological outcome

Frequency	Percent
53	15.9

A multidisciplinary approach

Frequency	Percent
51	15.3

Philosophical reflections ie let nature takes its course

Frequency	Percent
47	14.1

The use of evidence, research and statistics to help decide

Frequency	Percent
38	11.4

Not starting life support / withdrawing life support

Frequency	Percent
36	10.8

An individual approach to decision making

Frequency	Percent
33	9.9

Pain and suffering of the infant

Frequency	Percent
31	9.3

Antenatal factors / maternal health

Frequency	Percent
28	8.4

Right to life of the baby

Frequency	Percent
17	5.1

Size, weight, gestation of baby

Frequency	Percent
16	4.8

Honest discussion with the parents regarding the outcome

Frequency	Percent
13	3.9

Where the baby was born and did it need transport

Frequency	Percent
10	3.0

Labour and delivery

Frequency	Percent
8	2.4

- *Selected comments from this section*

"Parents, siblings, family understand the potential prognosis including quality of life. Discussed at appropriate level of understanding. Multidisciplinary team approach". (6)

"Evidence based, accurate interpretation of data, multidisciplinary approach. Guidelines from NICU policies. Response of baby". (21)

"Family involved in all decisions. Often nature takes its course anyway. Do all that is possible from the outset then judge every individual case". (36)

"Often the best interest of severe prem is overclouded by the best interest of either the parents or the doctors. Often nature is aborting the fetus in its best interest". (40)

"If the baby is extremely fetal it may be best for us to wrap baby up and let parents cuddle baby and have an opportunity to say goodbye". (41)

"If the baby didn't initiate respiration at birth I think it should be given to the parents and allowed to die peacefully. Survival of the fittest". (46)

"All babies under 26/40 should be questionably resuscitated, these babies do not have the ability to survive with good outcomes". (55)

"I personally don't believe that anybody with severe mental retardation have a good quality of life. The best interests of babies must be decided by those who will be the primary carers". (61)

"Prior to delivery the outcomes should be discussed fully with the parents. Babies rely on others to make the best decision for them. All concerned must have access to all information pertaining to the infant". (63)

"We don't have any good population based studies on outcomes of series or geographical, hospital etc based studies. The limitations of these are obvious when you try to use them to help inform parents". (74)

"Assessment of family situation and dynamics to determine stability, problem solving abilities communication and support. These babies do not have their best interests served by a dysfunctional family". (82)

"Do not resuscitate them. They are beautiful human beings and they are someone's child, however their road to recovery if ever is cruel and long and very uncertain with very little success". (109)

"I feel that most of them should be allowed to die without being traumatised in neonatal units. If we are determined to save 24 weekers and less who gives us rights to destroy 20 weekers in the same hospital". (131)

"Should not be put through all the torture unless there is an absolute guarantee that they would be without chronic illness or disabilities". (139)

"Sympathetic responses would come into play. Would I want these treatments and interventions on my infant. Are we doing what is right for this infant? Are our actions improving the outcomes for these babies?" (160)

"24 weekers are different to less than 24 weekers. We need to be mindful of what purpose and whose benefit from pushing the boundaries of extra uterine life. I think sometimes parents in their hope get caught up in wanting everything done and some neonatologist get caught up in their achievement without considering the long term implications". (180)

"It's not just the babies. They often do OK for the first 1-2 weeks in the honeymoon period. It's a trauma to the parents and family". (216)

"Do not actively resuscitate babies born in poor condition and with weights less than 550 grams. Provide parents with honest, realistic information on prognosis". (229)

"If you have to support a baby less than 24 weeks with lots of drugs and ventilation to maintain its life, and the baby is not responding or is suffering to stay alive then I believe there should be a decision with the parents about withdrawal of support. I do not believe a baby's life should be saved at all costs. This is not a dollars and cents approach it is about quality of life". (314)

"If prolongation of life is of no benefit to them, decisions and moral judgement should be considered and strongly recommended eg palliative treatment / care / comfort". (327)

"9 years experience in NICU seeing the arduous journey taken and the appalling result at the end of it". (336)

"This is difficult to answer. In answering logically it would be to care, love and support baby to the best possible standard. To offer the best neonatal care available and to minimise pain and suffering. When this standard is not enough, to be able to allow the baby to rest peacefully and withdraw treatment and give the baby respect and dignity to the end. Unfortunately this is sometimes not our decision and emotions are often involved". (388)

Section 23

23: Specific ethical issues of concern to the nurse about the care of babies of 24 weeks gestation and less.

- **Content analysis of the nurse's statements**

Concern for the parents

Frequency	Percent
73	24.7

Outcomes / prognosis of the baby

Frequency	Percent
70	23.6

Continued treatment despite major impairment / brain damage

Frequency	Percent
57	19.3

Parents must be informed of all possibilities

Frequency	Percent
46	15.5

Withdrawal of life support

Frequency	Percent
45	15.2

Concern that baby will feel pain and suffer

Frequency	Percent
41	13.9

Medical egos / fear of litigation / how information is given

	Frequency	Percent
Fear of litigation	9	3.0
How information is given will influence parents decision	10	3.4
Medical ego	6	2.0
Making decisions on their own	15	5.1
Conflicting wishes between doctors & parents	1	.3
Total	41	13.9

Philosophical statements

Frequency	Percent
32	10.8

Concern about research and experimentation on these tiny babies

Frequency	Percent
30	10.1

Society costs and resources

Frequency	Percent
28	9.5

Nurses suffer emotionally because of the decisions that are made

Frequency	Percent
26	8.8

Treating all infants regardless

Frequency	Percent
26	8.8

Who should decide; the doctors, parents, ethics committee etc

Frequency	Percent
20	6.8

Parental expectations may not be realistic

Frequency	Percent
19	6.4

Require cutoff for viability and treatment

Frequency	Percent
19	6.4

Babies must be treated individuals / no hard and fast rules

Frequency	Percent
18	6.1

Society also has a vested interest

Frequency	Percent
15	5.1

The personal morals of the medical staff are used to make decisions

Frequency	Percent
11	3.7

The nurses disagree with the decisions which are made

Frequency	Percent
9	3.0

Right to life of the baby

Frequency	Percent
9	3.0

Concern that the babies will be handicapped

Frequency	Percent
8	2.7

Begin treatment if that is what the parents want

Frequency	Percent
8	2.7

Whose right: the baby or the parents

Frequency	Percent
7	2.4

What is legal / illegal

Frequency	Percent
5	1.7

- *Selected comments from this section*

"If there are decisions being made that the nursing staff do not agree with, then the option of not caring for that particular patient should be available". (2)

"Egos and the medical challenge of these babies get in the way of best outcomes for individual babies". (3)

"Parents who have never had any experience with disabilities find it hard to imagine that a perfect looking baby may end up severely disabled. They may base their decisions of care for their baby on unrealistic ideals of the possible prognosis". (6)

“Uncomfortable about decisions not to resus 24 weekers and less as they are an unknown quantity until you see them”. (11)

“Who are we to decide who lives and who dies? Who are we to give the parents a lifetime burden of a handicapped child? Who are we to deprive this child of a chance of a life”. (13)

“Neonatologists making decisions on their own without large discussions with parents and nurses. Neonatologists who treat for fear of legal action despite parental wishes and prognosis”. (16)

“At present less than 24 weeks is pushing the extremes of viability”. (25)

“When do you say ‘enough is enough’ in respect of baby and parents wishes”. (27)

“Life and death decisions ie another person being in the hands of an individual with all the baggage that the individual carries”. (28)

“Having to continue to care for infants that obviously have a poor prognosis, but the parents are reluctant to withdraw treatment”. (33)

“Many occasions parents wish to hold and cuddle baby before death. Once infant has been prodded and poked and nearly dead they allow them to cuddled the baby before death. Many times the baby does not even look like the beautiful baby they delivered” (41)

When parents refuse to ‘give up’ for whatever reason or when a decision is being made by parents which is prolonged and taking too long. The suffering imposed on the infant affects me as a nurse caring for the infant when I feel that the infant should die with dignity”. (47)

“When ceasing treatment on a 24 weeker I sometimes wonder if the right decision has been made. What if the infant could have turned out alright in the end?” (58)

“We can keep babies alive longer with technology, but until babies fail to reach milestones we have no idea how profoundly a handicap will there if there is one at all”. (61)

“When parents believe so strongly in life at all costs that they are unwilling to withdraw ventilatory support on a long term 24/40 when it is obvious that the infant will eventually suffer a prolonged and possibly painful death”. (63)

“Who has the right to say yes or no as the infant can’t talk for itself. The infant has to live through life in a NICU 24 hours per day not the parents”. (77)

“Is it right that we as health professionals “play God” to these infants who in the majority of cases without intervention would die”. (82)

“Parents who want ‘everything possible’ done for their child do not seem to be given appropriate information as to the future of an handicapped child. Their interests seem to be for themselves not the welfare of the child”. (94)

“The baby is not thought about – we have the technology so we feel we must always use it”. (105)

“If we did not intervene with our high technology they would just die. We are intervening in the natural selection of life”. (122)

“When things appear absolutely hopeless and most nursing staff agree what we are doing to keep the baby alive is not in its best interest, but medical staff keep pushing on and give false hope to parents”. (132)

“Sometimes feel the baby has more rights than the parents who will spend the rest of their lives looking after the child”. (145)

“Use of their bodies for experimental purposes eg practicing intubation…should be allowed to die with dignity”. (157)

“Once resuscitation is initiated should you continue with care no matter what the outcome will be?” (202)

“We seem to get these babies to survive at all costs without looking at what happens once theses babies get out of the nursery doors”. (208)

“Unethical for doctors to practice on these babies with no concern for their ultimate outcome. Unethical to continue intensive care treatment when a 24 weeker gestation infants has a grade IV IVH. Unethical to continue intensive care when ABGs are consistently poor. Unethical to keep babies alive just to skite that your NICU has had a 22/40 and 23/40 gestation infant survive”. (217)

“We consider the right to life but need to consider the right to die”. (227)

“Parents are often very short sighted and act selfishly. Medical staff are often just as blind and allow their own religious beliefs to cloud their thinking”. (241)

“Do the parents really have a say? A paediatrician said if you present to labour ward and have a baby 20-24 weeks then you are giving consent for treatment . I told him I’d stay at home if under 24 weeks” (243)

“Have looked after 22 week triplets whose parents did not want intervention and the neonatologist decided to intervene. No 1 died within minutes of birth, No 2 died at 1 week of age in a particularly horrible way (perforated bowel from NEC), No 3 died at 24 hours of age. The decision was taken from the parents by someone who thought they knew better”. (280)

"The medical opinion and terminology used to inform parents. I realise some doctors are obviously better at communication than others, but telling parents the baby has a 'bruise in its brain' when in fact the baby has a grade II to III IVH leaves a lot to be desired. To me a bruise gets better with no side effects". (340)

"When in modern medicine did it become such a terrible thing to allow a human being to die with dignity. Doctors can not save everyone; they may save the baby but if the mind is gone what is the point. Without cognitive intelligence can we love, or dream or think, then what is left is only a shell. Decisions need to be made for the best interest of the baby". (345)

"Sometimes it is obvious that we are 'practising' our care on these tiny ones to further our expertise, rather than genuinely save quality of life for survivors. Often we 'throw everything' at the baby (all our available technologies and treatment) not really knowing what will work and then 'hope for the best'. Is this survival at any cost"? (391)

Section 24

24: Specific concerns of the nurse about the long term outcomes for babies of 24 weeks gestation and less.

- **Content analysis of the nurse's statements**

Concern for the family unit

Frequency	Percent
140	45.0

Long term community support

	Frequency	Percent
Drain on society	19	6.1
Strain on support agencies	3	1.0
Cost to taxpayer	43	13.8
Community expectations	2	.6
Who will look after child when parents die	4	1.3
Educational	8	2.6
Lack of community support	24	7.7
Total	103	33.1

Long term disabilities

	Frequency	Percent
Neurological	40	12.9
Physical	3	1.0
Developmental	3	1.0
2 or more disabilities	39	12.5
Total	85	27.3

Ongoing problems as a result of extreme prematurity

Frequency	Percent
56	18.0

Difficult to know which will have a good or bad outcome

Frequency	Percent
49	15.8

Major deficits and handicaps

Frequency	Percent
43	13.8

Concern for quality of life

Frequency	Percent
39	12.5

Who will care for the child?

	Frequency	Percent
Who should care for the child	10	3.2
Who will care once the child becomes an adult	16	5.1
Socio-economic issues	4	1.3
Total	30	9.6

The decision

	Frequency	Percent
Has to be made quickly	2	.6
The time it takes to know about problems	2	.6
Need for medical staff to tell the truth / realistic	26	8.4

Total	30	9.6

Concern for breakdown of relationship

Frequency	Percent
23	7.4

Child should be given a chance

Frequency	Percent
16	5.1

Philosophical questions ie are we doing the right thing

Frequency	Percent
15	4.8

The rise of technology

	Frequency	Percent
Technology is available to save babies	6	1.9
But 20-30 years ago	5	1.6
Total	11	3.5

Concern about the long term effects of treatment

Frequency	Percent
8	2.6

Withdrawal of life support

Frequency	Percent
7	2.3

Term babies have poor outcomes as well

Frequency	Percent
6	1.9

The risk of child abuse

Frequency	Percent
4	1.3

- *Selected comments from this section*

"Long term care of baby once it grows into a dependent retarded adult!" (4)

"How do you know how they feel, if they cannot express how they feel?, and yet how can you deny a life if you don't give it just one more chance". (6)

"I have seen many surviving 24 weekers. Some are quite handicapped, particularly the early survivors, but many are very well and lead normal lives. In any case they are very much loved by their families and enjoy good quality of life". (11)

"Who should look after and pay for the handicapped results of the experiments before we get it right? Yes eventually we will be able to treat 20 weeks and less but should we, what is the point? Unless of course it's my child". (13)

"There is much that cannot be predicted at birth with regard to their long term outcome. Parents are pressured to make a rapid decision, and I feel may benefit by counseling by other people with similar personal experiences". (16)

"So much effort is put into the care of these infants by many people with so few having a perfect outcome". (26)

"Many of these infants are being sentenced to a less than optimal life experience that is an ongoing drain on available resources". (28)

"I often wonder what we are creating. Will these babies in 20-30 years time have a great increase to susceptibility to such things as cancers, gastro problems, immunological problems, reproduction problems, as well as having neurological problems or not. It creates a great strain on family and family life". (32)

"Many times families have broken up under the strain of having a 24 weeker or less. The baby that goes home takes up time, effort and money. The community do not support these parents. Often a single parent takes the brunt of caring for the baby". (41)

"The worst ones have a very stormy neonatal period ie loss of bowel through NEC, renal failure, hydrocephalus, congenital abnormalities, lung cysts with BPD. From my experience at present a vast majority of survivors seem to be left with major deficits after months in hospital". (50)

"I always worry about the long term outcome of these tiny babies. Therefore it has become a habit with me to try and find out if they are doing well once they have gone home. I often worry how the poor parents would cope with a severely handicapped child". (58)

"Who will care for them when their parents can no longer do so if they (the child) is severely handicapped. Also includes birth asphyxia, near drownings, head trauma from

multiple injuries. Can society afford it? Who will decide?? I'm glad I'll be gone myself before society will be called upon to act on these questions!" (61)

"The potential poor neurological and associated handicaps which can occur with this gestation. The effects on people's lives, their marriages, other siblings because more focus will be on the handicapped child". (63)

"That the parents are really given correct information before they embark on the 'life at all costs path'. They must be aware of the probable outcome". (70)

"Major concerns are with the families of these infants. If we as a society are going to fund the resuscitation and management of these infants, should we not examine further the level of funding available for the family in the meeting of expenses for the long term care of the various handicaps they are predisposed to. The long term community support and early intervention programmes for these infants would also need careful consideration as proof of society's support for these families who generally would be experiencing major difficulties economically and psychologically and family disruption". (82)

"The drain on society to care for these people when the parents realise they cannot manage". (113)

"There must be a stage at which the immaturity (physiologically) of body systems must not permit survival. We do not know long term follow up results to 15 years to determine whether theses children's quality of life will be satisfactory". (116)

"What sort of genetic pool will come from saving theses babies?" (137)

"I think serious thoughts are needed on whether we are saving these babies because we can no matter what their long term prospects are". (151)

"I would not want a handicapped child of my own, but am always aware that I've never been in this situation, and so empathise fully with parents". (158)

"The burden on the parents is real and often unrealised by them. Marriages breakup, siblings are deprived. And yet there are some true survivors at times, that maybe should be encouraged to live". (163)

"I would have to be walking around with my head in the sand not to be, however I don't have the arrogance to presume my quality of life (no handicaps) is an absolute requirement for a successful or happy life. I may be involved in a car accident tomorrow – I hope they don't put me down without a chance". (179)

"I've seen parents after the babies have survived have to come to terms with having a less than perfect baby and now all the fuss has died down the stark reality is often not wanted by parents. I think predicting some babies outcomes is like playing Russian roulette and you hope that the chamber is empty (gun). But I think that this can happen

regardless of gestation from 24-40 weeks. Everybody wants an Einstein but not all will ever get an Einstein". (180)

"They usually have lots of readmissions to hospital with chest infections, and problems thriving. I know a few who have ended up with oral aversions and needed gastrostomy feeding due to oral suction and in and out feeding tubes. This is a huge ongoing cost to an already stressed health system. We can't even look after our elderly". (198)

"They are not babies forever and I believe that's when the parents realise the significance of the situation. They are no longer cute but very time consuming and draining on the family dynamics". (236)

"One I looked after who the parents asked for it to be resusced – he was placed on a high frequency ventilator at 23 weeks. The parents were extremely apprehensive, at 100 days this infant was still ventilated had ROP grade 3-4, was not on full feeds. The parents in this case had been lead down the garden path, and were looking at taking a very handicapped infant home. We need to think, before we act!" (241)

"They might be seen as a burden to society, but as care providers we are here to serve and help those who are in need". (260)

"I often feel that consultants are only interested in getting the children out of the hospital alive to substantiate their numbers rather than worry about the life long sentence the family is lumped with". (285)

"Studies show there are severe mental, developmental and physiological problems among VLBW infants that may result in parental mental problems and abuse of these children". (291)

"The majority have some form of neurological impairment which becomes a major burden on society. Society should not have to count the costs for medical experimentation". (296)

"There is a gross lack of support for these babies and parents once discharged. This is especially so in surgical areas. I feel the burden we place on these families is very great and I am amazed at what some families endure, however I am also saddened at the large numbers of family breakdowns". (317)

"You can't keep salvaging them yet have no community resources available for them". (318)

"The general community should know outcomes and possibilities, so they can have realistic expectations. Because the baby in New Idea or Woman's Day did well, doesn't mean their baby will". (331)

"Medical personnel do not always give a clear picture to parents of the future outcome of the 24 weekers. Parents are often not able to make critical decisions or ask same in their traumatic stage of first weeks of life". (355)

"I am concerned that we have no firm way of predicting outcomes so the number of infants with disabilities is rising as we have more survivors". (391)

"How will they cope in a highly literate technological economically rational society where social supports are gradually being withdrawn – or where if you can't 'contribute in a meaningful way' you won't get welfare support. Care facilities are of poor quality and sparse quantity". (406)

Section 25

25: Further comments

- *Selected comments from this section*

"Generally I believe 'let nature take its course". Yet as a neonatal nurse, providing the simplest of care may save the life of any baby in the neonatal age group. Where do you draw the line in saving lives? I don't think there ever is a line…just one big grey area. Between all members of the medical team, the law and the family there is too many scenarios and the baby cannot speak for itself". (6)

"Parents should be told of all potential problems and they should then make an informed decision on whether to start, continue treatment. Treatment should be able to be discontinued at parent's request. Some parents may want a child at all costs and others may not want a handicapped child and both decisions should be respected by medical and nursing staff". (10)

"When I am involved with any prem baby, my thoughts are 'OK – you are here now, we'll give you the best chance we can' and if the baby does not make it, at least we tried. We ensure that the baby is as comfortable as possible and pain free and involve the parents in care as early as possible while being frank and realistic about their conditions. Who knows? That next 24/40 baby that survives might one day be the first female Australian Prime Minister or President, or find a cure for cancer? We just don't know". (11)

"I do not believe that every infant of 24 weeks gestation should be resuscitated. It is totally individual, dependent on the antenatal history, weight, parents wishes. We should not build up hopes of parents and family, but we must be able to explain to them in terms they understand what is happening. Starting and stopping life support for these infants are difficult decisions for all staff to make". (26)

"I appreciate that it is very easy to have opinions on this subject when one is not (and hopefully would never be) parents / grandparents. I feel that the initial and ongoing costs

of care (as well as quality of life) of these children need to be weighed up against the needs of the rest of the community including the elderly". (28)

"I used to love working in the neonatal intensive and special care area. Then medical personnel began experimenting more and more without really considering that a 'life' was in the bed. Medical and nursing staff become less experienced and caring. Research overlooks ethical or sound reasoning. There has to be fully qualified staff working in this area, not new graduates or adults wanting just a job". (38)

"I strongly believe we change peoples lives for the worst with our technology". (41)

"Very grey area. Ethical concerns tainted with religious beliefs. Often not focused on long term outcome but medical staff playing god and becoming heroes". (43)

"Sometimes when I was looking after infants less than 24 weeks I feel so frustrated – why are we keeping them alive? I've recently looked after twins 24 weeks gestation – one with CP, kidney failure and loss of both feet (they became gangrenous and literally fell off)". (46)

"It would be interesting to follow the families of the survivors and note how many families have survived intact. A lot of the parents separate because one or other cannot cope with the amount of care and time the infant requires long term".(50)

"NICU is fraught with more ethical dilemmas than any other area. A lot of clinicians switch off from this". (57)

"Whilst I can understand the anguish of a family with a very immature infant, I feel they often do not understand what the future holds for them or their infant. On a practical level perhaps the health dollars should be used in other ways – perhaps to prevent the births of 24 weekers – antenatal care and research". (62)
"Some 23-24 week infants do quite well with minimal neurological deficits, but these are the minority. Glossy magazines paint a rosy picture about all these so called 'miracle' babies, but they don't tell of the pain, suffering and heartache experienced by both baby and parents, nor of the potential handicaps in years to come. Some parents will only hear what they want to hear and will not listen to or believe 'bad' news which makes it even more difficult to be the baby's advocate when things are going poorly. It then becomes a huge shock to them if the baby then dies. Perhaps this may be avoided is some treatment guidelines could be established before the baby is born and discussed fully with the parents before the baby is resuscitated". (63)

"The number of infants of 24 weeks gestation or less surviving the immediate neonatal period I believe is small in relation to the total population passing through the NICU. For this reason I believe every baby should be given the chance of survival providing this does not mean prolonging the inevitable, or prolonging a life of constant and persistent pain for the sake of the research".(66)

“A very valuable study. Made me realise I need to do some reading – my ethical knowledge is a bit dim. The questionnaire made me really think. It concerns me greatly what these babies go through despite all the efforts put in to minimise the trauma and the dynamics on the families. I hate to admit it, but often my first though is ‘Oh no, not another 23 weeker – why don’t we just let it go!!! (It wasn’t meant to live!). The birth of a baby is such a highly emotional event – a difficult time to be making life and death decisions especially where there is only the ‘image’ of the future and not the ‘actual reality”’. (77)

“Where there is breath there is life. How do we define the struggle of an infant of 24 weeks gestation? How do we declare that a particular infant does not have the right of life? We will not be there to support that child through the rest of his/her life – in this sense our compassion is only fleeting (not much use to the person)”. (91)

“Women need education about premature infants during early pregnancy – a) to recognise the signs and symptoms of prem labour – b) understand the implications. Every neonatal nurse I know would go bush rather than go to a tertiary center if they were in prem labour with a pregnancy of 24 weeks gestation or less”. (106)

“I have answered these questions as a neonatal nurse. I think my answers would be different as a parent”. (115)

“I personally dislike nursing 24 weekers. It’s not that I don’t wish them well, it’s purely the multisystem failure, skin excoriation, poor IV access and difficulty in maintaining blood pressure. I would rather the dollars be spent fixing the hip and knee joints and eye sight of our ageing population than inflicting such energy on a totally unknown quantity”. (133)

“This is a huge Q! and hard to be black or white; the grey area is huge. I firmly believe that there should be a viability cut-off for legal accountability. I have looked after 23 and 24 weekers who have survived with no or minimal disability who have visited the nursery again and again. This does renew your faith that at times you are doing the right thing. But I have also looked after many babies that treatment has been withdrawn and in all those cases I did not feel we were doing the wrong thing. I have also looked after babies that we all felt should have been withdrawn earlier but did die in the end. But the scary part is on a couple of occasions where we all thought the situation was grim and the baby should be turned off, This child survived with minimal or no problems. This is what makes it so hard”. (148)

“I feel very privileged to have worked at the intimate level of care for the neonate and their families regardless of outcomes – to be there to assist in the coping mechanisms of the parents, give compassion and care and as honest answers as possible. Parents ask nurses who they feel they can trust while gaining more understanding and knowledge. They are able to empower parents and give them guidance for more questions to be answered. Nurses are often the conduits between parents and medical staff”. (154)

"I feel a lot of decisions are made about treatment issues without consulting nurses. After all, are we not the people most intimately involved with the infant and parents. Often we are excluded from the neonatologist meeting with parents, because the neonatologist does not see any input from the nurses, but in reality when we are allowed to attend these meetings a relatively inexperienced nurse is looking after the baby so that when nursing input is required, they are unable to give their input due to lack of nursing experience. This affects the ability to make treatment decisions which are beneficial for all concerned". (155)

"This questionnaire was upsetting and hard to do, because I privately am concerned at the cost of these units, however I do not condone actively allowing to die – and yet nature usually knows best. The point is will these babes be self sufficient in later life? What are we saving these babies for – our glory? By making me answer these questions I have to put down in time and cement what I feel today, but tomorrow I may change my mind, and you won't know". (163)

"It is good that you are asking a nursing opinion. Ultimately, however our opinion will not matter whilst the patriarchal system continues to exist. This is why we will continue to treat every one no matter what". (171)

"My view is that parents should be given the opportunity to decide on the child's treatment, as it is not only the child's life to be considered, but also their lives, which will be changed dramatically forever. If they already have other children, then the ramifications are even more compounded". (190)

"I am glad I had term babies. I would hate to have a 23-24 weeker and 'in theory' would actively discourage any member of my family from insisting on full resuscitation and treatment if they were unfortunate enough to go into preterm labour or require delivery of a 23-24 weeker. As I said though that is the theory, I hope I would have the strength in practice". (199)

"We have to be careful of using technology for 'technology's sake' and losing sight of the long term picture. Babies and children with long term problems are often the cause of the breakdown in a relationship. Often other siblings are affected and they must be considered too". (244)

"As I work in a surgical center I only see the results of poor outcomes of these infants. I have spoken to the registrars who deliver these infants in the early hours without any backup who will say 'what can you do if they come out yelling?' (262)

"Ask the doctors – if this was your child, how would you realistically want it treated knowing all you do? Would you be willing to take the end product home with you?" (285)

"I do not think there are "black and white" answers. Each situation should be dealt separately taking into consideration several factors such as the possible outcome, present

severity of condition, parental opinions etc. Guidelines for treating theses infants should be developed, however they should be only guidelines that allow the freedom of flexibility in decision making". (291)

"If I had a baby 24 weeks or less I would hope the doctor would listen to me about my wishes of not having the baby treated. This has always been my wish, and I do not intend to change it". (296)

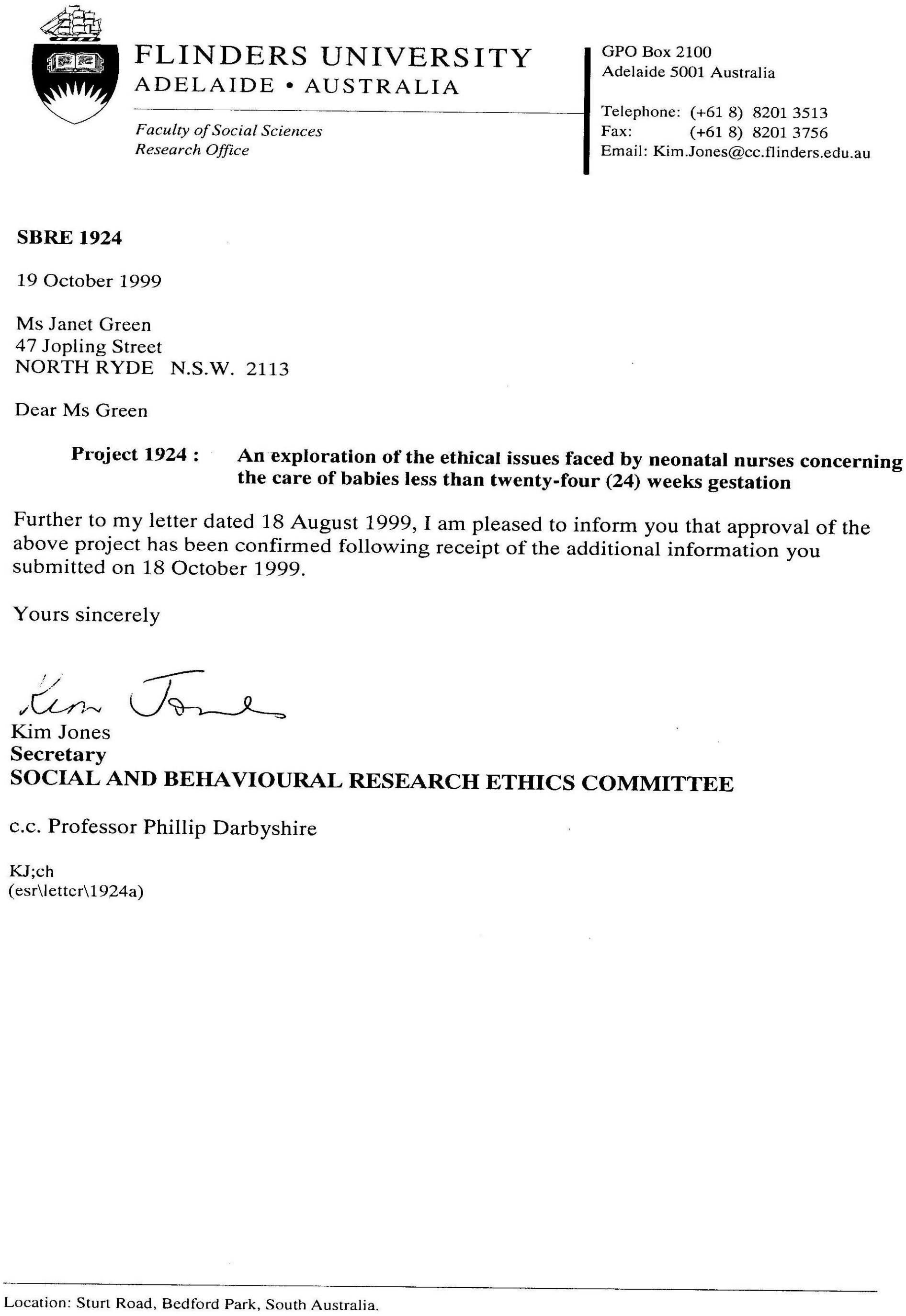
"Neonatal medicine needs to have a serious look at itself. Quality of life should be the fundamental driving force behind progress and not the will to play God at all costs. There has to be a limit at how early we are to save fetuses. Real advice to the full extent needs to be given to parents about the potential and real outcomes of babies born so early. Doctors need to ask themselves 'are they really being an advocate to the parents or to the infants by beginning resus on a still born fetus'". (345)

"If you were given a 10% chance of a successful outcome from surgery, would you take the chance?" (368)

"I have become very disillusioned with nursing. I see this as a huge shame, because up until about 2 years ago I adored it, and always thought of myself an extremely positive person. Neonatal nursing has eroded that quality somewhat. The ethical issues are primarily to blame, but other issues, namely staffing or lack of it are also a huge component. My view on babies less than 24 weeks is that I have not met one neonatal nurse or paediatric registrar who would allow their (mythical) 24 weeker to go through what we advocate as a profession, along with neonatologists as an acceptable thing to do. While not everyone wants or wishes their child to be a rocket scientist, the risks of severe impediment, not only neurologically are huge, but many parents cannot see beyond the neonatal period, and who could blame them". (378)

"When the medical staff do not include us in decisions when we are primary carers". (409)

APPENDIX C:
ETHICS APPROVAL



FLINDERS UNIVERSITY
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GPO Box 2100
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Telephone: (+61 8) 8201 3513
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Email: Kim.Jones@cc.flinders.edu.au

SBRE 1924

19 October 1999

Ms Janet Green
47 Jopling Street
NORTH RYDE N.S.W. 2113

Dear Ms Green

Project 1924 : **An exploration of the ethical issues faced by neonatal nurses concerning the care of babies less than twenty-four (24) weeks gestation**

Further to my letter dated 18 August 1999, I am pleased to inform you that approval of the above project has been confirmed following receipt of the additional information you submitted on 18 October 1999.

Yours sincerely

Kim Jones
Secretary
SOCIAL AND BEHAVIOURAL RESEARCH ETHICS COMMITTEE

c.c. Professor Phillip Darbyshire

KJ;ch
(esr\letter\1924a)

Location: Sturt Road, Bedford Park, South Australia.

APPENDIX D:
LETTER OF INTRODUCTION
PRE-TEST QUESTIONNAIRE

Dear Colleague,

I am undertaking research leading to the production of a thesis on the subject of "ethical issues faced by neonatal nurses regarding the care of babies less than twenty four (24) weeks gestation". I would be most grateful if you would volunteer to spare the time to assist in this project, by completing a pre-test of the questionnaire that I am planning to use which touches upon certain aspects of this topic.

I am asking you to please do the questionnaire and comment on the following:

- The length of time that that the questionnaire takes you (I need this for ethics approval).
- Document any difficulties that you have with the questions (ie ambiguity)
- Are there any issues that you believe that I have not covered at all, or at least superficially?
- Any comments that you would like to make about the questionnaire construction.
- Could you send the questionnaire and comments to me in the envelope provided.

Be assured that any information provided will be treated in the strictest confidence and none of the participants will be individually identifiable in the resulting thesis, report or other publications. You are, of course, entirely free to discontinue your participation at any time or to decline to answer particular questions.

Any enquiries you may have concerning this project should be directed to me at the address given above or by telephone on (02) 98780562 (H), (02) 9514-5740 (W), fax (02) 9514-5513 or e-mail Janet.Green@uts.edu.au

Yours sincerely,

Janet Green
PhD student
School of Nursing
The Flinders University of South Australia.

APPENDIX E:

LETTER OF INTRODUCTION – QUESTIONNAIRE

Dear Sir/Madam,

This letter is to introduce Janet Green who is a PhD student in the School of Nursing at Flinders University. She is undertaking research leading to the production of a thesis on the subject of the ethical issues faced by neonatal nurses concerning the care of babies less than twenty-four (24) weeks gestation.

Although Janet appreciates that you may not have had experience with caring for such tiny babies, she would nevertheless value your opinion, because she is interested in an Australian neonatal nursing perspective.

Janet would be most grateful if you would volunteer to spare the time to assist in this project, by completing a questionnaire which touches upon certain aspects of this topic. No more than thirty minutes on one occasion would be required.

Be assured that any information provided will be treated in the strictest confidence and none of the participants will be individually identifiable in the resulting thesis, report or other publications. You are, of course, entirely free to discontinue your participation at any time or to decline to answer particular questions.

Any enquiries you may have concerning this project should be directed to me at the address given above or by telephone on 08-8204-6468, fax (08-8204-7704) or e-mail (pdarbyshire@health.adelaide.edu.au)

This research project (Project 1924) has been approved by the Flinders University Social and Behavioural Research Ethics Committee. The Secretary of this Committee can be contacted on (08) 8201-3513, fax (08) 8201-5034, e-mail Kim.Jones@cc.flinders.edu.au.

Thank you for your attention and assistance.

Yours sincerely,

Professor Philip Darbyshire
Chair of Nursing
Flinders University School of Nursing and Women’s & Children’s Hospital
Adelaide
South Australia

APPENDIX F:
LETTER OF INTRODUCTION - INTERVIEW

Dear Colleague,

I am undertaking research leading to the production of a thesis on the topic of the ethical issues faced by neonatal nurses concerning the care of babies less than twenty four (24) weeks gestation.

I would be most grateful if you would volunteer the time to assist in this project, by granting an interview in which certain aspects of this topic will be explored. It is estimated that no more than one hour on one occasion would be required. Any information provided will be treated in the strictest confidence. Participants will not be individually identifiable in the resulting thesis, report or other publications. You are, of course, entirely free to discontinue your participation at any time or to decline to answer particular questions.

Since I intend to make a tape recording of the interview, I will seek your consent, on the attached form, to record the interview, to use the recording or a transcription in preparing the thesis, report or other publications, on condition that your name or identity is not revealed. It may be necessary to make the recording available to secretarial assistants for transcription, in which case you are assured that such persons will be advised of the requirement that your name or identity not be revealed and that the confidentiality of the material is respected and maintained.

Any enquiries you may have concerning this project should be directed to me at the address given above or by telephone on (02) 9514-5740, fax (02) 9514-5513 or e-mail Janet.Green@uts.edu.au

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee. The Secretary of this Committee can be contacted on (08) 8201-3513, fax (08) 8201-5034, e-mail Kim.Jones@cc.flinders.edu.au.

Thank you for your attention and assistance.

Yours sincerely,

Janet Green

PhD student

School of Nursing

The Flinders University of South Australia

APPENDIX G:

CONSENT FORM FOR INTERVIEW

I ....

being over the age of 18 years hereby consent to participate as requested in the ………………………………… for the research project on the ethical issues experienced by neonatal nurses concerning the care of babies less than 24 weeks gestation.

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to my information and participation being recorded on tape/videotape.
4. **I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.**
5. I understand that:
    - I may not directly benefit from taking part in this research.
    - I am free to withdraw from the project at any time and am free to decline to answer particular questions.
    - While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
    - I may ask that the recording/observation be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.
6. I agree to the tape being made available to other researchers who are not members of this research team, on condition that my identity is not revealed.

    I have completed the questionnaire.
7. **I have read a transcript of my participation and agree to its use by the researcher as explained.**
8. I have read the researcher's report and agree to the publication of my information as reported.
9. I have had the opportunity to discuss taking part in this research with a family member or friend.

SIGNATURES

Participant……………………………………………Date…………………………...

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher…………………………………………..Date…………………………

APPENDIX H:
LETTER OF ENDORSEMENT

25/10/99

To ANNA members

We would like to endorse the research that Janet Green is undertaking into:

"Ethical issues faced by neonatal nurses regarding the care of babies
less than twenty four weeks gestation".

Janet is a neonatal nurse and a Lecturer at the University of technology, Sydney and a member of the Association of Neonatal Nurses, NSW. Recently Janet has presented an overview of her research at several forums and we can commend its worth. She wishes to gain an Australian wide perspective of the ethical issues confronting neonatal nurses regarding the care of babies of marginal viability. There has been only one study which has explored neonatal nurses views, this was American and published in 1986; Janet's work is indeed timely.

Janet has gained permission to contact ANNA members through each state branch; confidentiality and anonymity of participants is assured. The project (1924) has been cleared by the ethics committee from the Flinders University of South Australia. We would encourage you to take the time to complete the questionnaire so a true national perspective can be gained.

Yours sincerely

Kaye Spence AM
A/Prof (Adjunct) Clinical Nurse Consultant
The New Children's Hospital
PO Box 351
Parramatta NSW 3515
Email: Kaye@nch.edu.au

Carmel Collins
Research Nurse/Midwife
Women's & Children's Hospital
72 King William Road
North Adelaide SA 5006
email: collinsct@wch.sa.gov.au

APPENDIX I:

DISSEMINATION OF THE FINDINGS OF THIS WORK

Introduction

There have been many positive outcomes from this study even before its submission as a PhD thesis. There have been numerous media interviews. This researcher sees the value of media involvement particularly for a topic such as this. The general public has been inundated with the concept of "miracle babies". Such an image is not reality for most of the babies born at 24 weeks gestation and less. It is important for nurses to contribute to the debates surrounding extremely premature infants, as they have a unique experience, which is different from other health professionals.

Media interest – PhD work featured:

Anonymous, 2000, 'Nurses speak out about microprem babies' *Australian Nursing Journal*, vol. 8, no. 2, August, pp. 33.

Australian Broadcasting Commission (ABC) QUANTUM (2000) [Online] Available: http://www.abc.net.au/quantum/stories/s128059.htm http://www.abc.net.au/quantum/stories/s133023.htm [12 June 2001].

Borland, M. 2000, 'Keeping microprems alive: An ethical dilemma', *Nursing Review*, August, pp. 18.

Dayton, L. 2000, 'Holding the baby: How far should neonatal carers go to save a child', *The Australian*, Thursday June 15, pp. 13.

McInerney, S. 2000, 'Preserving life at all costs – Nurses speak out', *UTS News*, Issue 9 12 June - 25 June, pp. 3.

Mather, J. 2007, 'Pushing the boundaries of survival', *Nursing Review*, March, pp. 13.

Pengally, J. 2001, 'Nurses feel they are torturing prem babies', *The Advertiser (Adelaide)*, Wed 7th Nov, pp. 9

Pirana, C. 2007, 'Nurses support ethical killing', *The Australian*, Thursday Feb 7th, pp. 5.

Sixty Minutes, 2001 '*At what cost*' (26th Aug) [Online] Available: http://news.ninemsn.com.au/sixtyminutes/stories/2001_08_26/story_400.asp http://news.ninemsn.com.au/sixtyminutes/stories/2001_08_26/story_401.asp [27 August 2001].

Sparke, C. 2001, 'Small miracles', *HQ*, Oct/Nov, pp.84-89.

The Australian Museum Society (TAMS), 2002, 'Ethics at the edge of life', **Muse,** ***Feb,***
March, April, pp. 12.

- PhD work featured on the University of Technology, Sydney's Faculty of Nursing, Midwifery and Health's website http://www.nmh.uts.edu.au/whatnew/microprem_babies.html
- PhD work featured on ABC radios Tony Delroy show 13th June 2000
- Interview with Jo White of 2SER FM Monday 26th of June 2000
- Participated in a panel on premature birth for ABC (Radio) Brisbane on 5th July 2000
- Interviewed on ABC Radio (Brisbane) (8th April 2003)

Conference papers

Green J (1997). Should we save tiny babies? NSW Association of Neonatal Nurses, Landmark Hotel, Potts Point, Sydney, NSW.

Green, J. (1999). Ethical dilemmas in the neonatal intensive care: The case of the microprem. Neonatal, Midwifery & Paediatric Conference. Canberra.

Green, J. (1999) Should we save all lives: The case of the microprem. Australasian Society for Human Biology Conference. Sydney.

Green, J. (1999). How to be totally confused – deciphering the outcomes of profoundly premature infants. Association of Neonatal Nurses of NSW Conference. Sydney.

Green, J. (2000). What every paediatric nurse should know about premature infants. 6th International Conference of Paediatric and Child Health Nurses. Perth, WA.

Green, J. (2001). When science and ethics collide: The quality of life for microprems. Australian Neonatal Nurses Association. Canberra

Green, J. (2001). Saving tiny babies: The ethical concerns of neonatal nurses. International Neonatal Nursing Conference, Sydney, (Nov).
Green, J. (2001). When caring and torture are the same thing. Qualitative Research Conference. Adelaide. SA.

Green, J. (2002). Can parents demand everything: The concept of futility in paediatrics. International Paediatric Nursing Conference. Manly, Sydney. NSW.

Green, J. (2002). Can parents demand everything: The concept of futility in neonatal care. Association of Neonatal Nurses of NSW conference. Bondi, NSW.

Green, J. (2003). Should extremely premature babies be used for experimentation? What neonatal nurses think? Australian Neonatal Nurses Association, Hobart, Tasmania.

Green, J. (2003). What child health nurses should know about growing premature infants. Tresillian Conference, Sydney.

Green, J. (2003). Dealing with sensitive data: Neonatal nurses views on saving extremely premature babies. Paediatric Research Seminar. Clinical Research: Impact on Practice, The Children's Hospital at Westmead, Sydney.

Green, J. (2004). Can parents demand everything? The concept of futility in neonatal intensive care. In Sickness and in Health: Shaping health care: Power and agency, Reykjavik, The University of Iceland.

Green, J. (2004). Who should make decisions about the survival of microprems? In Sickness and in Health: Shaping health care: Power and agency, Reykjavik, The University of Iceland.

Green, J. (2005). When caring and torture are the same thing, Australian Neonatal Nurses Association. Adelaide. March.

Green, J. (2005). Dealing with sensitive data. Research Café. University of Technology, Sydney.

Green, J. (2007). Scientific progress and the use of extremely premature babies as research subjects. International Neonatal Nursing Conference, Delhi, India.

Green, J. (2007). When caring and torture are the same thing: The ethics of keeping extremely premature babies alive. International Neonatal Nursing Conference, Delhi, India.

Conference papers (invited speaker)

Green, J. (2001). When mother nature and ethics collide: Should we treat babies less than 24 weeks gestation. Nepean Midwifery conference. Richmond.

Green, J. (2001). When mother nature and ethics collide: Ethical issues surrounding the newborn. Ausmed Publications Midwifery Conference. Melbourne.

Plenary session debate (2001): The place of greater safety at 25 weeks gestation: In utero or in NICU Perinatal Society of Australia & New Zealand, Canberra.

Green, J. (2001). Advance practice for neonatal nurses: the involvement of neonatal nurses in ethical decision making. Perinatal Society of Australia & New Zealand, Canberra.

Green, J. (2001). The ethics of saving tiny babies. Invited guest of the Queensland Branch of the Australian and New Zealand Perinatal Society. Brisbane, (May).

Green, J. (2001). Ethical issues surrounding the newborn. Wyeth pharmaceuticals dinner with the theme “Towards better babies”, Sydney, (June).

Green, J. (2002), The marginally viable newborn: What Australian neonatal nurses think. The Children’s Hospital at Westmead Ethics Symposium.

Green, J. (2004). The extremely premature baby: The neonatal nurse’s perspective. Westmead Hospital International Neonatal Intensive Care Conference, May.

Green, J. (2004). Ethics at the edge of life: Extremely premature babies. Wyeth pharmaceuticals dinner. Sydney, June.

Green, J. (2007). Medico-legal and ethical issues panel member. International Neonatal Nursing Conference, Delhi, India.