MATERNAL-FETAL MEDICINE

Antenatal counselling, resuscitation practices and attitudes among Australian neonatologists towards life support in extreme prematurity

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SUMMARY

A questionnaire survey of Australian neonatologists was conducted to ascertain their antenatal counselling and resuscitation practices, and attitudes towards life support in the extremely preterm infant. This study showed that in antenatal parental counselling, whether a paediatrician was given the opportunity to participate depends on the gestation at the time of the threatened preterm delivery. The counselling employed almost invariably covered mortality and morbidity. The obstetrician's opinion was considered to be of utmost importance. Both financial and moral obligations were found to be of little importance in counselling and resuscitation. Only one-third of institutions had guidelines for limiting resuscitation. The onus remained on the neonatologists concerning which infant to resuscitate, and the level of the resuscitation to be conducted.

INTRODUCTION

The survival of extremely low birthweight (ELBW, 500–999g) infants in Australia was reported to improve from 69% in 1993 to 72% in 1996.¹ For infants born in the State of Victoria in Australia in 1998, the infancy survival rate rose from 11.4% at 22–23 weeks' to 52% at 24–25 weeks' and 78% at 26–27 weeks' gestation.² Neurodevelopmental outcome for such infants born extremely preterm is more difficult to assess.³ Most recent studies from Australia and elsewhere have focused on survival and disability rates related to birthweight as opposed to gestation.^{4,5,6,7,8,9} A study of

Dr M Munro Newborn Services, Monash Medical Centre 246 Clayton Road Clayton Victoria 3168 Australia In Australia, resuscitation at birth was restricted to infants of 23 weeks' gestation or above, and neonatologists did not believe the legal system has a role to play in limiting or mandating resuscitation of extremely preterm infants. Neither were they concerned with the threat of litigation when they decide to limit resuscitation. The majority of neonatologists agreed with their institution's approach to life support in extremely preterm infants. One grey area was the question of withholding assisted feeding in an infant for which the decision to withdraw life support has been made. Australia lacked a current consensus policy on selective non-treatment. The establishment of national guidelines would be helpful to aid Australian obstetricians and neonatologists in their clinical practice.

ELBW infants born in the State of Victoria reported improved survival and neurodevelopmental disability rates in the 1970s and 1980s.⁶ However, there is no evidence of further reductions in adverse long-term outcome into the 1990s, which remain significantly higher in ELBW than in normal birthweight infants. Of concern is the report from the North Western region of England, which described an increase in the rate of disability in infants born at 23–25 weeks from 38 to 68% during two periods, 1984–1989 and 1990–1994.⁸

It remains controversial whether it is right to offer resuscitation and life support to an infant who has a high chance of postnatal death or long-term disability. This question has to be answered each time the paediatrician is called to counsel, resuscitate and provide life support treatment for an extremely preterm infant. How then does the Australian neonatologist approach these problems? The main aim of this study was to survey Australian neonatologists' attitudes towards antenatal counselling and resuscitation of the extremely preterm infant. Information was obtained on factors considered most important in counselling parents and in limiting

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resuscitation of the extremely preterm infant. The survey also focused on personal beliefs and criteria, and on how institutional policies influence resuscitation practices. A further aim was to ascertain personal attitudes towards life support of the extremely preterm infant.

METHODS

A questionnaire was sent to 100 neonatologists involved in neonatal care around Australia. The response rate among those who were in active practice was 70% (three were returned by neonatologists who had retired). The questionnaire had a combination of graded response and yes/no answers covering most areas of antenatal counselling, resuscitation practices and personal attitudes regarding life support. The study focused particularly on attitudes towards neonates of below 26 weeks' gestation. Biographic and demographic data was also gathered. Sixteen per cent of the respondents were female and 84% were male. The median age was 46 years (range 33-57 years). Seventy per cent were born in Australia and the same percentage graduated from an Australian medical school. Thirty-nine per cent completed their postgraduate training solely in Australia. Of the rest, the majority had training in either the United Kingdom or North America (USA or Canada), with a smaller number in either New Zealand or a combination of the above three. Ninety-three per cent indicated they had had subspecialty training in neonatology. The average number of annual deliveries in the hospitals where the respondents practised was 3647 (standard deviation (SD) 264). The average number of Neonatal Intensive Care Unit (NICU) annual admissions was 562 (SD 40).

RESULTS

Antenatal parental counselling

Gestational age has a strong influence on whether a neonatologist counselled parents prior to delivery (Table 1). At 22 weeks' only 24% always/often counselled parents, whereas at 25 weeks', 77% always/often counselled parents. Counselling always included survival prospects and almost always (95%) included risk of morbidity. The least important counselling issue was the financial cost to the family of intensive care; in 69% this was rarely/never discussed (Table 2). Of factors influencing the discussion on resuscitation, the most important one was the obstetrician's opinion. Again, financial cost to the family was the least important (Table 3). In over 90%, counselling was offered in the 'best interests of the infant' regardless of gestation (Table 4). A fairly even yes/no split was found for counselling 'based on the perception of the parents' wishes' at 22-25 weeks'. At 22 weeks, 86% would counsel 'towards non-resuscitation options'; this dropped to 14% by 24 weeks'.

Limiting of resuscitation

In limiting resuscitation of infants of 23–25 weeks', the opinion of the parents was often/always followed in 86% of cases (Table 5). A high probability of death or

Gestational age (weeks)	n	Never (< 5%) n (%)	Rarely (5–20%) n (%)	Sometimes (21-60%) n (%)	Often (61-95%) n (%)	Always (> 95%) n (%)
22	57	25 (40)	14 (23)	8 (13)	12 (19)	3 (5)
23	57	11 (17)	6 (10)	12 (19)	20 (32)	14 (22)
24	57	10 (16)	2 (3)	6 (10)	18 (30)	25 (41)
25	56	10 (17)	3 (5)	1 (2)	18 (30)	28 (47)

Table 1 How often are you called by obstetrians to counsel parents prior to delivery of an extremely premature infant?

 Table 2 Does your antenatal counselling of parents expecting an extremely premature infant (< 800g or < 26 weeks) include a discussion of the following outcomes?</th>

	n	Never (< 5%) n (%)	Rarely (5–20%) n (%)	Sometimes (21–60%) n (%)	Often (61-95%) n (%)	Always (> 95%) n (%)
The possibility of morbidity?	57	0 (0)	0 (0)	1 (2)	2 (4)	54 (95)
The likelihood of survival?	57	0 (0)	0 (0)	0 (0)	0 (0)	57 (100)
The possibility of no resuscitation in the delivery room?	57	1 (2)	3 (5)	13 (23)	17 (30)	23 (40)
The possibility of death in the delivery room?	57	1 (2)	2 (4)	8 (14)	10 (18)	32 (56)
The possibility of withdrawal of support in the NICU?	57	1 (2)	2 (4)	5 (9)	17 (30)	32 (56)
The possibility of death in the NICU, despite maximal medical intervention?	57	0 (0)	1 (2)	4 (7)	10 (18)	42 (74)
The financial costs to the family for NICU care	56	26 (46)	13 (23)	7(13)	4 (7)	6 (11)

	n	Never (< 5%)	Rarely (5–20%)	Sometimes (21–60%)	Often (61-95%)	Always (> 95%)
		n (%)	n (%)	n (%)	n (%)	n (%)
Teenage parent	56	21 (38)	17 (30)	11 (20)	4 (7)	3 (5)
Low socioeconomic status	57	32 (56)	15 (26)	5 (9)	3 (5)	2 (4)
Language barrier	56	21 (34)	13 (23)	13 (23)	5 (9)	4 (7)
Previous perinatal loss/es	55	11 (20)	17 (31)	14 (25)	7 (13)	6(11)
Allocation of health care resources	57	35 (61)	12 (22)	8 (14)	0 (0)	2 (4)
Obstetric opinion	56	6 (11)	15 (27)	19 (34)	10 (18)	6 (11)
Maternal risk factors (ie drug abuse, no prenatal care)	57	14 (25)	21 (37)	16 (28)	4 (7)	2 (4)
Financial costs to family of NICU care	57	40 (70)	14 (25)	2 (4)	1 (2)	0 (0)
Emotional burdens on family	57	10 (18)	22 (39)	12 (22)	9 (16)	4(7)

Table 3 How often do the following factors affect your discussion of resuscitation options when counselling parents expecting an extremely premature infant?

 Table 4
 For each of the gestational ages below, please answer Yes or No for each statement about your usual antenatal parent counselling practices at each gestational age

	Those answering YES at:				
	n	22 weeks' n (%)	23 weeks' n (%)	24 weeks' n (%)	25 weeks' n (%)
l counsel parents based on the best interests of the infant	56	51 (91)	51 (91)	54 (96)	55 (99)
l counsel parents based on my perceptions of the parents' wishes	55	23 (42)	28 (51)	29 (53)	25 (45)
I counsel directly towards non-resuscitation options	54	47 (87)	28 (52)	8 (8)	0 (0)
l strive for consensus between myself and parents regarding intensive care options	57	49 (86)	55 (96)	57 (100)	54 (95)
If parents disagree with my recommendation, I would:					
alter my treatment to accommodate the parents' wishes	53	29 (55)	46 (87)	43 (81)	33 (62)
consider legal action to limit their decision-making capacity	53	4 (8)	3 (6)	3 (6)	6 (11)
follow my recommendation	52	19 (37)	11 (21)	10 (19)	20 (38)

Table 5 How often are the following factors considered in your decision to limit resuscitation in the delivery room for infants 23–25 weeks'?

	n	Never (< 5%) n (%)	Rarely (5–20%) n (%)	Sometimes (21–60%) n (%)	Often (61–95%) n (%)	Always (> 95%) n (%)
Opinions of the parents	57	0 (0)	1 (2)	7 (12)	16 (28)	33 (58)
Opinions of other family members	57	16 (11)	25 (44)	13 (23)	1 (2)	2 (4)
High probability of death of the child	57	1 (2)	2 (4)	8 (14)	19 (33)	27 (47)
Future quality of life (severe disability/ medical problems)	57	1 (2)	3 (5)	10 (18)	21 (37)	22 (39)
Experience of pain by the child	57	14 (25)	19 (33)	8 (14)	7 (12)	9 (16)
Severe congenital anomalies	57	0 (0)	2 (4)	4 (7)	13 (23)	37 (65)
Moral/religious considerations	55	7 (13)	20 (36)	12 (22)	9 (16)	7 (13)
Emotional burden of patient care on family	55	6 (11)	21 (38)	16 (29)	6 (11)	6 (11)
Financial costs of NICU care to family	57	37 (65)	16 (28)	1 (2)	1 (2)	2 (4)
Allocation of health care resources	57	33 (58)	14 (25)	7 (12)	0 (0)	3 (4)
Threat of litigation	57	39 (68)	13 (23)	3 (5)	0 (0)	2 (4)

future severe disability was often/always a factor in limiting resuscitation in 80% and 76% of cases respectively. Financial cost to the family was rarely a factor for consideration; only 6% often/always taking this into account. The experience of pain while resuscitating the infant was felt to be rarely/ never important by over half of the respondents. Moral or religious considerations were often/always taken into consideration in 29%. The threat of litigation was never/rarely a consideration in 91%. If parents disagreed with the neonatologists' recommendations (Table 4), the treatment plan was more likely to be altered to accommodate the parents' wishes at 23–24 weeks' than at 22 weeks' or 25 weeks'. In that scenario, legal action to limit parental decision-making was felt to have no useful place by the majority, regardless of the gestation. In cases of disagreement, the majority believed the parents should decide (58%), with 35% believing the neonatologist should decide. Only 6% believed a judge/court or ethics committee should make the decision.

Resuscitation practices

Only one-third of the respondents worked in an institution that had written guidelines for the resuscitation of the extremely preterm infant. Of those that did have a policy, 57% of the neonatologists informed the parents of the actual policy. Overall, 78% of the respondents informed parents of their own personal criteria for initiating resuscitation in the delivery room. Of those that used their own personal criteria for initiating resuscitation, 54% used gestation as their guide, 5% used birthweight and 35% used a combination of both. The mean gestation and birthweight cut-off for initiating various stages of resuscitation are shown in Table 6.

 Table 6 Mean gestational age and mean birthweight

 limits for non-resuscitation

······	Gestational age (SD) (weeks)	Birthweight (SD) (grams)	
Intubation and ventilation	n ≤ 23 (0.09)	≤ 465 (12)	
Cardiac massage	≤ 24 (0.19)	≤ 561 (24)	
Medication for resuscitat (adrenaline)	ion ≼ 24 (0.2)	≤ 589 (30)	

Attitudes towards life support

Below 26 weeks', the majority considered a major congenital anomaly or grade 3-4 intraventricular haemorrhage (IVH) were acceptable indications for withdrawal of care (98% and 90% respectively). On the other hand an infant below 26 weeks' with a human immunodeficiency virus (HIV) positive mother proved a less clear-cut proposition for withdrawal of care (38% agreed this was an acceptable reason for withdrawal and 62% disagreed). Only 2% agreed with the proposal that 'all interventions should be undertaken to preserve life, however severe the prognosis'. A similarly low percentage agreed with the proposal that 'even with severe physical disability, life is better than death'. A slightly greater percentage (8%) agreed with the proposal that 'even with severe mental disability, life is better than death'. There was an even split on the appropriateness of discontinuing fluid/nutrition in an infant for which the decision has been made to withdraw life support. Only 11% felt that their unit was 'too aggressive' with life support in infants below 26 weeks, while 7% felt that their unit was 'not aggressive' enough.

DISCUSSION

Antenatal parental counselling

With increasing gestational age, it was more likely that obstetricians would call a paediatrician to counsel the mother expecting a preterm delivery. This reflects the perceived increasing viability with increasing maturity and therefore the presumed 'need' for parental counselling. Throughout the survey, neonatologists considered financial costs to the family to be one of the least important factors. It is understandable that in Australia where parents are not required to pay for their infants' neonatal intensive care, this is an unimportant issue for the family. Indeed, our study of parental perceptions of intensive care options for very low birthweight infants revealed that 90% of those interviewed did not think financial considerations were important when making decisions about intensive care options for their infant.¹⁰ When limiting resuscitation, allocation of health care resources was never/rarely considered by 83% of those surveyed (Table 4). Should this be the case? The cost of a single day's assisted ventilation in the State of Victoria was estimated to be \$A1992.00 in 1997.¹¹ Avery argues that limiting care with marginal utility is a fair manner in the allocation of scarce resources.¹² On the other hand, Kravbill argues that the overall national cost of medical care, though almost always a source of concern to neonatologists and often to parents, ought not to influence decisionmaking on an individual infant.¹³ Both authors put forward compelling arguments while holding opposite viewpoints on the matter.

There is growing debate in the Australian healthcare system on whether there is a duty not to treat. A bold attempt has been made in the USA to address this issue. The Oregon Health Care Initiative attempted to prioritise use of healthcare resources according to three key factors: efficacy, cost, and value to societal members.¹⁴ It suggested that resuscitation of infants below 500g and below 24 weeks' gestation was not cost-effective and should not be publicly funded. However this proposal was vetoed by the US government, citing it as a breach of the Americans with Disabilities Act. In Australia where the public healthcare system is under increasing strain, consideration of limiting healthcare resources in a similar manner deserves consideration. From this survey of neonatologists, it seems unlikely that they would lend their support to similar initiatives to ration resources for the extremely preterm infant.

The obstetrician's opinion was the biggest factor influencing the discussion of resuscitation options when counselling parents expecting an extremely preterm infant. This is not entirely surprising as the parents may have already asked and indeed been given an opinion by their obstetrician regarding resuscitation options. Thus the need for early and close consultation with the neonatologist by the obstetrician involved is vital. Whereas neonatologists' opinions affect the newborn, obstetric decisions affect both the fetus and the newborn. 'Risky moral behaviour of obstetrical soothsaying' at 22–24 weeks' means that obstetricians' actions may irrevocably alter the clinical condition and therefore test unfairly the developmental capacities of the fetus or newborn.¹⁵

Limiting of resuscitation

This survey indicated that if parents disagreed with the neonatologist's recommendations, the treatment plan was more likely to be altered at 23-24 weeks' than at 22 weeks' or 25 weeks'. Probably, the decision not to resuscitate an infant born at 22 weeks' and to resuscitate at 25 weeks' was more clear-cut in the neonatologist's mind because the outcome at these gestations was more predictable. Thus the neonatologist could feel more confident in the counselling, if he had to override the parents' views. The opinion has been expressed that neonatologists are poor in assessing the prognosis for individual infants born at 24 weeks'.¹⁵ Consequently, the likelihood of survival with or without injury of extremely preterm infants is influenced by 'opinions and associated behaviours of people who prejudge the biological incapacities before they are demonstrated'. This could be interpreted as a self-fulfilling prophecy. Studies in Australia and the USA have shown that paediatricians and obstetricians underestimated the chance of survival and the potential for a good infants.16,17 outcome in extremely preterm Obstetricians tended to underestimate the prognosis by a greater degree.

The parents' opinion was of paramount importance to the neonatologist when limiting resuscitation at 23–25 weeks', as 86% of respondents often/always considered the parents' opinions. Unfortunately conflict of opinion does arise. In Australia, there is less regard for the threat of litigation compared to the USA where there have been landmark legal cases concerning family versus healthcare teams in decisionmaking.^{18,19}

Moral or religious considerations were often/ always taken into consideration by only 29% of respondents. Moral obligations of the perinatal specialists to the pregnant woman, fetus and newborn are complex, and they may change with the transition from fetus to newborn.²⁰ Obstetricians' views of their moral obligations to the fetus may be different from neonatologists' views of their moral oblications to the newborn. An understanding of and respect for these views can aid perinatal specialists in resolving interdisciplinary conflicts and can help in solving fetal and neonatal ethical dilemmas.

Resuscitation practices

Only one-third of neonatologists worked in an institution that had written guidelines on the resuscitation of the extremely preterm infant. Of those that did, only 57% would inform parents of the actual policy. Could it be that the neonatologists disagree with their institution's policy? After all, a higher percentage (78%) would inform parents of their own personal criteria for initiating resuscitation in the delivery room. One, therefore, cannot assume that by producing institutional guidelines, they will necessarily be followed. If this is the case at an institutional level, an effort to draw up national guidelines for resuscitation practices may not be helpful.

Of those who used their own personal criteria for initiating resuscitation, 54% used gestation and only 5% used birthweight with the rest using a combination of both. This probably reflects the difficulty of estimating the weight of a newborn requiring resuscitation. Therefore, it is imperative that both obstetricians and neonatologists have accurate and up-to-date information regarding the prognosis at different gestations. More studies examining outcome related to gestational age are required. The lower the gestation or birthweight, the less aggressive was the resuscitation offered. This probably reflects the poor outcome when aggressive resuscitation including adrenaline was required in extreme preterm infants.^{21,22,23} It was reported that 78% of infants born below 29 weeks who required adrenaline for resuscitation at birth either died or had neurodevelopmental disability.²¹

Attitudes towards life support

Australia has no national guidelines for selective nontreatment in newborn infants, although personal guidelines have been published.²⁴ National policies published in the United Kingdom²⁵ and the USA²⁶ have generally agreed and emphasised that the decisionmaking process should be a joint one between the physician and the parents. We found that 98% of respondents believed it was acceptable to withdraw life support in an extremely preterm infant confirmed to have a major congenital anomaly, and 90% believed it was acceptable when Grade 3 or Grade 4 IVH developed. However, we entered the 'grey area' with an infant born below 26 weeks' to an HIV-positive mother, as 38% agreed it was acceptable to withdraw life support. The chance of intact survival for such an infant has to be weighed up against his/her chance of contracting HIV and subsequent morbidity and mortality. The latter depends on whether the mother has received treatment to lessen the chances of vertical transmission and the cost and efficacy of new treatment modalities if the infant does acquire HIV.

Our survey showed an almost even split over the question of appropriateness of discontinuing fluid/nutrition in an infant for which the decision has been made to withdraw life support. The United Kingdom guidelines²⁵ only touched briefly on this delicate issue, and as a consequence have been criticised.²⁷ The criticism was that nurses should be

as equally involved as the parents and neonatologists in the decision-making process, and nurses may feel that they are withholding 'basic comfort and dignity' by withholding assisted feeding. This practice might be less common in the United Kingdom compared to Australia and the USA. The USA national policy actually states that neonatologists are not 'breaking the law' by withholding nutrition in an infant for whom life support has been withdrawn.²⁶

The majority of respondents agreed with their NICU's policy regarding life support for infants below 26 weeks'. Only 11% felt their NICU was too aggressive and 7% felt their NICU was not aggressive enough. For this minority, their work must at times be both frustrating and distressing. A national consensus on this matter could potentially be of benefit by prompting NICUs to examine their own policies.

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