

Occasional Survey

End of Life Decision and Care in Neonatal Care Unit

MSC WONG, BCC LAM

Abstract

Purpose: To identify the different causes of neonatal death and the proportion preceded by end of life decision. To review the end of life practice including consensus building, comfort care program, bereavement support and autopsy in our neonatal unit. **Methods:** A retrospective chart review on infants died in the neonatal care unit in Queen Mary Hospital in the period between July 1998 to October 2002. **Findings:** During the study period, there were a total of 793 neonatal intensive care admissions with 40 deaths. Among these 40 death cases, 28 (70%) deaths were preceded by end of life decision with futile treatment (54%) and poor quality of life (46%) as the motives. The end of life decision was followed by withdrawal and withholding support in 43% and 57% respectively. Sixty-eight percent of end of life group received opioid analgesia for pain relief, sedation or respiratory distress. The median time between withdrawal and death was 2.75 hours (range from 3 minutes to 28 hours). Forty-five percent of our patients had postmortem or paramortem examination. **Conclusion:** With advancement of neonatal intensive care technology, similar to most modern neonatal intensive care units, majority of our neonatal deaths were preceded by end of life decision. The decision was mostly based on futility of treatment or quality of life issues. Consensus building within the management team and parental involvement is of utmost importance. Adequate analgesia and comprehensive care including comfort care, provision of private environment, family and bereavement support are essential.

Key words

Analgesia; End of life decision; Neonates

Introduction

With advances in neonatal intensive care technology, neonatologists are able to save infants who in the past would have been considered non-salvageable. Making an end of life (EOL) decision at the appropriate moment is vital to ensure that patients benefit maximally from modern technology without becoming victims of pointless short-term or long-term suffering.

Neonatologists need to withdraw or withhold life-sustaining treatment much more often than general paediatricians. The percentage of neonatal death following

EOL decision varies from 10% to more than 80%.¹⁻⁴ In most modern neonatal intensive care units (NICU), more than 50% of deaths are preceded by the withdrawal or withholding of life-sustaining treatment.⁵ EOL decision for newborn infants is mostly based on futile treatment and quality of life. Futile treatment implies the baby has already entered the process of dying and intensive care is simply prolonging death rather than saving life. Withdrawal of life support bases on a 'quality of life' decision implies the baby may well survive. However, the survival is associated with substantial neurodevelopmental or physical handicap that will radically limit the child's ability to participate in human experience and will render him or her forever dependent on a caretaker for everyday living.⁶

Once redirection of care is decided, a comprehensive comfort care program involving physical, psychosocial and spiritual support should be provided to the infant and the family. This study was undertaken to review our current practice on end of life decision and care.

Department of Paediatrics and Adolescent Medicine, Queen Mary Hospital, 102 Pokfulam Road, Hong Kong, China

MSC WONG (黃小珍) MBBS, MRCP(UK)

BCC LAM (藍章翔) FRCP(Edin, Lond), FRCPCH(UK), FHKCPaed

Correspondence to: Dr MSC WONG

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Patients and Method

A retrospective chart review was performed on infants who died in the neonatal care unit of Queen Mary Hospital in the period between July 1998 to October 2002. The patients with death occurring in neonatal care unit during the study period were identified using the computer database. Each record was reviewed with the following information noted including gestational age, mode of delivery, birth weight, apgar scores, sex, primary diagnosis, age of death, antecedent events leading to death and decision of withdrawal or 'do not resuscitate' policy. For those patients with EOL decision preceding death, we further look into the type of life support being withdrawn or withheld and the use of analgesic support. We also measured the time interval between withdrawal of life support to death. The aim of this study is to identify and review 1) the conditions leading to end of life decision; 2) the issue of treatment futility versus quality of life; 3) the process of consensus building; 4) the comfort care program with emphasis on the use of analgesia; 5) bereavement support and home death and 6) the rate of postmortem examination.

Results

During the study period, there were a total of 793 neonatal intensive care admissions with 40 deaths. The overall mortality of all NICU admissions was 5%. The demographic data of these infants are presented in Table 1. Among these 40 cases, 28 deaths (70%) were preceded by

withdrawal or withholding of life-sustaining treatment while the remaining 12 deaths (30%) followed failed aggressive treatment. The two main reasons supporting EOL decision included futile treatment for 15 (37%) and quality of life for 13 (33%). The major diagnoses of the death cases for each category are listed in Table 2. For the group with EOL decision based on quality of life issue, it consisted of 5 cases of major chromosomal abnormalities (four cases of trisomy 18 and one case of 46XY 5q+) and one case of syndromal disorder (congenital Marfan Syndrome with multiple severe valvular problem and intractable heart failure). The other two were extreme premature babies (both

Table 2 Major diagnoses and cause of death

	Number
Group 1 – followed failed aggressive treatment	12
Hydrops foetalis	2
Congenital diaphragmatic hernia	3
Congenital cystic adenomatoid malformation	1
Pulmonary hypoplasia	1
Extreme prematurity	2
Congenital heart block	1
Septicaemia + extreme prematurity + pneumothorax	1
Sudden infant death syndrome (posterior urethral valve + convulsion)	1
Group 2 – End of life decision based on futile treatment	15
Congenital diaphragmatic hernia with pulmonary hypoplasia	2
Extreme prematurity	1
Congenital heart block after failed pacing	1
Necrotizing enterocolitis + multiorgan failure	3
Short gut + multiorgan failure	2
Cytomegalovirus hepatitis + multiorgan failure	1
Liver +/- splenic rupture	2
Chronic diarrhea and liver failure	1
Nemaline myopathy + multiorgan failure	1
Disseminated herpes infection + multiorgan failure	1
Group 3 – End of life decision based on quality of life	13
Extreme prematurity	2
Complex cyanotic heart + chronic renal failure	1
Short gut	2
Hypoxic ischaemic encephalopathy	1
Trisomy 18	4
Neonatal marfan + multiple valvular problem	1
Chromosomal abnormality	1
Epidermolysis bullosa + sepsis	1

Table 1 Demographic data of infants died in the neonatal unit (n=40)

Sex	Male	27
	Female	13
Gestational age (weeks)	Preterm	n=24
	Median	27.5
	Range	24-36
	Term	n=16
	Median	39
	Range	37-41
Birth weight (gm)	Preterm	n=24
	Median	1212
	Range	520-2640
	Term	n=16
	Median	2882
	Range	1655-3720
Birth place	Inborn	22
	Outborn	18
Age of death (days)	Median	13.5
	Range	1-323

born at 24 weeks with birth weight of 520 gm and 648 gm respectively) with bilateral grade IV intraventricular haemorrhage. Concerning the group with EOL decision based on futile treatment, all of them had various causes leading to the common pathway of multiorgan failure resistant to appropriate treatment.

All 28 cases of death with EOL decision had consent for 'Do Not Resuscitate' (DNR) policy obtained from parents after thorough discussion. Eighteen (64%) babies were on ventilator and 16 (75%) were on inotropic support. EOL decision led to withdrawal of treatment in 12 (43%) patients that included withdrawal of ventilation and / or inotropic support. EOL decisions based on futility of treatment were more commonly (2/3) resulted in active withdrawal of life support treatment in addition to DNR policy.

Opioid analgesia was administered to 19 (68%) of 28 patients with the diagnosis listed in Table 3. Most of them suffered from conditions that were perceived to cause pain like necrotizing enterocolitis, chronic peritonitis, liver and splenic rupture, epidermolysis bullosa with surgical wounds and lots of skin breakage, disseminated congenital herpes simplex infection, trisomy 18 with respiratory distress during the terminal stage. Opioid analgesia was administered more frequently to patients with withdrawal of life support than to patients with withholding of support (92% vs 50%). Analgesia was more likely to be used in patients with EOL decision based on futility (80%) compared with the group based on quality of life (54%). The indications, route of administration and dosage of opioid analgesia, sedatives and anaesthetic agent were summarised in Table 4. Morphine was used more frequently compared with fentanyl. Midazolam and chloral hydrate

Table 3 Diagnosis and terminal events of the 19 patients with opiate analgesia given at the time of withdrawal or withholding of life support

Diagnosis	Number
Necrotizing enterocolitis and short gut	7
Liver and splenic injury + multiorgan failure	1
Extreme prematurity	3
Chronic peritonitis	1
Liver failure	2
Disseminated herpes simplex infection	1
Trisomy 18	2
Epidermolysis bullosa and sepsis	1
Chronic renal failure + complex cyanotic heart disease	1
Total	19

were used in 39% (11) and 11% (3) of patients. Anaesthetic agent was used in one patient for uncontrolled seizure and was stopped before withdrawal of life support. Nutritional support was provided for all these babies up to the terminal stage. Enteral feedings were continued in 10 patients, 18 babies were on intravenous fluid while one baby continued to receive total parenteral nutrition.

The median time from life support discontinuation to death for the 12 patients was 2.75 hours (range from 3 minutes to 28 hours). In spite of an existent program to assist and facilitate home death, we had no case of home death. Bereavement support was offered to all parents. It included counselling, assessment of their emotional states, psychological support including addressing their personal concern, guilt feelings, religious needs, answering questions with empathy and attending needs of the parents. The whole family including siblings and close relatives were encouraged to hold the baby, take photos or video depending on parental preference. The bodies were treated with respect and were cleaned and dressed up with their own clothing. Bereavement kit including bonnets and memory cards were prepared. Important information pamphlets on postmortem examination, handling of dead body and decision on cremation were given to parents.

Table 4 Use of analgesia and other medications in EOL care

ANALGESIA	Indications	
	Pain relief	9
	Comfort	8
	Respiratory distress	2
	Type and route	
	Morphine	16
	IV infusion	10
	IV bolus prn	8
	Oral	3
	Fentanyl	3
	IV infusion	2
	IV bolus prn	2
SEDATIVES	Indications	
	Sedation	14
	Type and route	
	Midazolam	11
	IV infusion	5
	IV bolus prn	11
	Chloral hydrate	3
ANAESTHETIC AGENT	Type and route	
	Thiopentone	1
	IV infusion	1

Parents were encouraged to discuss with the medical personnel and the medical social worker on their choice, special preferences and needs. A comfort card with contact number was given to parents for further enquiry or counselling. Nurses from the bereavement support team reassessed their emotional states by telephone follow up. Follow up meeting was arranged with the medical team to discuss on postmortem results. Outline of the end of life care program was listed in Table 5.

The need for postmortem examination was raised by the medical team in 28 patients (70%). Ten requests were refused by either parents (9) or waived by pathologist (1). Eighteen (45%) of these 40 deaths had postmortem (15) or paramortem (3) examination. For the remaining 12 patients (30%), no postmortem was requested as definite cause(s) of death had been identified.

Discussion

In our study, around 70% of death cases in our neonatal unit were preceded by EOL decision. It is similar to Wall and Partridge findings in 1997.⁷ A study in Netherlands

showed that futile treatment was the main motive accounting for 76%, while poor quality of life accounted for only 18%.⁵ We have a more balanced ratio of 54% and 46% for futile treatment and quality of life from our study. The quality of life issue usually poses more difficulty to both health care professionals and parents, as quality of life is a subjective notion. What considered as poor quality by some, may be considered as reasonable by others. Hence the decision is not entirely medical, it involves ethical and moral consideration. Hence consensus building and involvement of parents are particularly important when EOL decision is based on quality of life issue.

Concerning the withdrawal of life support, parents should be properly informed of the diagnosis, prognosis, latest medical assessment and possible intervention available. Parent doctor communication should be continuous and conducted in a sensitive and caring manner. One should use language that layperson can understand. Sufficient time should be given for parents to make up their mind. Avoid giving the parents the feeling that EOL decision means abandonment or they carry the burden of decision-making.⁸ When disagreements or conflicts arise among members of the health care team and / or the family, further actions at conciliation should be attempted. These include discussion with other family members and health care workers, obtaining a second opinion from other intensive care expertise and seek decision from institutional ethic committee. As a last resort, when there is a major disagreement among the management team and family, and further conciliation failed, one may consider transferring the patient to an alternative physician. The intensive care measures should continue until further discussion has resulted in consensus on how best to proceed in the interests of the patients. Parental agreement is essential in decision based on 'quality of life' aspect. Parents had been involved in making 79% of decision in Netherlands study⁵ while in our study; our parents had 100% involvement.

Once redirection of care is decided, there is a paradigm shift from preservation of life and cure (saving life) to promoting quality of life and care (saving death). For medical care plan, it shifts from active intervention to physical, psychosocial and spiritual support for the patient and the whole family. For parents and relatives, there is a shift from hope of survival to helping their baby through death.

The process of a newborn dying should be handled with respect and aim at a pain free, dignified, family and staff supported death. Comfort care is important and these include pain management, supplemental oxygen, feeding

Table 5 End of life care program

• Medical decision
- Futility
- Quality of life
• Management team consensus
• Parental communication and counselling
• Parental participation and consensus
• Comfort care
- Pain relief
- Nutritional support
- Skin care
- Minimise invasive monitorings or procedures
• Family support
- Assessment of parental emotional state, religious belief
- Chaplain or medical social worker support if indicated
• Bereavement care
- Private environment as a family room
- Allow siblings and other close relatives to join in
- Encourage skin contact
- Photo and video
- Bereavement kit
- Memory card
- Information on postmortem and handling of dead body
- Follow up counselling

recommendations, dressing changes and skin care, etc. Pain management in neonates tends to be neglected because of the traditional myth that newborn infants do not feel pain because of immature central nervous system and lack of pain memory. The severity of pain was also frequently underestimated. In fact the pain pathways are completely myelinated by 30 to 37 weeks gestation. Even non-myelinated fibres do carry pain stimuli. Recent evidence has established that neonates, including those born prematurely, are capable of manifesting both behavioural and physiologic response to nociceptive stimuli. This has led to wider acceptance that infants should be treated with appropriate analgesia.⁹⁻¹² However, some physicians may still be concerned that opioid analgesia might hasten an infants death by respiratory depression. Partridge and Wall in 1997 studied 121 neonatal deaths upon withdrawal or withholding of treatment, there was no difference in the mean death time between the groups with or without morphine, concluding that death was not hastened by the provision of pain relief. It was recommended that administration of opioid analgesia to prevent unnecessary pain and suffering at the time of life support withdrawal, even with the risk of respiratory depression and hypotension may represent rational and humane care for dying neonates.¹³ In our study, opioid analgesia was administered in 92% (11/12) and 50% (8/16) of patient with withdrawal and withholding of life support respectively. It was administered in 80% (12/15) and 54% (7/13) of patients in the group of futile treatment and quality of life respectively. The differences were probably related to our perception that those infants in the group of futile treatment usually suffered more from both the disease and various modern technologies including invasive monitorings, investigations and treatments before they came to the common pathway of multiorgan failure. While those patients in the group of quality of life usually had conditions associated with substantial neurodevelopmental or physical handicap rather than painful situation. For other medications, there is a need to reverse the effect of muscle relaxants, which do not relieve pain, but may hasten death. Supportive medication including the continuation of inotrope, which stimulates cardiac function, increases blood pressure is inconsistent with the provision of a peaceful and pain free death. Among our 16 patients with inotropic support in the EOL group, eight of them had withdrawal of inotropic support while the rest had reduction or no further escalation of dosage. Nutritional support was continued in most of the infants at end of life care.

Most parents are quite concerned about the duration of

dying process, they should be encouraged to discuss this issue and an honest admission of uncertainty rather than inappropriate estimate of the time is important. McHaffie's study showed that 22% of parents expressed reservations about the length of the dying process, which they reported had taken from 3 to 36 hours.¹⁴ In our study, the median time from withdrawal to death was 2.75 hours (range from 3 minutes to 28 hours). It must be emphasised to the parents that a lingering death is not inevitably associated with pain and suffering for the baby. The team should encourage parents to focus on the details of the compassionate care offer to their babies rather than how long it takes.⁸ A quiet room with home like environment should be provided as it allows privacy and comfort for the whole family. This room should be adjacent to NICU area and is equipped with oxygen and suction.¹⁵ If immediate death is not anticipated, family can have the opportunity to bring the child home and have the baby as a family member until death occurred. The potential benefits and burden of a home death versus a hospital death for an infant and family need to be discussed. For those families who would like to bring their dying infant home, they should be offered adequate psychological and medical preparation. Ongoing support should be available through 24-hour hotline service. Other supports from community nurse, medical social worker and regular home visit are also important. Clear instruction on necessary procedure upon death of infants should be given.¹⁶ We have no case of home death during the studied period. It may be accounted for by low parental and family acceptance of home death in our society.

Concerning postmortem examination, it is an additional stress for parents as most of them are concerned about the possible disfigurement and mutilation to the body of their love one. In these situations, the option of limited postmortem can be discussed with the family. In our study, postmortem examination was requested in 70% of all deaths with a fairly high refusal rate of 36%. However, it is important to emphasise that parents' decision should be respected and it is inappropriate to use the coroner as a means of obtaining a postmortem examination, unless the death occurs in suspicious circumstances and is thought to be caused by accident, violence, or neglect. We had a lower postmortem examination rate (45%) compared with other reported rates of 48% to 79%.^{17,18} It might be explained by the fact that the need for autopsy was not initiated by the medical team in 30% of deaths as the diagnosis for the primary condition and the cause of death had been identified.

Conclusion

Most of our neonatal deaths were preceded by EOL decision based on futility of treatment and quality of life issues. Consensus building within the management team and parental involvement is of utmost importance. EOL decision should be supported by a comprehensive comfort care program including adequate analgesia, provision of social, psychological and bereavement support to family members.

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