ORIGINAL ARTICLE

Decision making and modes of death in a tertiary neonatal unit

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Aims: To study the frequency and reason for withdrawal/withholding of life sustaining treatment (LST) and do not resuscitate (DNR) orders in infants who died in a tertiary neonatal unit.
Methods: Infants who died at Homerton University Hospital between January 1998 and September 2001 were studied by retrospective analysis of patient records.
Results: The case notes of 71 (84%) of 85 infants who died were studied. Mode of death was withdrawal of LST in 28 (40%), DNR in 11 (15%), withholding of LST in two (3%), and natural in 30 (42%) infants. Withdrawal of LST was discussed with the parents of 39 seriously ill infants; 28 (72%) parents agreed. There was no difference in birth weight and gestational age of babies whose parents agreed or refused withdrawal of LST. White and Afro-Caribbean parents and those from the Indian subcontinent (20 of 23) were more likely to agree to withdrawal of LST than Black African or Jewish (eight of 16, p = 0.015) parents. The median age at withdrawal of LST was 4 days (range 1–57). The median duration between discussion and the parents agreeing to withdrawal of LST was 165 minutes (range 30–2160), and median duration between withdrawal of LST and death was 22 minutes (range 5–210). The most common reason for withdrawal of LST was complications of extreme prematurity (68%).
Conclusion: The most common mode of death was withdrawal of LST, and the most common reason was complications of extreme prematurity. The ethnic and cultural background of the parents influenced agreement to withdrawal of LST.

Advances in neonatal medicine have resulted in the survival of babies previously considered non-viable. However, the morality of providing life sustaining treatment (LST) including intensive care in these circumstances has been questioned, as survival may impose considerable burdens of morbidity and neurodevelopmental impairment on babies, carers, and society. All neonatal teams therefore regularly face the need to make decisions to withhold or withdraw LST or to issue do not resuscitate (DNR) orders.

Ethical and legal guidance has been produced by professional (Royal College of Paediatrics and Child health, British Medical Association)[1 2] and regulatory (General Medical Council) bodies.[3] The core guiding principle is the professional's duty to act in the best interest of the patient.[1–3] In neonatal intensive care, this duty is exercised in partnership with parents. The duty to provide clinical benefits needs to be balanced against the duty to prevent harm by prolonging a life that is burdened by unreasonable suffering, or merely postponing death.[4 5] Legally, there is no obligation to provide inhuman, futile, or burdensome treatment.[6]

Despite such guidance and the professional precedent of withholding or withdrawing LST,[7] doubt and controversy remain. The aim of this study was to record the modes of death in a tertiary neonatal unit. In particular, we wished to determine the prevalence of decisions to withhold or withdraw LST or to issue DNR orders, and to examine the process underpinning such decision making.

SUBJECTS AND METHODS

The study was conducted at the Homerton University Hospital, London, which is a tertiary neonatal intensive care unit without onsite facilities for surgery. Medical records of all infants admitted to the unit who died between January 1998 and September 2001 were retrospectively analysed. Data were collected on gestational age, birth weight, sex, ethnicity, and mode and cause of death, together with details of withdrawal/withholding of LST, DNR orders, professionals involved in decision making, and postmortem examination.

The mode of death was classified as follows:

(1) Withdrawal of LST: death attributable to the elective discontinuation of ongoing life support.
(2) Withholding of LST: death attributable to the withholding of treatment necessary for immediate survival after birth including surgical intervention and resuscitation (hand ventilation by bag, endotracheal tube ventilation, external cardiac massage, or administration of adrenaline).
(3) DNR orders: do not initiate any of the procedures outlined in (2) above or further resuscitation in babies already ventilated in the event of clinical deterioration.
(4) Natural: death occurring despite maximal intensive care.

We determined the primary diagnoses contributing to death based on the attending neonatologist's notes, clinical summary, and the death certificate. The primary causes of death were classified as follows:

- Extreme prematurity and complications of prematurity (intracranial haemorrhage, necrotising enterocolitis, sepsis).
- Respiratory failure (severe hypoxaemia or hypercapnoea secondary to conditions such as respiratory distress syndrome, chronic lung disease, meconium aspiration syndrome, pneumonia, and pulmonary hypoplasia).
- Hypoxic ischaemic encephalopathy.
- Congenital and chromosomal anomalies.

Abbreviations: DNR, do not resuscitate; LST, life sustaining treatment

RESULTS

During the 45 month study period, 1807 babies were admitted to the neonatal unit. Eighty five (4.7%) died; the case notes of 71 (84%) of these were available for analysis. The median (range) gestational age, birth weight, and age at death of the study population was 24 weeks (22–41), 685 g (445–3235), and 5 days (1–134) respectively. Table 1 shows details of mode of death. The mode of death was withdrawal or withholding of LST or DNR order in 41(58%) babies.

Withdrawal or withholding of LST and DNR orders

The possibility of withdrawal of LST was discussed with 39 parents of seriously ill children; 28 (72%) agreed to withdrawal. Discussions were held with parents a median of 165 minutes before agreement to withdraw LST was documented (table 2). Discussion with parents of all babies who died as a result of withholding LST (n = 2) and DNR order (n = 11) were documented in the notes. DNR orders were reviewed on a regular basis. White parents, those from the Indian subcontinent, and Afro-Caribbean parents (20 of 23) were more likely to agree to withdrawal of LST than Black African or Jewish (eight of 16, p = 0.015) parents (table 3). Of the 11 sets of parents who refused the option of withdrawal of LST, three (including two Orthodox Jewish families) gave religion as the primary reason. Six of these 11 babies died despite maximal intensive care, but, in five, treatment was limited by means of a DNR order, which was agreed with the parents.

Figure 1 shows the diagnoses associated with the decision to withdraw or withhold LST or issue DNR orders. Decisions to withdraw LST were more often associated with complications of extreme prematurity (19 out of 28; 68%). DNR orders were more often associated with the presence of respiratory failure, congenital anomalies, or hypoxic ischaemic encephalopathy. The two children in whom LST was withheld had congenital anomalies. The gestational age, birth weight, and age at death of the infants whose parents agreed to withdrawal of LST did not differ significantly from those whose parents did not agree. The median age at withdrawal of LST was 4 days. Death followed withdrawal of LST in a median time of 22 minutes (table 2). In all infants in whom LST was withdrawn, ventilatory support was discontinued under opiate analgesia. No babies were receiving muscle relaxants at the time of withdrawal of ventilation.

Professionals involved in decision making

The consultant in charge and other clinical team members involved in the care of the baby (sister in charge, junior doctors, and nurses) were all involved in decision making process. Two or more consultants were involved formally in the decision making process in 18 (44%) of the 41 babies who died subsequent to withdrawal, withholding LST or issue of DNR orders.

Postmortem examination

Postmortem examination was discussed with 37 (52%) of the 71 parents of the babies who died; of these 15 (40.5%) agreed. The median age at death was 2 days (1–30) for babies who had a postmortem examination, which was significantly less than the median age of death 6 days (1–93) for babies of parents who declined (p = 0.04). More parents of babies who died naturally (nine of 16) agreed to postmortem examination than parents of babies who died as result of withdrawal of LST/DNR (six of 21), but the difference was not significant (p = 0.087).

Table 1 Mode of death in 71 newborn babies

Mode of death	Number of infants
Withdrawal of LST	28 (40)
DNR orders	11 (15)
Withholding LST	2 (3)
Natural	30 (42)

Values in parentheses are percentages.
LST, Life sustaining treatment; DNR, do not resuscitate.

Table 2 Withdrawal of life sustaining treatment

Category	Accepted (n = 28)	Refused (n = 11)	p Value
Gestational age (weeks)	24 (22–40)	24 (23–40)	0.57
Birth weight (g)	645 (445–2336)	680 (460–3225)	0.70
Age at death (days)	4 (1–57)	7 (2–134)	0.26
Male/female	17/11	7/4	0.58*
Duration of discussion (min)†	165 (30–2160)	Not applicable	–
Time to death (min)‡	22 (5–210)	Not applicable	–

Values are median (range). p Values were obtained using Student's *t* test except where indicated.
*Fisher's exact test.
†Duration between discussion and parent agreeing to withdrawal.
‡Duration between withdrawal of care and death.

Table 3 Ethnicity and parents agreeing to or refusing withdrawal of life sustaining treatment (n = 39)

Ethnicity	Agreed (n = 28)	Refused (n = 11)
White	13 (87)	2 (13)
Black African	7 (54)	6 (46)
Afro-Caribbean	4 (80)	1 (20)
Jewish	1	2
Indian subcontinent	3	0

Values in parentheses are percentages.

DISCUSSION

Although withdrawing or withholding of LST has been an acknowledged part of neonatal practice for 30 years,[7] there remains much variability in practice both within the United Kingdom and elsewhere. The percentage of newborn babies who died after withdrawal or withholding of LST increased

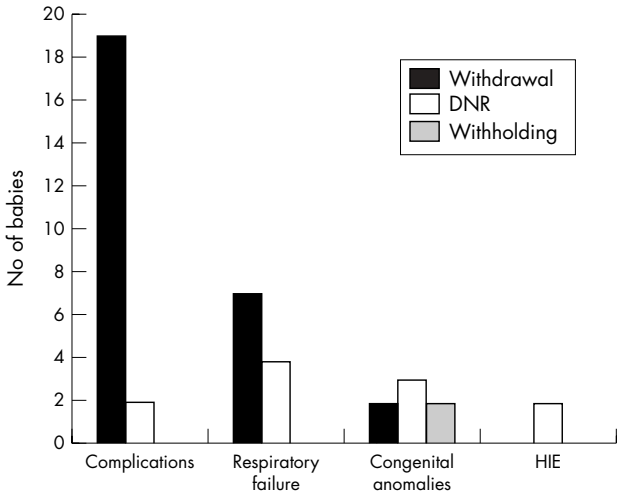

Figure 1 Diagnosis in 41 babies who died after withdrawal or withholding of life sustaining treatment or do not resuscitate (DNR) orders. HIE, Hypoxic ischaemic encephalopathy; complications, complications of extreme prematurity.

Table 4 Post mortem examination

Mode of death	Yes	Refused	Not asked
Withdrawal of LST	4	11	13
DNR	2	4	5
Withholding LST	0	0	2
Natural	9	7	14
Total	15 (21%)	22 (31%)	34 (48%)

LST, Life sustaining treatment; DNR, do not resuscitate.

from 14% to 30% between 1973 and 1986,[7 8] and a more recent study indicated that 65% of deaths in neonatal intensive care units followed withdrawal of LST.[9] One factor in the reported variability of withdrawal of LST is the role of ethnicity and parental religious beliefs.[10] In the present study, 40% of deaths followed withdrawal of LST. Nearly all white parents but only 54% of Black African parents agreed to withdrawal of LST, with religious and personal beliefs being a factor. Similar factors may have contributed to the relatively low rate of DNR orders, which effectively provide for limitation of treatment.

All forms of medical intervention (including initiation and withdrawal of LST) require valid and informed consent.[11] However, parents may not understand, assimilate, use, or reflect on information they have been given, especially in circumstances involving the serious illness of their baby.[12] In this study, the reported interval between discussion of withdrawal of LST and its initiation may have been insufficient for this purpose. The median age at withdrawal of LST in this series was broadly comparable to that reported in a study where the overall time for decision making was felt to have been adequate.[13] End of life decision making may produce conflicts within teams, between parents, and between parents and the team, which may occasionally require legal resolution. Discussion between the neonatal consultant and the parents, the wider family, and any counsellor or advocate they might choose is mandatory to reduce conflict.[14] No cases in this study required independent resolution.

In earlier studies, the major causes for withdrawal of LST were cited as major congenital anomalies[7 8] or hypoxic ischaemic encephalopathy.[8] Congenital anomalies leading to withholding of LST were found in only two babies in the current series and may reflect changes produced by more effective antenatal diagnosis and intervention. In contrast, in this as in other more recent studies,[9 14] the most common reason for withdrawal of LST was complications associated with extreme prematurity.

During withdrawal of LST, every effort must be made to relieve pain and distress by the appropriate use of sedatives or analgesics.[15–18] In our unit, sedation by opiate infusion is routine during mechanical ventilation, and this was maintained in all cases during withdrawal of ventilation. It is also our practice to withdraw antibiotics, total parenteral nutrition, and oxygen therapy, and to discontinue monitoring. However, the basic requirement of fluid and enteral feeds are continued. The issue as to whether the effect of muscle relaxants should be allowed to wear off before discontinuing ventilation is controversial.[19] It would be our usual practice to allow the effect of muscle relaxants to wear off before discontinuing ventilation, but no baby in this series was receiving muscle relaxants at the time of ventilation withdrawal. In exceptional circumstances, if the baby improves after the decision to withdraw LST, the case must be discussed with parents and all the professionals involved while intensive care is continued.

Despite the importance of the autopsy in establishing a final diagnosis and providing genetic advice,[20 21] there has been a worldwide decline in the neonatal autopsy rate.[22 23] The low rate of autopsy in this study may also be due to failure to ask (only 52% had a documented discussion). In this series, more parents of babies who died during active treatment consented to autopsy than in the withdrawal of LST/DNR group.

Active withdrawal of LST was a common mode of death in our medical tertiary neonatal unit, the most common reason being complications of extreme prematurity. However, considerable differences exist between neonatal intensive care units in the prevalence of decisions on withdrawal of LST. Although ethnicity, cultural backgrounds, and religious beliefs of parents are an acknowledged cause of variability, staff factors and local practice cannot be ignored. Large scale multicentre studies including units that provide surgical care will be necessary to analyse these factors further and to explore outcomes for babies whose parents refuse DNR order or withholding or withdrawal of LST.

Key points

- A common mode of death in a tertiary neonatal unit is active withdrawal of LST.
- A common reason for withdrawal of LST is complications of prematurity.
- Religion and culture influence whether parents agree to withdrawal of LST.

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IMAGES IN NEONATAL MEDICINE

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Palpebral ecchymosis and cerebral venous thrombosis in a near term infant

Cerebral venous thrombosis (CVT) is rarely diagnosed in newborn babies.[1] Seizures, haemorrhagic venous infarcts, and, in particular, intraventricular haemorrhage are the most common signs of CVT in term newborns.[2] Little is known about the neuroradiological and clinical presenting findings of CVT in preterm babies.

We observed bilateral palpebral ecchymosis in a 35 week gestation preterm baby (fig 1A) with major bleeding in the posterior fossa on an ultrasound brain scan (first day of life). Computed tomography imaging on the second day confirmed the haemorrhage and showed an unexpected venous thrombosis (''empty delta sign'', a triangle of decreased density caused by the contrast enhanced blood flowing around the clot) of the torcular Herophili (fig 1B). The haematoma was surgically drained and an intraventricular reservoir was inserted to treat the acute obstructive hydrocephalus.

Factor V Leiden, Factor II, and MTHFR mutations were negative; motor and cognitive impairments were observed at 1 year of age.

The association between palpebral ecchymosis and CVT is intriguing, as palpebral veins empty, throughout the ophthalmic vein, into the sinus cavernous and thereafter into the transverse sinus. A clot in the major cerebral veins is likely to cause increased venous pressure predisposing to major or minor bleeding similarly to those affecting palpebrae.

Spontaneous palpebral ecchymosis is an extremely rare finding which can be associated with CVT, as recently observed in an adult patient.[3]

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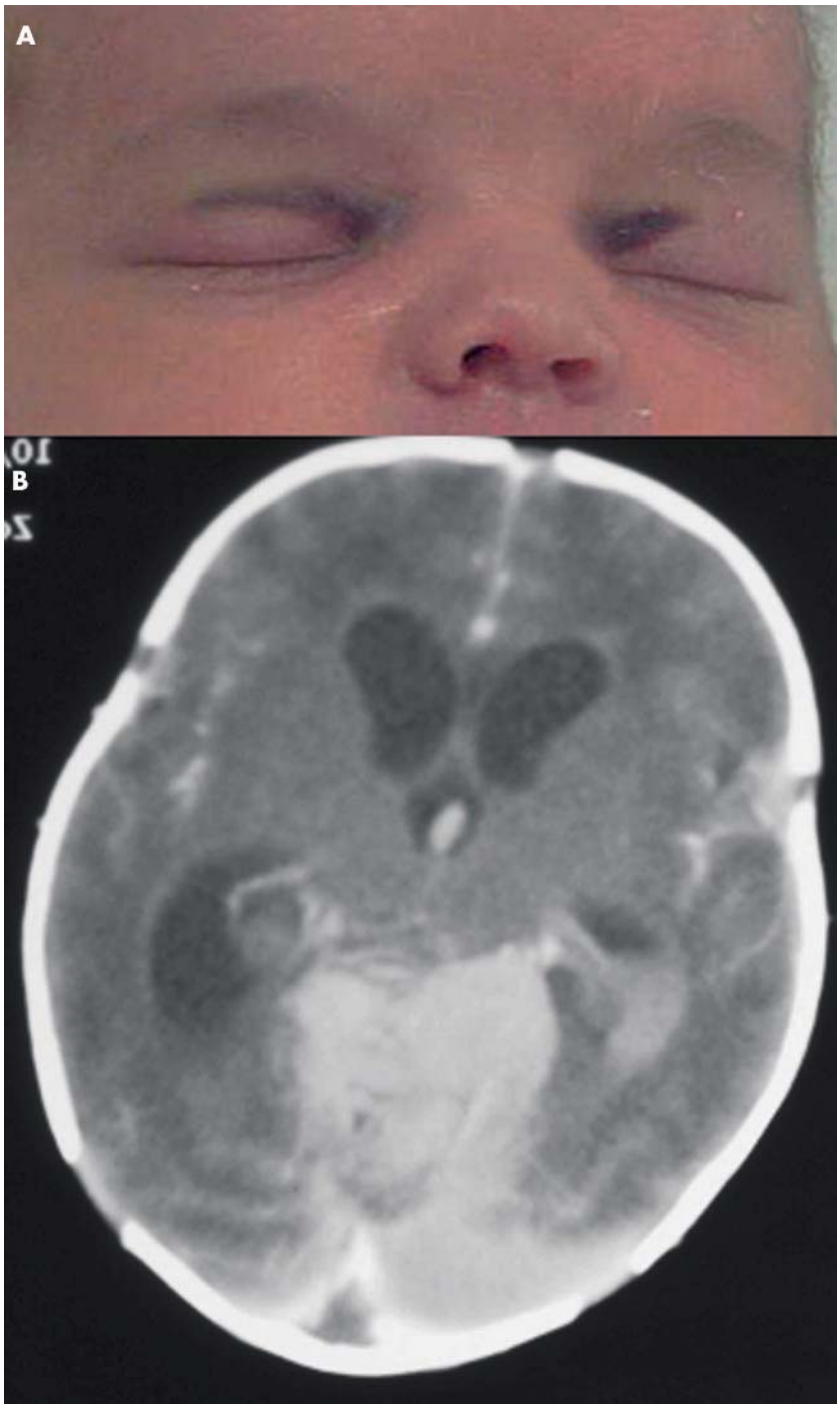

Figure 1 (A) Bilateral palpebral ecchymosis. (B) Computed tomography scan showing venous thrombosis (''empty delta sign'' of torcular Herophili), posterior fossa bleeding, and ventriculomegaly.

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