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End-of-life decisions in delivery room and neonatal intensive care unit

ROMAINE ARLETTAZ, DIETO MIETH, HANS-ULRICH BUCHER, GABRIEL DUC & JEAN-CLAUDE FAUCHÈRE

Clinic of Neonatology, University Hospital, Zurich, Switzerland

Abstract

Background: The increase in neonatal survival in recent decades has been followed by an increase in later disabilities. This has given rise to many new ethical issues. In different countries, efforts are being made to define ethical guidelines regarding withholding or withdrawing intensive care and end-of-life decisions in critically ill newborn infants. These guidelines have to be differentiated from ethical decision-making models which structure the process of decision making for an individual child. Such a framework has been in existence in our clinic for 10 years. *Aim:* The aims of this study were to evaluate how end-of-life decisions are taken in our perinatal centre and to analyse whether these decisions are consistent with our framework for structured ethical decision making. *Methods:* 199 consecutive neonatal deaths over 5 y were evaluated. *Results:* In 157 cases (79%), end-of-life decisions were taken according to our ethical framework; in the remaining 42 cases (21%), the baby died before this could be done. In 92% of cases, parents were involved in the decision and, in all cases but one, agreed with the decision. A patient's life was never intentionally and actively terminated.

Conclusion: In contrast to earlier years, in-hospital death in our clinic is nowadays usually preceded by structured and documented medical end-of-life decisions.

Key Words: *End-of-life decisions, ethics, gestational age, intensive care, neonatal*

Introduction

Continuous and rapid progress in neonatal medicine in recent decades has led to an increase in neonatal survival, particularly in very preterm infants. At the same time, concern about morbidity and unfavourable long-term outcomes in some of these patients is being raised, and physicians are increasingly faced with ethical issues.

In 1976, the Swiss Academy of Medical Sciences published the first guidelines, which have since been revised twice, regarding withdrawal of intensive care in babies with severe malformations or severe asphyxia [1–3]. This step was very important, not only because it was the first set of guidelines regarding end-of-life decisions for newborns in Europe, but also because it reflected Swiss neonatologists' concern about ethical aspects in neonatal medicine. Regarding the management of extremely preterm infants below 26 wk of gestation, the Swiss Society of Neonatology published guidelines in 2002 [4].

Many countries or centres are currently developing guidelines for the treatment of extremely preterm infants. However, the publications of the EURONIC group [5–10] have emphasized the large variations in neonatal ethical issues between up to 11 European countries. Lantos et al. [11] and Lorenz [12] demonstrated similar differences in Canada and the USA. In Europe, the Netherlands took a pioneering role in this subject, with the Dutch Society of Paediatrics publishing its guidelines in 1992 [13], with further publications relating to them published since then [14–18].

In our perinatal centre in Zurich, a group formed in 1994, composed of three neonatologists, three neonatology nurses, an ethicist and a clergywoman, created a framework for ethical decision making in neonatal intensive care [19,20]. In a structured and documented process, the team members caring for the baby have to find the best solution on which all of them agree. The discussion is conducted by a leader who is not involved in the patient's care and has special training for

Correspondence: Romaine Arlettaz, Clinic of Neonatology, University Hospital, Frauenklinikstrasse 10, CH-8091 Zurich, Switzerland. Tel: +41 1 255 35 82. Fax: +41 1 255 44 32. E-mail: romaine.arlettaz@usz.ch

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moderating the ethical discussion. These formal decision meetings are attended by the baby's caretakers (physicians and nurses), and sometimes by specialists of other disciplines (ethicists, obstetricians, theologians), and are organized in the following three situations: (1) extremely preterm infants below 26 wk, (2) newborns with severe malformations, (3) newborns with a poor neurological prognosis. Each team member, as well as the parents, is able to call for a meeting. After the meeting, the parents are fully informed about the treating team's proposal, having the possibility to veto it if they cannot agree. If no consensus can be reached, the baby continues to be treated until the next meeting 12 or 24 h later. Further description of the framework used for the purpose of the study is presented in a separate publication [19,20, and Baumann-Hölzle et al.].

To study the impact of this new framework, which has been in place since 1996 at our clinic, we decided to apply the classification of the Dutch Society of Paediatrics and to study prospectively how end-of-life decisions are taken.

Aims of the study

The aims of the present study were: (1) to evaluate prospectively how end-of-life decisions are taken in our perinatal centre, including in the delivery room; (2) to see if these decisions are consistent with our framework for structured ethical decision-making; and (3) to compare our results with the Dutch publications [14,15].

Methods

All consecutive neonatal deaths at the same perinatal centre were analysed over 5 y. We considered as eligible all babies with a gestational age (GA) $\geqslant 24\ ^{0}/_{7}$ wk of gestation that died before discharge from hospital. Babies who died in the delivery room were also analysed. Stillbirths were excluded.

For each baby, a form (short-form questionnaire consisting of 14 questions) was filled out by the senior registrar or the consultant in charge at the time the baby died.

The newborns were classified into six groups according to the report "Doen of Laten" [13,14,16]: category 1—cases in which intensive treatment was judged to be warranted and was continued until death; category 2—cases in which intensive treatment was withheld because the patient was judged unable to survive; category 3—cases in which intensive treatment was withheld because the patient's prognosis was judged to be very poor; category 4—cases in which intensive treatment was withdrawn because the patient was judged unable to survive; category 5—cases in which intensive treatment was withdrawn because the patient's prognosis was judged to be very poor; category 6—cases in which intentional and active termination of the patient's life was involved.

Furthermore, we analysed the setting in which the end-of-life decision took place, and whether this was compatible with our ethical framework.

Table I. Characteristics of the 199 infants and clinical situations responsible for the decision to withhold or withdraw intensive care.

Median gestational age (wk)	26	(range 24 to 42)
Proportion of infants <26 wk	42% (84)	
Median birthweight (g)	850	(range 380 to 4300)
Proportion of infants <1000 g	63% (126)	
Proportion of singletons	80% (160)	
	n (199)	%
Time of death		
first day of life	132	66
first week of life	182	91
within 28 d	195	98
Clinical situations responsible for the decision to withdraw or withhold intensive care		
extreme prematurity <26 wk	63	32
birthweight <500 g	12	6
respiratory disease of any cause[a]	52	26
severe malformations[b]	27	14
hypoxic-ischaemic encephalopathy	15	8
other brain lesions[c]	16	8
septicemia	9	4
necrotising enterocolitis	5	2
total	199	100

[a] Including surfactant deficiency, meconium aspiration syndrome, pulmonary hypoplasia, lung malformations and hydrops.
[b] Including chromosomal abnormalities, brain malformations, thoracic malformations, untreatable heart diseases and unclear dysmorphic syndromes.
[c] Including severe intracranial haemorrhage, ischaemic lesions and brain tumour.

Results

Between 1 January 1997 and 31 December 2001, 9817 live-born infants were delivered at our perinatal centre. Of these, 3093 newborns were hospitalized in the neonatal unit. One hundred and ninety-nine newborns $\geqslant 24\ ^{0}/_{7\ \mathrm{wk}}$ died, either in the delivery room or in the neonatal unit. The neonatal mortality was 2%.

The characteristics of the 199 babies studied and the causes of death, or reasons to withhold or withdraw intensive care, are shown in Table I.

Eighty-two babies (41%) died in the delivery room in the following three situations: (1) when the decision not to resuscitate the baby was taken antenatally (68 newborns); (2) when the decision was taken in the delivery room to withdraw intensive care treatment (five newborns); and (3) when neonatal resuscitation was unsuccessful (nine newborns). In the 68 cases

discussed antenatally, the obstetricians were involved in the decision.

The classification of the infants into the six categories mentioned above gave the following results:

Category 1

For 16 newborns (8%), intensive care treatment was continued until death. Eleven infants had severe respiratory distress. The remaining five died of necrotizing enterocolitis (3), septicaemia (1) and severe asphyxia with unsuccessful resuscitation (1). All infants deteriorated very quickly, and there was no time available for an ethical discussion.

Category 2

In 42 cases (21%), the decision not to start intensive treatment was taken because the patient was judged unable to survive. Two-thirds of them (26/42) were extremely preterm infants below 26 wk of gestation, or preterm infants with severe growth retardation and an estimated birthweight below 500 g. In all of these cases, treatment consisted of compassionate care, with all infants staying with their parents in the delivery room until death. The remaining one-third (16/42) were babies with severe malformations considered incompatible with life. The most frequent malformations, mostly diagnosed antenatally, were chromosomal anomalies (of which trisomy 18 was the most frequent), severe congenital heart diseases and brain malformations (anencephaly, holoprosencephaly). Four infants had multiple malformations. The majority of these infants died in the first 2 d of life, but one infant with Cornelia de Lange syndrome and pulmonary atresia lived for 7 wk and was treated in the neonatal unit. There was a termination of pregnancy in a 24-wk boy with a complex congenital heart disease; neonatologists were not involved in the decision to terminate the pregnancy, and were not present at birth. This live-born baby could be considered as belonging to category 6. However, "intentional and active termination of the patient's life" occurred prior to birth.

Category 3

In 66 cases (33%), the decision not to start intensive treatment was taken because the long-term prognosis was judged to be very poor. The neonatologists filling in the forms put 15 infants both in category 2 and 3, because they considered the chance of survival, but also the prognosis, extremely poor, which can be the case, for example, for a preterm infant born at 24 wk of gestation. Except for two, all newborns in this category were preterm infants below 26 wk of gestation, sometimes associated with severe growth retardation and microcephaly. They all died in the delivery room.

Category 4

In 63 cases (32%), intensive care treatment was withdrawn because the patient was considered to have no chance of survival. These infants had severe respiratory distress (38), lethal malformations (10), septicaemia with shock (7), necrotizing enterocolitis with multiorgan failure (2) or severe hypoxic-ischaemic encephalopathy (6). Nine of these 63 infants died in the delivery room; the remaining 54 newborns died in the neonatal intensive care unit (NICU).

Category 5

For 42 newborns (21%), the decision to withdraw intensive care treatment was taken because the long-term prognosis was considered to be very poor. The vast majority of infants had brain lesions diagnosed on ultrasound scan or on MRI, consisting of intraparenchymal haemorrhage, severe ischaemic lesions or encephalopathy caused by perinatal asphyxia. Again, neonatologists filling in the forms put eight newborns both in category 4 and 5. One example is a baby born at 28 wk of gestation, who developed necrotizing enterocolitis with circulatory collapse, respiratory insufficiency, extended bowel necrosis and severe intracranial haemorrhage. This infant was considered to have a very poor chance of survival but also a very poor prognosis, if he survived.

Category 6

A patient's life was never intentionally and actively terminated (except the termination of pregnancy). When an end-of-life decision was taken in babies under mechanical ventilation, they were given a dose of an opiate in a therapeutic dose prior to extubation. For the non-ventilated babies, opiates were given in a therapeutic dose if they showed signs of pain or distress. A total of 88 newborns (44%) were given opiates: 4/82 babies who died in the delivery room and 84/117 babies who died at the NICU.

In all 183 decisions of withholding or withdrawing intensive care, the baby died.

The end-of-life decision was taken by the caretakers after a regular team meeting in 73 cases (37%), and after an emergency meeting in a further 84 cases (42%). Thus, a total of 157 cases (79% of the total) were discussed according to our framework within the treating team, and a consensus about end-of-life decision was reached. In 21% of newborns, the decision was taken by the physician in charge. Babies who died in the delivery room had significantly fewer ethical meetings than those who died at the NICU (Figure 1).

The number of regular ethical meetings ranged from one to five per infant, but in the majority of cases, only one meeting was performed. Usually, there was a common need from nurses and doctors to discuss the

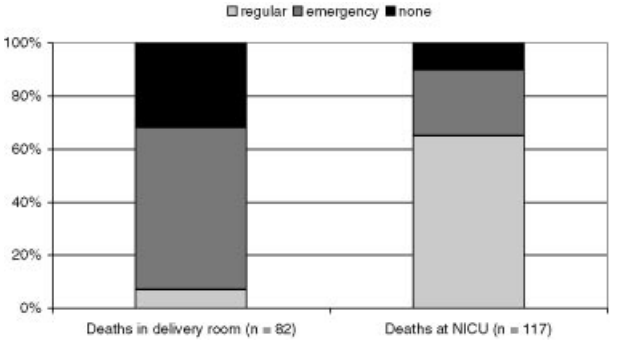

Figure 1. Percentage of regular or emergency ethical decision performed.

patient's situation. Nurses and physicians were always present at the meeting; ethicists and clergymen sometimes attended the meeting as well.

Forty-two newborns (21%) died without the formal ethical meeting taking place. Seventy-six per cent of them (32) died shortly after birth in the delivery room. In all cases, it was mentioned that the "need for an ethical meeting was not met because the decision was obvious (27 cases), or because of lack of time (four cases)". One additional case was a termination of pregnancy: the neonatologists were not involved in the decision and were not present at birth.

Involvement of the parents occurred in 173 cases; 157 of them after the formal ethical discussion, and 16 without it. One hundred and fifty-nine parents were actively involved in the decision (92%). They were given full information about the condition of the baby, the prognosis, the different therapeutic possibilities and the approach that the treating team would take. Fourteen parents (8%) could not be fully informed, either because of language problems (13) or because of lack of time in an emergency C-section (1).

Except for one case, the parents agreed with the decision proposed by the treating team. In the situation in which the parents did not agree, the baby was a full-term neonate with very severe hypoxic-ischaemic encephalopathy. The parents wanted to gather their relatives from abroad, which would have taken a further 2 to 3 days. The treating team refused in the interest of the baby, which was extubated and died in his parents' arms. In a discussion with the parents a few days after death, they showed understanding and accepted our decision.

In all but nine cases, the babies died in the arms of their parents. Seven of the nine remaining newborns died in the delivery room when the mother was still in the operation room, and two babies were triplets whose parents did not wish to be present when intensive care treatment was withdrawn. These two triplets died in the nurse's arms.

It is a routine in our unit to arrange an appointment with the parents 3 mo after a patient's death. This discussion occurred in 64% (127/199) of cases.

Discussion

In the present study, placement of the babies into the six categories described above demonstrated that only 8% of newborns had intensive treatment until death. In all cases, deterioration was so sudden that end-of-life discussion was not possible. The remaining newborns showed an equal placement between categories 2+3 and categories 4+5. The percentage of babies in categories 2+3 and 4+5 is very high and has to be related to the GA in our newborn population: the median GA was 26 wk, and 63% of newborns had a GA below 28 wk. Our clinic has a restrictive approach regarding intensive care treatment in preterm infants at the threshold of viability, and also in babies with a birthweight below 500 g.

In both "withholding intensive care treatment" groups (2 and 3) and "withdrawing intensive care treatment" groups (4 and 5), a very poor prognosis was at least as important as the inability to survive. This clearly shows that the outcome played an equally or even more important role than survival. The decision not to start life-sustaining treatment in an extremely premature infant was generally taken not on the basis of the very low probability of survival, but on the basis of the very low probability of survival without severe handicap. This ethical approach differs from results published elsewhere [5,6,8,11,21].

In the decision-making process, the prognosis, the expected outcome of treatment in terms of quality of life, and the burden placed on the patient by the treatment (pain, discomfort and physical limitation) play an equal role. When life support measures are withdrawn (categories 4 and 5), everything should be done to allow the infant to die peacefully (comfort care). If necessary, opiates can be used for adequate pain control at doses that might have a life-shortening effect [22,23]. In contrast, the use of drugs with the primary intention to end the patient's life (category 6) is against Swiss law and not consistent with the ethical position in this country.

Comparison with the Dutch studies of de Leeuw et al. [14] and Kleine et al. [15] is shown in Table II.

Table II. Comparison between the Swiss study and both Dutch studies. Thirty babies (15%) were allocated to two different categories.

	Kleine et al. 1993 (n=185)		De Leeuw et al. 1996 (n=181)		Arlettaz et al. 2003 (n=199)	
	n	%	n	%	n	%
Category 1	74	40	35	19	16	8
Category 2	17	9	10	5	42	21
Category 3	–	–	5	3	66	33
Category 4	58	31	88	49	63	32
Category 5	35	19	43	24	42	21
Category 6	1	1	–	–	–	–

Table III. Comparison between the newborn population in the Swiss and the Dutch study.

	De Leeuw et al. 1996 ($n=181$)		Arlettaz et al. 2003 ($n=199$)	
	n	%	*n*	%
Gestational age (wk)				
<28	36	19.9	125	62.8
28–31	53	29.3	29	14.6
32–36	30	16.6	24	12.1
>36	62	34.3	21	10.5
Birthweight (g)				
<1000	49	27.1	126	63.3
1000–1499	40	22.1	26	13.1
1500–2499	38	21.0	22	11.1
>2499	54	29.8	25	12.5

There are two major differences. First, the percentage of babies treated until death was 40% in the first Dutch study [15], 19% in the second one [14] and 8% in our study. This demonstrates, in the second Dutch study and in the Swiss study, a commitment towards the need for discussing withholding or withdrawal of intensive care and preparing the parents. The second major difference concerns the percentage of babies in categories 2 and 3: this percentage is much higher in our study than in both Dutch studies. To explain this difference, we must consider the differences in the newborn populations (see Table III). In our study, there were three times more preterm infants <28 wk of gestation than in the study of de Leeuw et al. (63% vs 19.9%) [14]. A limitation in the comparison between our study and those of de Leeuw and Kleine [14,15] is the fact that we allocated 30 babies to two different categories and therefore counted twice, which is not completely correct. Further, our study also took into consideration babies who died in the delivery room, which is not the case for the paper of de Leeuw et al.

Very few studies have analysed end-of-life decisions in the delivery room. In the publication of McHaffie et al. [24], the subject of withdrawal of intensive care was mentioned antenatally or during labour in only 6/59 cases (10%). In the present study, 82 babies (41%) died in the delivery room and were included in the analysis, which is rarely the case in publications about end-of-life decisions. Of the 42 newborns that had no ethical discussion, the majority of them were very immature infants who died in the delivery room.

Why are ethical decisions about unborn babies so difficult to take? There are several possible reasons. The emotional burden for a mother about to deliver a baby with a poor chance of normal life is very high and makes giving information to the parents particularly delicate. Further, it is difficult to give prenatally precise information about the survival chances and the neurological outcome of a baby. Finally, the mother is an "obstetrical patient" and decision making requires adequate team work between neonatologists, obstetricians and midwives.

In the last decade, the literature has unanimously emphasized the importance of the parents' involvement in the decision-making process [11,14,16,21,24–29]. In our study, this was shown to be the case in 92% of infants. In the literature, Cuttini et al. [5] demonstrated large variations across eight European countries regarding parental role. McHaffie et al. [24] insisted that, contrary to doctors' fears, parents trust caretakers and are willing to be involved in the decision-taking process. They demonstrated that most NICU doctors and nurses believe that parents should be involved in the decision, but only a minority of 3 to 6% felt that the parents should take responsibility for the decision [24]. Many authors emphasize that, if possible, sufficient time should be given to the parents before a decision is taken, and also afterwards, to let them bid farewell to their baby [14,21,24]. However, too slow a farewell might prolong the suffering of the baby and draw out its death [21,24,29,30]; it should therefore be avoided in the interest of the baby.

Follow-up discussion with the parents a few months after a baby's death is useful, in order to see how they are coping with bereavement, and also because some questions regarding the baby's treatment, the end-of-life decision and the autopsy findings have to be discussed. Although a follow-up meeting with the parents is routine in our unit, it occurred in only two-thirds of cases—usually for babies who were hospitalized at the NICU. Some parents did not want a meeting, some could not be traced and some were not contacted. These were usually parents who lost their baby very soon after birth and did not have intensive contact with the neonatologists. However, the pain of losing a baby, even if he or she died shortly after birth, should never be underestimated.

Conclusion

In our perinatal centre, end-of-life decisions were structured and documented medical decisions in accordance with our ethical framework in 80% of cases. The remaining 20% demonstrates that more effort is needed, particularly in the prenatal and the immediate postnatal period. Parents were involved in 92% of decisions, which is good considering language barriers and emergency situations. In all cases but one, the parents agreed with the team's decision. In no case was a patient's life terminated actively after birth. Further, the withholding of intensive care seems to be more common in our babies compared with the Dutch studies. This is partly explained by the differences between both newborn populations—our newborns being much more premature—and partly by the more restrictive therapeutic approach of our clinic.

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