ARTICLE

End-of-Life Decisions in Dutch Neonatal Intensive Care Units

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Objective: To clarify the practice of end-of-life decision making in severely ill newborns.

Design: Retrospective descriptive study with face-to-face interviews.

Setting: The 10 neonatal intensive care units in the Netherlands from October 2005 to September 2006.

Patients: All 367 newborn infants who died in the first 2 months of life in Dutch neonatal intensive care units. Adequate documentation was available in 359 deaths.

Outcome Measures: Presence of end-of-life decisions, classification of deaths in 3 groups, and physicians' considerations leading to end-of-life decisions.

Results: An end-of-life decision preceded death in 95% of cases, and in 5% treatment was continued until death. Of all of the deaths, 58% were classified as having no chance of survival and 42% were stabilized newborns with poor prognoses. Withdrawal of life-sustaining therapy was the main mode of death in both groups. One case of deliberate ending of life was found. In 92% of newborns with poor prognoses, end-of-life decisions were based on patients' future quality of life and mainly concerned future suffering. Considerations regarding the infant's present state were made in 44% of infants.

Conclusions: Virtually all deaths in Dutch neonatal intensive care units are preceded by the decision to withdraw life-sustaining treatment and many decisions are based on future quality of life. The decision to deliberately end the life of a newborn may occur less frequently than was previously assumed.

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THE INCREASING ABILITY TO save and extend the lives of newborns with technology have created discussions about the role of physicians in making decisions regarding the timing and modes of death and dying of newborns. End-of-life decisions are those made by physicians that result or probably result in causing or hastening death.

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They include the decision to withhold or withdraw life-sustaining treatment and the decision to deliberately end a newborn's life with lethal drugs. The deaths of many newborns are often preceded by an end-of-life decision.[1-6] Most studies describing end-of-life practices do not make the important distinction between withholding or withdrawing treatment in situations in which death is imminent or the newborn is moribund and the situation in which this takes place in stabilized newborns for quality-of-life reasons. Only a few studies have reported details about what the physicians' considerations leading to end-of-life decisions are and how they are used. Moreover, only a very small number of publications from the Netherlands and Flanders have reported some details about the considerations that lead to the decision to deliberately end a newborn's life.[4,7,8] As a consequence, real insight in medical end-of-life practice has remained limited. Also, comparing outcomes between units is difficult. For example, a higher survival rate, and possibly a higher disability rate, may be seen if most extremely premature babies are aggressively resuscitated and withdrawal of care is less frequently offered in a particular unit.[9] With the purpose of clarifying end-of-life practice in severely ill newborns in the Netherlands, we performed a nationwide retrospective study to determine when and how physicians make end-of-life decisions.

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Table 1. Characteristics of 359 Newborns Who Died Before 2 Months in 10 Dutch NICUs During 12 Months

Characteristic	Deaths, No. (%)
Gestational age, wk	
<30	123 (34)
31-36	92 (26)
≥37	144 (40)
Birth weight, g[a]	
<500	5 (1)
500-1000	84 (23)
1000-1500	50 (14)
1500-2500	66 (18)
≥2500	154 (43)
Sex	
M	210 (58)
F	149 (42)
Age at death, d	
Early neonatal death, <7	215 (60)
Late neonatal death, 7-27	107 (30)
Postneonatal death, >27	37 (10)

Abbreviation: NICU, neonatal intensive care unit.
[a] Birth weight–specific neonatal mortality rate for the Netherlands during the study period: less than 500 g, 91%; 500 to 1000 g, 38%; 1000 to 1500 g, 4.9%; 1500 to 2500 g, 0.96%; and 2500 g or greater, 0.04%.[15] Data on birth weight were missing in 2 cases.

METHODS

We performed a retrospective descriptive study of Dutch end-of-life practices in severely ill newborns. Clinical care for these newborns is centralized in 10 level III neonatal intensive care units (NICUs). In the Netherlands, physicians are considered to be ultimately responsible for end-of-life decisions.

NEWBORN AND STUDY CHARACTERISTICS

We reviewed the files of 367 newborns who died in the first 2 months of life in 10 NICUs in the Netherlands from October 2005 to September 2006 according to the Dutch perinatal registry. Infants who died immediately after birth in the delivery room were not included. The patients were eligible for the study when a medical file was available for review. We found 359 deaths with complete documentation and extracted information from the medical files on birth weight, gestational age, day of death, and diagnoses (using both clinical data and autopsy materials when available). We examined the attending physicians' daily notes and death summaries to determine whether or not death had occurred with a preceding end-of-life decision. We defined end-of-life decisions as medical decisions with the effect or the probable effect of hastening death. They included decisions to withhold or withdraw life-sustaining treatment and to deliberately end the life of a newborn. Deliberate ending of a life was defined as administering lethal drugs to end or shorten the life of a newborn. With respect to deliberate ending of life, we focused on newborn infants who were physiologically stable to facilitate comparison with our earlier reports.[8,10]

CLASSIFICATION OF DEATHS

We used the physicians' motives for withholding or withdrawing life-sustaining treatment as documented in the files to categorize the newborns as group I, II, or III in accordance with a 2-dimensional classification from the literature.[11,12] One researcher (B.E.) reviewed all files to ensure consistency of classification. The classification is based on the infant's prognosis and dependency on intensive care for physiologic stability. Group I encompasses physiologically unstable infants whose death is imminent. Newborns who are actually dying (heart rate falling, blood pressure dropping, and oxygen saturation dropping) are included as are those with inoperable life-threatening congenital defects or with diseases that the medical team considers untreatable. Group II consists of physiologically stabilized intensive care–dependent newborns with very poor prognoses. Newborns in this group have a theoretical chance of survival, but the predicted quality of life is very poor. Many newborn infants with severe hypoxic ischemic encephalopathy are included in this group together with newborns with chromosomal or neurological disease and extreme premature infants with grade IV intracranial bleedings with clinical symptoms. Group III encompasses stable newborns with very poor prognoses and severe suffering who were not dependent on intensive care.

First, we identified the patients belonging to group I. Next, we held interviews with the attending physicians of all newborns who did not clearly fall into group I to categorize them as belonging to group I, II, or III. Finally, we used a semistructured interview containing both closed- and open-ended questions to cross-check the assigned category and to ascertain the physicians' considerations that led to each prognoses-based end-of-life decision. We asked the physicians to describe the end-of-life decision-making process and to pay special attention to the considerations used for the decision. The considerations were grouped into categories derived from the literature post hoc[13,14] and cross-checked again for accuracy with the physician. We requested the physicians to consult the infants' medical files during the interviews. An experienced pediatrician (A.A.E.V.) interviewed the physicians, with 1 interview covering multiple infants. The interviews lasted between 30 and 45 minutes per patient and they were recorded and analyzed separately by 2 researchers (A.A.E.V. and B.E.). A subset of interviews took place in the presence of a qualified legal scholar (J.H.H.M.D.). In these, the physicians were asked whether or not their motives for an end-of life decision were related to legal considerations and if so, to which. We will separately report on the outcomes of this part of the interviews as well as about which treatments were withdrawn and the use of medication as a part of end-of-life decisions.

We assured the physicians that the interview would be held anonymously. The interval between the end-of-life decision and the interview was 3 to 14 months. The study design complied with Dutch legislation on medical file research.

STATISTICAL ANALYSIS

We compared the causes of death by using the χ^2 test for categorical variables. $P < .05$ was considered statistically significant.

RESULTS

Of the 367 newborns who died during the 12-month study period in the Dutch NICUs, complete documentation was available for 359 deaths (98%). The main demographic data and patient characteristics are presented in **Table 1**. The main causes of death in full-term patients were asphyxia (47%) and congenital malformations (37%) (**Table 2**). The most common cause of death in infants younger than 30 weeks of gestational age was multi-organ failure after sepsis/necrotizing enterocolitis (34%), followed by complications of extreme prematurity (31%). The distribution of causes of death was similar in all 10 units.

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Table 2. Cause of Death by Gestational Age in Newborns Younger Than 2 Months

Cause of Death[a]	No. of Primary Organ Dysfunctions: Brain	Heart/Circulation	Lungs	MOF	Total, No. (%)
		<30 wk (n=123)[b]			
Asphyxia	1	0	0	9	10 (8)
Congenital anomalies	0	1	4	3	8 (7)
Sepsis/necrotizing enterocolitis	1	2	2	37	42 (34)
Extreme prematurity[c]	1	0	5	32	38 (31)
Respiratory insufficiency	0	0	11	4	15 (12)
Intracranial bleeding	4	0	0	6	10 (8)
		31-36 wk (n=92)[d]			
Asphyxia	7	1	2	10	20 (22)
Congenital anomalies	1	6	7	20	34 (37)
Sepsis/necrotizing enterocolitis	1	3	1	16	21 (23)
Respiratory insufficiency	0	0	11	1	12 (13)
Intracranial bleeding	0	2	0	3	5 (5)
		≥37 wk (n=144)[e]			
Asphyxia	33	2	1	32	68 (47)
Congenital anomalies	4	30	5	14	53 (37)
Sepsis/necrotizing enterocolitis	0	0	0	13	13 (9)
Respiratory insufficiency	1	0	5	1	7 (5)
Intracranial bleeding	3	0	0	0	3 (2)

Abbreviation: MOF, multi-organ failure (if dysfunction of 2 or more organs led to death).
[a] Mortality rate: (number of deaths/number of newborns admitted to the neonatal intensive care unit) × 100.[15]
[b] Mortality rate of 15%.
[c] Gestational age younger than 27 weeks.
[d] Mortality rate of 5%.
[e] Mortality rate of 10%.

Of 359 deaths, 340 (95%) were preceded by an end-of-life decision and 19 (5%) of the infants died while receiving cardiopulmonary resuscitation. Eighty-eight percent of end-of-life decisions included withdrawal of treatment, often combined with some form of withholding of treatment, while 12% included only the decision to withhold treatment.

A total number of 208 of 359 deaths (58%) were classified as having no chance of survival (group I) and 150 (42%) as having poor prognoses (group II) (**Figure**). There was no difference in the percentage between patients in groups I and II between the 10 centers. One newborn with type II osteogenesis imperfecta was classified as not being intensive care dependent but as having a poor prognosis and severe suffering (group III). The attending physician intentionally increased the morphine dose until death occurred after it became evident that the patient's intolerable suffering could not be relieved otherwise. They issued a certificate declaring the newborn's natural death. The medical team at the unit reviewed the case several weeks after the infant's death and concluded that in retrospect, their practice could best be described as deliberate ending of life. The case was not reported to the legal authorities. Comparison of causes of death between infants in groups I and II showed that congenital malformation caused death more often in group I and asphyxia caused death significantly more often in group II ($P < .001$) (**Table 3**).

In 56 of 359 patients (16%), 2 end-of-life decisions were made. The physician's first decision not to intensify treatment because adding treatment was disproportional was followed by the final decision to withdraw treatment because clinical deterioration had occurred. The median interval between both decisions was 24 hours (range, 0.4-425 hours). Ten of these patients were initially categorized in group II but were changed to group I at the time of the final end-of-life decision.

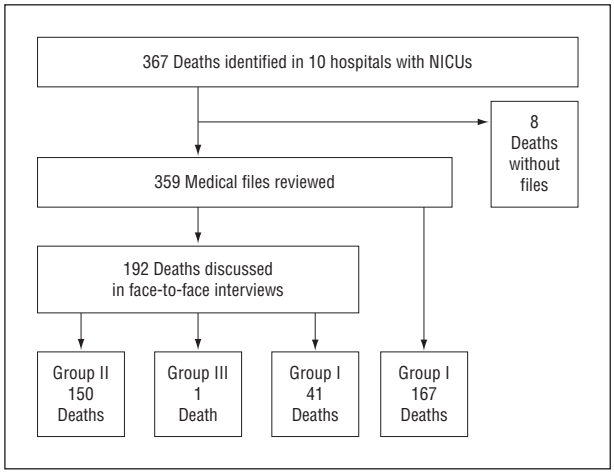

Figure. Study flowchart. NICU indicates neonatal intensive care unit.

Interviews were held with 80 physicians who cared for 147 of the 150 newborns. Data were missing on 3 deaths because we were unable to find the 2 physicians involved. The number of patients cared for by 1 physician ranged from 1 to 4 (mean, 1.8).

Table 4 presents the quality-of-life considerations used by the physicians in end-of-life decision making. In most cases (119 of 147) more than 1 consideration was used.

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Table 3. Comparison of Cause of Death in Groups I and II

Diagnosis	No. (%) Group I[a] (n=208)	Group II[b] (n=150)
Asphyxia	41 (20)	57 (38)[c]
Congenital anomalies	69 (33)	25 (17)[c]
Sepsis/necrotizing enterocolitis	50 (24)	26 (17)
Extreme prematurity[d]	14 (7)	24 (16)[c]
Respiratory insufficiency	25 (12)	9 (6)
Intracranial bleeding	9 (4)	9 (6)

[a] Unstable newborns whose death was imminent.
[b] Stabilized newborns with a very poor prognosis who were dependent on intensive care for survival.
[c] $P < .05$.
[d] Gestational age younger than 27 weeks.

Table 4. Considerations Used for End-of-Life Decisions in 147 Newborns With Very Poor Prognoses[a]

Characteristic	No. of Cases
Considerations regarding the newborn's present state with respect to quality of life	
Treatment does not contribute to medical condition	48
Treatment is disproportionate	33
Considerations regarding the future quality of life[b]	
Predicted inability to be engaged in any kind of communication with other people, verbally or nonverbally	18
Predicted lack of self-sufficiency	2
Expected hospital dependency	2
Predicted suffering[c]	112

[a] Group II. From interviews with the responsible physician; 3 interviews were missing.
[b] According to previously published classification.[13]
[c] In this category, suffering encompasses pain, dyspnea, and other kinds of physical suffering but also the burden suffered by the patient resulting from anomalies in the other categories, including the suffering that is intrinsic to having a disability.

In 135 of 147 patients (92%), considerations regarding the patient's expected future quality of life were used and mostly concerned predicted suffering or inability to be engaged in any kind of communication with other people, verbally or nonverbally. In 71 patients, considerations regarding the infant's present state with respect to quality of life were used, while in 64 patients, both types of considerations were deemed important. Physicians reported that parents had been involved in all decisions in group II involving withdrawal of treatment.

COMMENT

This retrospective descriptive study investigated end-of-life decisions in newborns in Dutch NICUs during the course of 1 year. The study has yielded 3 important findings. First, this study showed that end-of-life decisions were made in 95% of all deaths. This indicates that physicians play a prominent role in the timing and modes of death and dying in Dutch NICUs. Second, we report that of all the newborns who died, 58% had been classified as having no chance of survival, while 42% were stabilized newborns with poor prognoses. In the latter group, most end-of-life decisions were based on the infant's future quality of life and mainly concerned future suffering (76%). Third, we found only 1 case of deliberate ending of a newborn's life. This suggests that deliberate ending of life in severely ill newborns may occur less frequently in the Netherlands than was previously assumed.

More than 95% of deaths in the NICUs in our study occurred after withdrawing or withholding of potentially life-saving treatment. This proportion is substantially higher than that described in the literature on neonatal end-of-life care dating from the 1970s and 1980s.[16,17] It is also slightly higher than the rates reported more recently in studies from other units in the United States, Europe, and Australia (58%-93%).[1-4,6,10,18-22] A possible explanation for the high rate is the use of different, more restrictive definitions of end-of-life decisions in other studies.[2,3] In our study, the decision to withdraw a ventilator in newborns who were dying was taken as an end-of-life decision, whereas in other studies, these cases were classified as deaths despite maximal support[3] or had unclear classification.[18,19] Another explanation could be that legal support for treatment withdrawal in the Netherlands might make physicians more willing to document end-of-life decisions. The high rate may reflect the referral base of the NICUs. In the Netherlands, high-risk neonatal care is centralized in the 10 NICUs, and referral of severely ill newborns takes place at least partly to ensure careful end-of-life decision making. Moreover, it is likely to reflect the prevailing approach of Dutch neonatologists. Physician end-of-life decision making has been a topic of debate for several decades in the Netherlands.[12,23,24] From 1990 to 1997, reports by the Royal Dutch Medical Association and by the Dutch Pediatric Association on the medical and ethical acceptability of end-of-life decisions were published and reflect the views of the medical profession on the subject.[13,25] Two situations for withholding or withdrawing life-sustaining treatment are recognized: first, when there is no chance of treatment succeeding and death is imminent (comparable with group I in our study), and second, when despite survival being possible, the outcome for the infant is predicted to be extremely poor (group II). With respect to the newborns in the first group, it is regarded as less than ideal for a patient to die while hooked up to a ventilator; therefore, artificial ventilation is withdrawn preferably before the actual dying process (with bradycardia, etc) begins.[12] This is done to give the parents the opportunity to say their goodbyes and to let the infant die in what physicians perceive as a dignified way: in the arms of the parents and disconnected from a ventilator. With regard to the newborns in the second group, the position is held that not only is the survival of the infant important but also the future child's quality of life, if he or she were to survive. Intensive care treatment is used to overcome a life-threatening period in life and it should only be initiated and continued when there is a reasonable prognosis for the infant after this period.[13] Both reports share the view that both the life-ending and life-prolonging decisions should be legitimized. According to these reports, pro-

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longation of intensive care treatment in situations in which the prognosis is very grim might not always be in the infant's best interest. The quality-of-life considerations, as operationalized in the reports, should be bound strictly to medical criteria.[14]

In the Netherlands, end-of-life decisions are initiated by physicians and parents are virtually always involved.[26,27] Consensus between parents and the team is always reached. Although this division of roles is considered appropriate in the Netherlands, it can be challenged. The physicians' prominent role may mean that they also control the nature and amount of information that they offer the parents and that they sometimes make decisions in situations in which their perspectives may be limited or colored. Several studies have suggested that intensivists routinely overestimate bad outcomes and conflate acute critical illness with long-term prognosis.[28-33] In addition, the question remains how the best interest of the infant should be defined and whether or not the physician is the best person to make that judgment.

Our second finding that in 42% of deaths quality-of-life considerations were used to justify withdrawal or withholding of therapy is difficult to compare with other reports on newborn end-of-life care because most studies describe the physician's attitude regarding end-of-life decisions and not the practice.[31,32,34-37] Even when withdrawal of care is described, the distinction is rarely made between the newborns who would have died despite intensive interventions (group I) and those who were extubated for quality-of-life reasons (group II).[7,18,38-40] Only 2 studies report on withdrawal of therapy for quality-of-life reasons in roughly equivalent groups in 5% to 16% of deaths.[2,3]

Two types of quality-of-life considerations can be distinguished in our results: those concerning the infant's present state (used in 48% of the decisions) and those concerning the infant's expected future state (used in 92% of cases). Our findings confirm that Dutch physicians consider future quality of life to be critically important. They are prepared to withhold or withdraw life-sustaining treatment exclusively based on the predicted quality of life. In virtually all end-of-life decisions, consultation took place with other physicians and parents were always involved. The high rate of involvement of other physicians and parents may reflect the physicians' awareness that decisions concerning quality of life can never be based on a single opinion.

A concern about the high rate of quality-of-life considerations is that the outcome of the decision-making process could become highly dependent on the physician's opinion about what is in the infant's best interest, specifically with respect to the child's future disability. Whether this is compatible with the infant's legal right to equal treatment in equal cases and protection against discrimination under international human rights law is currently under discussion[41]; we are also investigating this topic.

Our third finding concerned a single patient in group III with type II osteogenesis imperfecta, whose death was retrospectively categorized as deliberate ending of life. Two previous surveys on end-of-life decisions in the Netherlands reported that deliberate ending of life in newborns not dependent on life-sustaining treatment preceded 1% of deaths.[7,20] This proportion represents 15 to 20 cases annually. One report from Flanders reported a mortality rate of 7%, mainly in newborns before the seventh day of life.[4] Our study suggests that the frequency of deliberate ending of life may have dropped considerably. A possible explanation could be the improved and more accessible prenatal screening resulting in more terminations of pregnancies with congenital malformations.[42] This relates to the fact that since 2006, all pregnant women in the Netherlands have been able to participate in an ultrasonography program for the detection of congenital anomalies at 20 weeks' gestation. However, the incidence reported in our study needs to be considered with caution, as we could not disregard that a newborn in group III may have been referred from the NICU to a local hospital (without a NICU) or discharged home, where deliberate ending of life took place. In group III we also did not include cases in which death might have been caused by the use of palliative care medication with potentially life-shortening effects around the time of withdrawal of life-sustaining therapy. Another relevant consideration is that estimations from the surveys could have been based on a different classification of end-of-life decisions and regarded newborns as younger than 12 months. We restricted our study to newborns younger than 2 months.

In the Netherlands, the decision to deliberately end a newborn's life is regarded legally and morally very differently from the decision to withhold or withdraw life-sustaining therapy. The first is in principle a criminal offense (murder or homicide), whereas the latter is in principle a medical decision that can be without consequences in the field of criminal law. Based on 2 court cases held in the mid-1990s, known as the Prins and Kadijk cases,[43,44] it is now accepted under certain circumstances that the physician who deliberately ends a newborn's life can claim impunity, ie, the defense of necessity. In such circumstances, the patient's suffering should be extreme, thus compelling the physician to choose between the duty to save lives on the one hand and to do everything possible to prevent unbearable suffering on the other. If the physician then exercises due care and reports the case to the juridical authorities, deliberate ending of life may be justified. The requirements of due medical care were formulated for the first time in the Prins and Kadijk cases. These requirements also constitute the fundaments of the Groningen Protocol for the deliberate ending of life in severely ill newborns.[8]

During the period of our study, physicians had the legal obligation to report all cases of the deliberate ending of the life of newborns to the juridical authorities.[8] We were unable to determine why the group III case was not reported. Previous studies have suggested that some other acts of deliberate ending of life in newborns in the past may also have remained unreported.[10,45] A nationwide survey examined the physician's opinion regarding the reporting procedure in 1994 and reported the lack of clarity of the review procedure as a key reason for physicians' nonreporting.[7] After repeated requests for more transparency and clarity about the review procedure of deliberate termination of life of newborns, in 2007 the Dutch government established a multidisciplinary expert com-

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mittee to review these cases. The committee advises the public prosecution if the physician has acted in accordance with specific requirements of careful practice.[46] The effects of these recent developments on the physician's preparedness to report their cases of deliberate ending of life in the future are yet to be established.

We recognize several limitations to this study. The first is its retrospective nature, though the fact that the medical files were available for scrutiny during the interviews may have limited potential inaccuracy in the physicians' recall. Another limitation is that findings are based on the physicians' perception and not on those of other care providers or the parents. Finally, as legal immunity could not be guaranteed, we cannot exclude the possibility that, despite our measures to ensure that the study was held anonymously, the physicians' responses in relation to the deliberate ending of life might not always reflect actual practice. A strength of our study is that all NICUs in the Netherlands participated.

In conclusion, we have found that virtually all deaths in Dutch NICUs are preceded by the decision to withdraw life-sustaining treatment and many decisions are based on the predicted future quality of life. Deliberate ending of life in severely ill newborns may occur less frequently than was previously assumed.

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Announcement

Trial Registration Required. In concert with the International Committee of Medical Journal Editors (ICMJE), *Archives of Pediatrics and Adolescent Medicine* will require, as a condition of consideration for publication, registration of all trials in a public trials registry (such as http://ClinicalTrials.gov). Trials must be registered at or before the onset of patient enrollment. This policy applies to any clinical trial starting enrollment after July 1, 2005. The trial registration number should be supplied at the time of submission.

For details about this new policy, and for information on how the ICMJE defines a clinical trial, see the editorials by DeAngelis et al in the September 8, 2004 (2004;292:1363-1364) and June 15, 2005 (2005;293: 2927-2929) issues of *JAMA*. Also see the Instructions to Authors on our Web site: www.archpediatrics.com.

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