Medical end-of-life decisions made for neonates and infants in the Netherlands

Agnes van der Heide, Paul J van der Maas, Gerrit van der Wal, Carmen L M de Graaff, John G C Kester, Louis A A Kollée, Richard de Leeuw, Robert A Holl

Summary

Background Advances in neonatal intensive care have lowered the neonatal death rate. There are still some severely ill neonates and infants, however, for whom the application of all possible life-prolonging treatment modalities may be questioned.

Methods We did two studies in the Netherlands. In the first we sent questionnaires to physicians who had attended 338 consecutive deaths (August–November, 1995) within the first year of life (death-certificate study), and in the second we interviewed 31 neonatologists or paediatric intensive-care specialists and 35 general paediatricians. The response rates were 88% and 99%, respectively.

Findings In the death-certificate study, 57% of all deaths had been preceded by a decision to forgo life-sustaining treatment; this decision was accompanied by the administration of potentially life-shortening drugs to alleviate pain or other symptoms in 23%, and by the administration of drugs with the explicit aim of hastening death in 8%. A drug was given explicitly to hasten death to neonates not dependent on life-sustaining treatment in 1% of all death cases. No chance of survival was the main motive in 76% of all end-of-life decisions, and a poor prognosis was the main motive in 18%. The interview study showed that parents had been involved in making 79% of decisions. The physicians consulted colleagues about 88% of decisions. Most paediatricians favoured formal review of medical decisions by colleagues together with ethical or legal experts.

Interpretation Death among neonates and infants is commonly preceded by medical end-of-life decisions. Most Dutch paediatricians seem to find prospects for survival and prognostic factors relevant in such decisions. Public control by a committee of physicians, paediatricians, ethicists, and legal experts is widely endorsed by paediatricians.

Lancet 1997; **350:** 251–55

Department of Public Health, Erasmus University Rotterdam, PO Box 1738, 3000 DR Rotterdam, Netherlands (A van der Heide MD, Prof P J van der Maas MD); **Institute for Research in Extramural Medicine, Vrije Universiteit Amsterdam** (Prof G van der Wal MD); **Statistics Netherlands, Voorburg** (C L M de Graaff MA, J G C Kester MA); **and Paediatric Association of the Netherlands** (L A A Kollée MD, R de Leeuw MD, R A Holl MD)

Correspondence to: Dr Agnes van der Heide (e-mail: vanderheide@mgz.fgg.eur.nl)

Introduction

Medical decision-making about the end of life for neonates and infants is under debate in the Netherlands. In 1995, 190 000 babies were born alive in the Netherlands, and 1041 died within 1 year of birth. The neonatal death rate in the Netherlands is among the lowest in the world, which reflects favourable economic circumstances and high-quality health care for mothers and children. 29% of neonatal deaths occurred on the day of birth, and another 28% occurred within 1 week. Of all babies who died during the first week of life, 9% were born at gestational ages of less than 25 weeks, and 37% at gestational ages between 25 and 30 weeks. The cause of death was a perinatal disorder (such as perinatal asphyxia or complications of low birthweight) in 48%, and congenital malformations in 34%.

Although advances in medical knowledge and in neonatal intensive care have increased the possibilities of treating seriously affected infants, whether the application of every possible technique in all circumstances is appropriate is questionable.[1,2] For neonates who are seriously ill and have a very poor prognosis for neurological function, the benefit of extending life is doubtful. In 1992, the Paediatric Association of the Netherlands issued a report on the different circumstances under which life-sustaining treatment may be withheld or withdrawn from neonates.[3] It was recognised that there are very exceptional circumstances in which the intentional ending of life by administration of a lethal drug may be considered; the administration of potentially life-shortening drugs may be necessary for adequate terminal care. The intentional ending of life should, under Dutch law, be reported to the coroner to enable judicial examination. In 1995, three cases of intentional ending of life in neonates were reported.[4]

The Netherlands has 110 general hospitals that provide clinical paediatric care. Eight university hospitals and two large general hospitals have neonatal intensive-care units. Paediatricians attend about 80% of all hospital deaths among neonates and infants.

The aims of the present study were to give an overview of practices and attitudes about end-of-life decisions for neonates and infants in the Netherlands. The study paralleled an assessment of the judicial notification procedure for physician-assisted death, and was commissioned by the ministers of health and of justice.[4,5]

Methods

We did two studies. In the first study we sent questionnaires to physicians who attended 338 consecutive deaths of neonates and infants to obtain estimates of the frequency of end-of-life decisions and their main characteristics. In the second study we interviewed 66 paediatricians in a stratified sample to obtain descriptions of the patients, physicians, and situations involved, and to investigate opinions about public control in end-of-life decision-making among Dutch paediatricians.

	Number replying "yes"	
	Neonatologists* (n=31)	General paediatricians (n=35)
Had withdrawn life-sustaining treatment		
No chance of survival	31 (100%)	23 (68%)†
Poor prognosis for later life	30 (97%)	14 (40%)†
Had withheld life-sustaining treatment		
No chance of survival	20 (67%)	21 (66%)‡
Poor prognosis for later life	17 (55%)	10 (30%)§
Had administered drug with explicit intention of ending life‖		
Ever administered	14 (45%)	11 (31%)
Never administered, but could conceive of situations in which they would	9 (29%)	17 (49%)
Would never administer, but would refer to another physician	6 (21%)†	6 (20%)†
Would never administer or refer patient	1 (4%)†	0

*Neonatologists and intensive-care specialists. †Answers missing for one participant. ‡Answers missing for three participants. §Answers missing for two participants. ‖Whether or not after a preceding decision to forgo life-sustaining treatment.

Table 1: **Paediatricians' statements about their practices for end-of-life decisions (interview study)**

Death-certificate study

The causes of death for all inhabitants of the Netherlands are reported to Statistics Netherlands. Patients are not mentioned by name on the cause-of-death forms, but the names of the reporting physicians are given. Details of 338 consecutive deaths in children aged under 1 year between August and November, 1995, were obtained (32% of 1041 deaths in this age-group in 1995). For 26 deaths, no medical decision about the end of life could have been made (for example, in sudden infant death syndrome), and no questionnaire was sent. Questionnaires were sent to physicians for the remaining 312 deaths. To ensure anonymity of the physicians and the patients, questionnaires were coded and contained no identifying information. Codes were removed by the notary to whom the questionnaires were sent by the responders. 299 (88%) questionnaires were returned. The questionnaires consisted of 23 questions. Key questions were whether life-sustaining treatment had been withheld or withdrawn, whether a potentially life-shortening drug had been used, and whether these acts had been intended to hasten death. Results were weighted for non-response for age, sex, and cause and place of death.

Interview study

We interviewed neonatologists, paediatric intensive-care specialists and general paediatricians face to face; interviewees were randomly selected from the national official register. Since death among neonates mainly occurs in intensive-care units, we aimed to interview a third of all 77 Dutch neonatologists or intensive-care specialists, and a similar number of general paediatricians (out of about 600). To be selected, paediatricians had to have been practising in their specialty since at least Jan 1, 1994, and to have worked at the same institution since then. Of 32 neonatologists or intensive-care specialists who were invited to participate, one did not meet this criterion; of 38 general paediatricians, two did not meet this criterion and one refused to take part in the study (99% response rate). Therefore, we interviewed 31 neonatologists or intensive-care specialists and 35 general paediatricians. These 66 physicians attended about a quarter of all deaths among children aged under 1 year during 1995 in the Netherlands.

The classification of end-of-life decisions was primarily based on the type of practice done or not done and, by contrast to the death-certificate study, on the prognosis for the infant. Interviewees were asked if: they had ever withdrawn or withheld life-sustaining treatment from an infant because there was no chance of survival, or because of an extremely poor prognosis for later life; or if they had ever administered a drug to an infant explicitly to hasten the end of life.

The forgoing of life-sutaining treatment was defined as "withdrawing or withholding every medical or surgical treatment aimed at prolonging life"; palliative care (eg, hydration, provision of warmth, pain relief) may have been continued after such a decision. For each of these decisions the last such death, if any, was discussed and interviewees were asked to consult medical charts during the interview. At the end of the interview, questions were asked about the interviewee's opinions on end-of-life decision-making in neonatology and on review procedures for these decisions.

Six experienced physicians each interviewed 10–15 paediatricians; the interviewers were trained in interview skills, to use our structured questionnaire, and to explain key terms. An appraisal was made of each interview by the interviewer and an investigator (AvdH). The interviews lasted 2·5 h on average. To obtain valid estimates for the Netherlands, we calculated weights based on the proportion of neonatologists and intensive-care specialists who were represented in the sample, and on the proportion of all deaths among children aged under 1 year that the general paediatricians had attended.

Results

Death-certificate study

Of all deaths among children aged under 1 year in this study (n=299), 36% occurred in a neonatal intensive-care unit, 51% in a hospital but not in a neonatal intensive-care unit, and 14% not in hospital.

In 24% of cases, death occurred suddenly and unexpectedly, and in 14% treatment was continued until death. In the remaining 62%, an end-of-life decision preceded death. This percentage varied with the place of death; for neonatal intensive-care units it was 87%, for deaths in other hospital departments (mostly paediatric wards) 56%, and for deaths not in hospital 21%.

In 57% of cases, death was preceded by the withdrawal or withholding of life-sustaining treatment. Most of these decisions were made because there was no chance of survival (77%) or a poor prognosis for later life (18%); 5% could not be assigned to either category. In 23% of all deaths, the decision to forgo treatment was followed by the administration of drugs (generally opioids) to alleviate pain and symptoms, in doses that may have shortened

	% of cases*							
	Immaturity	Complications of prematurity	Congenital abnormalities				Perinatal asphyxia	Acquired diseases
			CNS	Heart	Multiple	Other		
Life-sustaining treatment withdrawn								
No chance of survival (n=49)	1 (1%)	9 (14%)	1 (1%)	5 (14%)	11 (31%)	7 (9%)	7 (18%)	8 (13%)
Poor prognosis (n=36)	0	14 (33%)	5 (13%)	0	4 (18%)	2 (3%)	9 (31%)	2 (3%)
Life-sustaining treatment withheld								
No chance of survival (n=36)	7 (24%)	3 (6%)	7 (24%)	4 (7%)	13 (33%)	1 (1%)	0	1 (4%)
Poor prognosis (n=22)	3 (22%)	2 (12%)	6 (20%)	0	6 (28%)	3 (6%)	1 (10%)	1 (2%)
Drug administered with explicit intention of ending life (n=22)†	0	1 (2%)	6 (35%)	1 (8%)	6 (29%)	1 (8%)	6 (16%)	1 (2%)

CNS=central nervous system. *Row percentages shown based on weighted data. †Whether or not after a preceding decision to forgo life-sustaining treatment.

Table 2: **Diagnosis in neonates and infants in whom death was preceded by a medical end-of-life decision (interview study)***

	Number replying "yes"	
	Neonatologists/paediatric intensive-care specialists (n=31)	General paediatricians (n=35)
Not conceivable without approval of parents		
To forgo life-sustaining treatment because of poor prognosis	28 (93%)*	27 (77%)
To administer a drug with explicit intention of ending life	31 (100%)	27 (77%)
Approval of parents important for careful decision-making		
To forgo life-sustaining treatment because of poor prognosis	28 (97%)†	32 (91%)
To administer a drug with explicit intention of ending life	29 (100%)*	34 (100%)*
Forgoing of life-sustaining treatment is a medical decision that has to be reviewed		
All cases	16 (52%)	18 (51%)
Some cases	11 (36%)	12 (34%)
No cases	4 (13%)	5 (14%)
Administration of a drug explicitly to end life is a medical decision that has to be reviewed		
All cases	29 (94%)	32 (91%)
Some cases	2 (7%)	3 (9%)
Administration of a drug explicitly to end life is a medical decision that has to be reviewed		
Before	11 (36%)	12 (35%)
After	7 (23%)	2 (6%)
Both	13 (42%)	20 (59%)*
Administration of a drug explicitly to end life is a medical decision that has to be reviewed before intervention‡		
By caregivers involved	11 (46%)	19 (59%)
By independent medical professionals	19 (79%)	21 (66%)
By committee not restricted to medical professionals	18 (75%)	18 (56%)
By public prosecutor§	1 (4%)	2 (6%)
By others	0	1 (3%)
Administration of a drug explicitly to end life is a medical decsion that has to be reviewed after intervention‖		
By caregivers involved	4 (20%)	7 (32%)
By independent medical professionals	11 (55%)	13 (59%)
By committee not restricted to medical professionals	15 (75%)	13 (59%)
By public prosecutor§	2 (10%)	1 (5%)
By others	2 (10%)	4 (18%)

*Answers not available for one participant. †Answers not available for two participants. ‡More than one answer allowed; n=24 for neonatologists; n=32 for general paediatricians. §This category was not offered for control before administration, but nevertheless mentioned by some respondents. ‖More than one answer allowed; n=20 for neonatologists; n=22 for general paediatricians.

Table 3: **Paediatricians' statements about decision-making (interview study)**

life. The estimated shortening of life was less than 1 month in 84% of babies and more than 1 month in 11% (in 4% the length of time could not be estimated). In 8% of deaths, the decision to forgo life-sustaining treatment was combined with drugs given explicitly to hasten death. Life was shortened by less than 1 month in 67% and by more than 1 month in 33% of babies. In 26% of cases, no drug with a potentially life-shortening effect was given.

In 4% of all deaths, the only decision made had been to give drugs to alleviate pain and symptoms in doses that may have shortened life. These decisions were not made because of prognosis for later life in any case; life was not shortened by more than 1 week.

The decision to give a drug explicitly to hasten death to an infant not dependent on life-sustaining treatment preceded 1% of deaths; if the deaths in this study are representative of a whole year, this proportion represents 10–15 deaths of this type per year in the Netherlands.

Interview study

When interviewed, most paediatricians said that they had withdrawn or withheld life-sustaining treatment from a neonate or infant at least once (table 1). More interviewees had done this because there was no chance of survival than because of a poor prognosis for later life. 26% of the general paediatricians had never withdrawn life-sustaining treatment, but could conceive of situtaions in which they would be prepared to do so; similarly, for withholding treatment 16% of neonatologists or intensive-care specialists and 23% of general paediatricians would be prepared to do so. 45% and 31%, respectively, had given drugs explicitly to end life, irrespective of whether a preceding decision to forgo life-sustaining treatment had been made. Furthermore, 29% of neonatologists or intensive-care specialists and 49% of general paediatricians who had not done so could conceive of situations in which they would give such drugs. Only one respondent (an intensive-care specialist) was unable to give drugs to end life or refer patients to a colleague prepared to do so.

Table 2 shows further details for the last cases in which an end-of-life decision was made. Congenital abnormality was the most frequent diagnosis for which life-sustaining treatment was forgone (56%). Complications of premature birth or immaturity were the main diagnoses in a third of the cases—immaturity mainly for the withholding of treatment and prematurity mainly for the withdrawal of treatment. Among babies for whom treatment was withdrawn or withheld because there was no chance of survival, the estimated shortening of life was less than 1 month in 73% and 95%, respectively (less than 24 h in 47% and 65%, respectively); among babies for whom treatment was withdrawn or withheld because of poor prognosis, life was shortened by less than 1 month in 31% and 10%, and more than 6 months in 30% and 26%, respectively.

Decisions to give drugs explicitly to end life were made for 48% in infants among whom life-sustaining treatment had earlier been forgone. Congenital defects of the central nervous system, multiple congenital abnormalities, and perinatal asphyxia were the most frequently involved diagnoses. Life was shortened by less than 1 month in 63%, and more than 5 years among 16%

of babies. In all of the latter babies, severe brain damage precluded favourable neurological outcome.

Parents were involved in 79% of decisions. End-of-life decisions never went against parental wishes in these cases. The most common reason for not involving parents was that "it was so obviously the only correct decision". Consultation of colleagues was also common and occurred in 88% of cases. (In the death-certificate study, 89% of end-of-life decisions were discussed with parents and 81% with colleagues.)

Approval of parents was thought to be important for careful decision-making (table 3). 23% of the general paediatricians, however, thought that the forgoing of life-sustaining treatment and the administration of a drug explicitly to end life can very occasionally, occur without the parents' approval. The most common reason for this answer among interviewees was that parents should not in every case be forced to share the responsibility to forgo treatment, and that some parents are not able to judge the child's prognosis adequately.

Only one of the cases discussed of actively ending an infant's life had been reported for judicial examination. Although almost all paediatricians thought that decisions to end an infant's life by administration of a drug should be reviewed by some form of public control, not all judged this to be relevant in all or some cases of forgoing life-sustaining treatment (table 3). Opinions varied on whether review should take place before or after the event. Of the respondents who thought review should always occur for the decision to end an infant's life by administration of a drug, most thought that independent medical professionals are best equipped to do the review, possibly together with legal and ethical experts. The public prosecutor was thought to be the proper reviewing authority by only a few respondents, although such review forms the core of the current judicial notification procedure for physician-assisted death.

Discussion

This overview is based on two national studies with high response rates. The willingness to cooperate in this study may have been increased by letters that were sent before the start to all paediatricians by the president of the Royal Dutch Medical Association and the Chief Inspector for Health Care, and by the president of the Paediatric Society of the Netherlands. These letters explained the aims of the studies and emphasised the importance of cooperation. Immunity from legal prosecution was also guaranteed in relation to all data collected.

Empirical studies on medical end-of-life decisions in neonates and infants are scarce. Studies in the USA and Denmark (published between 1973 and 1989) found that life-sustaining treatment had been withdrawn or withheld in between 10% and 20% of cases.[6–8] Whitelaw[9] reported a substantially larger treatment withdrawal rate of 70% among 75 prospectively followed newborn infants in an intensive-care unit in the UK. High frequencies (86% and 82%) of treatment withdrawal were reported in two studies from Canada and the USA.[10,11] Since the advances in medical technology and neonatal intensive care have occurred mainly in the past two decades, the differences between these studies may be due partly to when they were done. Three studies on end-of-life decision-making in neonatology[12–14] have been done in the Netherlands. In four intensive-care units[12,13] in 1990 and 1993, life-sustaining treatment was forgone in 59% and 81% of all deceased infants, respectively. In the third study, all deaths during 1990–94 in one neonatal intensive-care unit were analysed. 80% of deaths immediately followed the withdrawal of artificial ventilation, and additional sedative drugs were given to all these babies. 18% of deaths were spontaneous, as expected, and 2% of deaths were caused by the intentional administration of a lethal dose of a drug. In all these studies, two-thirds of the end-of-life decisions were made because there was no chance of survival.

In our study, which includes deaths in intensive-care units and elsewhere throughout the Netherlands, medical end-of-life decisions preceded 62% of all deaths in children aged under 1 year, mostly involving the withholding or withdrawal of life-sustaining treatment. In neonatal intensive-care units, the frequency was 87%, which confirms results from the previous studies in intensive-care units. Although end-of-life decisions are less common in other settings, they are not exceptional.

The international debate on end-of-life decisions in neonatology often focuses on the acceptability of motives that are not exclusively medical in making decisions. When there is no chance of survival and treatment is futile according to current medical standards, physicians are morally and legally entitled to withhold or withdraw life-sustaining treatment.[15,16] In the USA, other factors were excluded from end-of-life decision-making in the Baby Doe regulations, although subsequent comments suggest that these regulations in fact illustrate that these other factors cannot be ignored, since they state that an irreversible coma warrants the withdrawal of treatment.[17,18] Dutch paediatricians seemed in our study to promote quality-of-life considerations as an important reason to forgo life-sustaining treatment in a substantial number of cases. This type of argument is also deemed to be acceptable by many of the Dutch paediatricians, although the legal implications of this practice are not completely clear, as is true for the role of parents. Although in the Netherlands end-of-life decisions are judged to be medical decisions for which physicians are initially responsible,[16] parents are, if possible, involved in making decisons, and when they are, end-of-life decisions are not made without their consent.

Studies that include decisions abut administration of potentially life-shortening drugs, whether or not a decision was made to forgo life-sustaining treatment, are rare. The hastening of death mostly occurs as the inevitable but not desired result of the alleviation of pain or symptoms. In the main, drugs were administered explicitly to hasten the deaths of infants for whom life-sustaining treatment had been forgone previously. In most of these cases the administration of drugs was thought to be unavoidable to ensure good clinical practice in terminal care.[3] This type of practice probably explains the large proportion of paediatricians who admitted in our interview study that they had given life-shortening drugs. A straightforward distinction between the active ending of life and provision of terminal care that intentionally or unintentionally hastens death may not always be easy to make. The administration of a drug explicitly to hasten the death of an infant not dependent on life-sustaining treatment is rare in the Netherlands.

The administration of a drug to an infant to hasten death is subject to criminal law in the Netherlands, and should, as physician-assisted death, be reported to the

coroner to enable judicial examination. Physicians who act in accordance with accepted practice, as formulated by courts and the medical profession, will not be prosecuted.[19] However, the consequences of reporting physician-assisted death in an incompetent patient, such as an infant, remain unclear. Two physicians were prosecuted for assisting in the death of a neonate; both were acquitted because the acts were deemed to be medically necessary. Physician-assisted death for neonates is, however, virtually never reported. Nevertheless, the open debate in the Netherlands on euthanasia and related practices in neonatology provided conditions under which these practices could be thoroughly investigated. No similar data about the administration of life-shortening drugs are available from other countries.

A study of physician-assisted death in the Netherlands showed that the frequency of euthanasia (ie, administration of a drug given intentionally to end life at the patient's explicit request) increased from about 1·8% in 1990 to about 2·4% in 1995; medical backgrounds of patients remained virtually unchanged and the adherence to guidelines improved.[4,5,20] The frequency of ending life without the patient's explicit request, which is sometimes identified as undesirable and resulting from a liberal attitude towards euthanasia and physician-assisted suicide, decreased from 0·8% to 0·7%. The current judicial notification procedure was, therefore, thought to have at least partly achieved its goals of stimulating openness and careful practice without evoking undesirable side-effects. Whether this conclusion is applicable to neonates cannot be decided from our study. The results should be viewed in the light of the low neonatal mortality rate in the Netherlands, which limits their applicability to other populations. Among neonates, life-sustaining treatment in many cases has to be started before the prognosis and the future quality of life can be assessed without sufficient certainty. We found that decisions to withhold or withdraw life-sustaining treatment, or, rarely, to give life-shortening drugs, seemed to occur only when diagnostic tests and the response of the patient to treatment showed that, despite medical possibilities, chances of long-term survival were absent or that the prognosis for later life was extremely poor.

Nearly all paediatricians believed that some form of public control on decision-making about the end of life in neonates is necessary. Nevertheless, the current judicial notification procedure was rejected by most paediatricians. In the Netherlands, two working groups commissioned by the government are studying possible conditions for end-of-life decision making, and the required forms of public control in this area and the related topic of late pregnancy termination (after 24 weeks). A formal procedure by which cases are reviewed before or after death by independent colleagues and other experts, and only in exceptional cases referred for judicial review, will probably result in more effective public control.

Contributors

Agnes van der Heide coordinated the study and was involved in designing the questionnaires and collecting and analysing data. Paul van der Mas and Gerrit van der Wal were principal investigators and supervised all parts of the study. Carmen de Graaff and John Kester designed the questionnaire and analysed the data for the death-certificate study. Louis Kollée, Richard de Leeuw, and Robert Holl advised on the study design, the questionnaires, and interpretation of the data. All authors contributed to the writing of the paper.

Acknowledgments

We thank Johannes J M van Delden, Marja A Dost-Mulder, Elles S Goes, Johanna H Groenewoud, Magda M Henke-Kulakowska, Wout A Lasut, Caspar W N Looman, N T Mulder-Mulder, Henk Noort, S M van Petten-Mulder, Marjolein Smit, and Dick L Willems for their contributions to the study; the members of the steering committee for their continuous support throughout the study; the hundreds of physicians who provided the study data; the interviewers; and the Royal Dutch Medical Association and the Chief Inspector of Health Care for their support.

The study was funded by a grant from the Ministry of Health, Welfare and Sports, and the Ministry of Justice.

References

1 Rivers RP. Decison making in the neonatal intensive care environment. *Br Med Bull* 1996; **52:** 238–45.
2 Anon. Ethics and the care of critically ill infants and children. American Academy of Pediatrics Committee on Bioethics. *Pediatrics* 1996; **98:** 149–52.
3 Nederlandse Vereniging voor Kindergeneeskunde. Doen of laten? Grenzen van het medisch handelen in de neonatologie (To treat or not to treat? Limits for life-sustaining treatment in neonatology). Utrecht: 1992.
4 van der Wal G, van der Maas P, Bosma JM, et al. Evaluation of the euthanasia notification procedure in the Netherlands. *N Engl J Med* 1996; **335:** 1706–11.
5 van der Maas PJ, van der Wal G, Haverkate I, et al. Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in the Netherlands, 1990–1995. *N Engl J Med* 1996; **335:** 1699–705.
6 Duff RS, Campbell AG. Moral and ethical dilemmas in the special-care nursery. *N Engl J Med* 1973; **289:** 890–94.
7 Campbell AG. Which infants should not receive intensive care? *Arch Dis Child* 1982; **57:** 569–71.
8 Eg-Andersen G. Prediction of outcome in 174 infants born after 24 to 28 weeks gestation. *Acta Paediatr Scand* 1989; **360** (suppl): 56–61.
9 Whitelaw A. Death as an option in neonatal intensive care. *Lancet* 1986; ii: 328–31.
10 Ryan CA, Byrne P, Kuhn S, Tyebkahn J. No resuscitation and withdrawal of therapy in a neonatal and a pediatric intensive care unit in Canada. *J Pediatr* 1993; **123:** 534–38.
11 Cook LA, Watchko JF. Decision making for the critically ill neonate near the end of life. *J Perinatol* 1996; **16:** 133–36.
12 de Kleine MJ, de Leeuw R, Kollée LA, Berger HM. Voortzetten of staken van levensverlegend handelen bij pasgeborenen: een onderzoek in 4 centra voor neonatale intensieve zorg. (Continuation or withdrawal of life-sustaining procedures in newborn infants: a study in 4 centres for neonatal intensive care.) *Ned Tijdschr Geneeskd* 1993; **137:** 496–500.
13 de Leeuw R, de Beaufort AJ, de Kleine MJK, van Harrewijn K, Kollée LAA. Forgoing intensive care treatment in newborn infants with extremely poor prognoses: a study in four neonatal intensive care units in the Netherlands. *J Pediatr* 1996; **129:** 661–66.
14 Brouwers HAA, de Vries LS. Doen of laten: hoe vaak? (To treat or not to treat: how often?) In: van Willigenburg T, Kuis W, eds. Op de grens van leven en dood (On the border between life and death). Assen: Van Gorcum, 1995.
15 Luce JM. Physicians do not have a responsibility to provide futile or unreasonable care if a patient or family insists. *Crit Care Med* 1995; **23:** 760–66.
16 Leenen HJJ. Handboek Gezondheidsrecht, deel 1: rechten van mensen in de gezondheidszorg. (Manual for health law, part 1: rights of people within the health care system.) Alphen aan den Rijn: Samson HD Tjeenk Willink, 1994.
17 Angell M. The Baby Doe rules. *N Engl J Med* 1986; **314:** 642–44.
18 Kopelman LM, Irons TG, Kopelman AE. Neonatologists judge the "Baby Doe" regulations. *N Engl J Med* 1988; **318:** 677–83.
19 van der Wal G, Dillmann RJM. Euthanasia in the Netherlands. *BMJ* 1994; **308:** 1346–49.
20 van der Maas PJ, van Delden JJM, Pijnenborg L, Looman CWN. Euthanasia and other medical decisions concerning the end of life. *Lancet* 1991; **338:** 669–74.