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.

Introduction Medical decision-making about the end of life for neonates and infants is under debate in the Netherlands. In 1995, 190000 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. 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. 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.

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.

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.
could have been made (for example, in sudden infant death in children aged under 1 year between August and November, 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 359 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 respondents. 299 (88%) questionnaires were returned.

The questionnaires consisted of 25 questions. K.ey 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. The questions also covered issues such as whether a potentially life-shortening drug had been used, and whether these acts had been intended to hasten death. The questionnaires aimed to interview a third of all 77 Dutch neonatologists or intensive-care specialists, and a similar number of general paediatricians face to face; 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 questionnaires also asked whether a potentially life-shortening drug had been used, and whether these acts had been intended to hasten death. The questionnaires also asked whether a potentially life-shortening drug had been used, and whether these acts had been intended to hasten death. The questionnaires also asked whether a potentially life-shortening drug had been used, and whether these acts had been intended to hasten death. The questionnaires also asked whether a potentially life-shortening drug had been used, and whether these acts had been intended to hasten death. The questionnaires also asked whether a potentially life-shortening drug had been used, and whether these acts had been intended to hasten death. The questionnaires also asked whether a potentially life-shortening drug had been used, and whether these acts had been intended to hasten death. 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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 forgo life-sustaining treatment because of poor 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 situations 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 3: Paediatricians' statements about decision-making (Interview study)

<table>
<thead>
<tr>
<th>Decision-making</th>
<th>Neonatologists/paediatric intensive-care specialists (n=31)</th>
<th>General paediatricians (n=35)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not conceivable without approval of parents</td>
<td>28 (69%)</td>
<td>27 (77%)</td>
</tr>
<tr>
<td>To forgo life-sustaining treatment because of poor prognosis</td>
<td>31 (100%)</td>
<td>27 (77%)</td>
</tr>
<tr>
<td>To administer a drug with explicit intention of ending life</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Approval of parents important for careful decision-making</td>
<td>28 (69%)</td>
<td>32 (91%)</td>
</tr>
<tr>
<td>To forgo life-sustaining treatment because of poor prognosis</td>
<td>29 (100%)</td>
<td>34 (100%)</td>
</tr>
<tr>
<td>To administer a drug with explicit intention of ending life</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Forgiving of life-sustaining treatment is a medical decision that has to be reviewed</td>
<td>16 (62%)</td>
<td>18 (51%)</td>
</tr>
<tr>
<td>All cases</td>
<td>11 (38%)</td>
<td>12 (34%)</td>
</tr>
<tr>
<td>Some cases</td>
<td>4 (13%)</td>
<td>5 (14%)</td>
</tr>
<tr>
<td>Administration of a drug explicitly to end life is a medical decision that has to be reviewed</td>
<td>29 (84%)</td>
<td>32 (91%)</td>
</tr>
<tr>
<td>All cases</td>
<td>2 (7%)</td>
<td>3 (9%)</td>
</tr>
<tr>
<td>Some cases</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Administration of a drug explicitly to end life is a medical decision that has to be reviewed before intervention</td>
<td>11 (36%)</td>
<td>12 (35%)</td>
</tr>
<tr>
<td>By caregivers involved</td>
<td>7 (23%)</td>
<td>2 (6%)</td>
</tr>
<tr>
<td>By independent medical professionals</td>
<td>13 (42%)</td>
<td>20 (59%)</td>
</tr>
<tr>
<td>By committee not restricted to medical professionals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>By public prosecutor§</td>
<td>1 (4%)</td>
<td>2 (6%)</td>
</tr>
<tr>
<td>By others</td>
<td>0</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>Administration of a drug explicitly to end life is a medical decision that has to be reviewed after intervention</td>
<td>4 (20%)</td>
<td>7 (33%)</td>
</tr>
<tr>
<td>By caregivers involved</td>
<td>11 (55%)</td>
<td>13 (59%)</td>
</tr>
<tr>
<td>By independent medical professionals</td>
<td>35 (75%)</td>
<td>13 (59%)</td>
</tr>
<tr>
<td>By committee not restricted to medical professionals</td>
<td>2 (10%)</td>
<td>1 (5%)</td>
</tr>
<tr>
<td>By public prosecutor§</td>
<td>2 (10%)</td>
<td>4 (18%)</td>
</tr>
</tbody>
</table>

*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. 

Table 3 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, to end an infant's life by administration of a drug should. Although almost all paediatricians thought that decisions to forgo 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.** Whitelaw** 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**4 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.**14,15** 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.**16,17** 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, parents are, if possible, involved in making decisions, and when they are, end-of-life decisions are not made without their consent.

Studies that include decisions about 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.**18** 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. 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. 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 Maas 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 Kollee, Richard de Leeuw, and Robert Heil advised on the study design, the questionnaires, and interpretation of the data. All authors contributed to the writing of the paper.

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