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End-of-life decisions for children under 1 year of age in the Netherlands: decreased frequency of administration of drugs to deliberately hasten death

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ABSTRACT

Objective To assess whether the frequency of end-of-life decisions for children under 1 year of age in the Netherlands has changed since ultrasound examination around 20 weeks of gestation became routine in 2007 and after a legal provision for deliberately ending the life of a newborn was set up that same year.

Methodology This was a recurrent nationwide cross-sectional study in the Netherlands. In 2010, a sample of death certificates from children under 1 year of age was derived from the central death registry. All 223 deaths that occurred in a 4-month study period were included. Physicians who had reported a non-sudden death (n=206) were sent a questionnaire on the end-of-life decisions made. 160 questionnaires were returned (response 78%).

Findings In 2010, 63% of all deaths of children under 1 year of age were preceded by an end-of-life decision—a percentage comparable to other times when this study was conducted (1995, 2001, 2005). These end-of-life decisions were mainly decisions to withdraw or withhold potentially life-sustaining treatment. In 2010, the percentage of cases in which drugs were administered with the explicit intention to hasten death was 1%, while in 1995 and 2001, this was 9% and in 2005, this was 8%.

Discussion and conclusion There has been a reduction of infant deaths that followed administration of drugs with the explicit intention to hasten death. One explanation for this reduction relates to the introduction of routine ultrasound examination around 20 weeks of gestation. In addition, the introduction of legal criteria and a review process for deliberately ending the life of a newborn may have left Dutch physicians with less room to hasten death.

INTRODUCTION

Sometimes an ill newborn may suffer so severely or its prospects are so grim that an end-of-life decision is made. Such end-of-life decisions include decisions to withhold or withdraw potentially life-sustaining treatment, decisions to alleviate pain or symptoms with possibly life-shortening drugs and decisions to administer such drugs with the explicit intention to hasten death. The latter decision is the most far-reaching and controversial.

In the Netherlands, two potentially influential changes have taken place recently. In 2007, ultrasound examination around 20 weeks of gestation was introduced as part of the routine prenatal screening programme. In the same year, the Dutch government set up a legal provision that makes it possible for a physician to deliberately end the life of a severely ill newborn without being prosecuted if certain criteria of due care are met.[1] This legal provision has come about in close collaboration with the field of paediatricians and stems from the so-called Groningen protocol.[2] Deliberately ending life is defined as 'the use of drugs by a physician with the explicit intention to end the life of a severely affected newborn'.[3] A newborn is taken to be a child under 1 year of age.[3] The criteria of due care are as follows: the child is suffering unbearably and hopelessly, the parents are fully informed about diagnosis and prognosis, the paediatricians and parents together have reached the conclusion that there are no other reasonable ways to relieve the suffering of the child, the parents have given consent, an independent physician has been consulted and the ending of life will be performed *lege artis*.[1] In addition, the legal provision requires that a physician who performs this act reports this to an expert committee (consisting of three paediatricians, a lawyer and an ethicist) that reviews these cases based on the criteria of due care. The expert committee has to inform the public prosecutor of its assessment, and the public prosecutor ultimately decides whether to prosecute (for murder or manslaughter) or not.[1]

We have repeated a nationwide questionnaire study that was previously conducted in 1995, 2001 and 2005 to assess whether the introduction of the ultrasound at 20 weeks of gestation as part of the routine prenatal screening programme and the legal provision for deliberately ending the life of a newborn have affected the frequency of end-of-life decision-making practices for children under 1 year of age.[4 5]

The research questions of this study were as follows: (1) How frequently are different types of end-of life decisions made for children under 1 year of age in the Netherlands in 2010? (2) Has this practice changed since 2007? (3) What are the characteristics of cases where physicians used drugs with the explicit intention to hasten death?

METHODOLOGY

In the Netherlands, all deaths are reported to Statistics Netherlands. In 2010, a total of 695 deaths of children under 1 year of age were reported. All 223 deaths that occurred between August and November 2010 were included in our sample. Based on the reported cause of death, cases were divided into those cases where death had come suddenly and unexpectedly (n=17) and cases

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where death could have been preceded by an end-of-life decision (n=206). Physicians who had reported a non-sudden death (n=206) were sent a questionnaire by mail. The questionnaire included questions about whether the death of the child could have been hastened (intentionally or unintentionally) by decisions to forego potentially life-sustaining treatment or by the use of potentially life-shortening drugs. A total of 160 questionnaires were filled in and returned (response rate 78%). Each case was weighted to ensure that the sample adequately reflects the proportions of infants by gender and place of death (at home, or in a hospital at a neonatal intensive care unit (NICU) or not at a NICU). This means that if the response rate for female infants was, for example, lower than the overall response rate, female infants in the sample weigh for somewhat more than one case to correct for that. This makes the data representative for all deaths of infants under 1 year of age in 2010 in the Netherlands.

FINDINGS

End-of-life practices in 2010

We found that, in 2010, 63% of all deaths of children under 1 year of age were preceded by an end-of-life decision (table 1). The vast majority were decisions to withdraw or withhold potentially life-sustaining treatment. Half of these cases also involved the use of possible life-shortening drugs to alleviate pain or symptoms. In 4% of all deaths, the administration of drugs with a possible life-shortening effect to alleviate pain or symptoms was the only end-of-life decision. In 1% of all deaths, drugs were given with the explicit intention to hasten death. All of these cases also involved a decision to withdraw or withhold life-sustaining treatment; there were no cases where death was intentionally hastened by the use of drugs without an accompanying decision to withhold or withdraw potential life-sustaining treatment.

Comparison with earlier years

In 1995, 2001 and 2005, comparable percentages (62%, 68% and 59%, respectively) of deaths of infants under 1 year of age were preceded by an end-of-life decision (table 1).[4 5] As of 2010, these end-of-life decisions were mainly decisions to withdraw or withhold potentially life-sustaining treatment. In 1995, 2001 and 2005, the percentage of cases in which drugs were administered with the explicit intention to hasten death, in combination with another end-of-life-decision, was 8% (95% CI 5% to 12%). In 2010, this percentage has decreased to 1%, (95% CI 0% to 4%). In 1995 and 2001, 1% of all deaths involved an isolated decision to use life-shortening drugs with the explicit intention to hasten the death of an infant (without another preceding end-of-life decision). In 2005 and 2010, no such cases were found.

Characteristics of 2010 cases where death was intentionally hastened by using drugs

The 2010 sample included only two cases where physicians indicated that they had administered drugs with the explicit intention to hasten death. The text boxes present some details of these two cases, based on the responding physicians' answers to the questionnaire.

DISCUSSION AND CONCLUSION

The Dutch practice of end-of-life decision-making for children under 1 year of age has changed little compared with 2005, 2001 and 1995. However, the frequency of using drugs to deliberately hasten death decreased in 2010. We believe that the routine ultrasound examination around 20 weeks of gestation and the legal provision for deliberately ending the life of a newborn, both introduced in 2007, can provide plausible explanations for this decreased frequency. We will explain why.

All 22 cases of deliberate ending of life that were reported to the public prosecutor between 1997 and 2004 concerned cases of children with severe spina bifida.[6] After 2007, however, only one case of deliberate ending of life was reported to the new expert committee that has to review these cases.[3] This one case did not concern a newborn with spina bifida, but it concerned a newborn with the lethal form of epidermolysis bullosa, for which no alternative could be found to relieve its severe pain and suffering.[3 7] It seems that spina bifida is no longer a reason to end a newborn's life. It has been demonstrated in earlier research that the introduction of the ultrasound examination around 20 weeks of gestation resulted in significantly fewer children with spina bifida (or other congenital abnormalities) being born, because many parents opt for termination of the pregnancy.[8] In the period between 2004 and 2006, in 44% of the cases of women carrying a foetus with a neural tube defect (eg, spina bifida), the pregnancy was deliberately terminated; in the period between 2007 and 2009, this percentage was 70 and in the period between 2010 and 2012, this percentage was 73. For foetuses with chromosomal abnormalities, the same trend

Table 1 End-of-life decisions for children under 1 year of age in 2010, 2005, 2001 and 1995 in the Netherlands

	2010 N=177*	2005 N=122	2001 N=233	1995 N=299†
	%‡			
Total end-of-life decisions	63	59	68	62
Life-sustaining treatment withheld or withdrawn	58	55	63	57
No possible life-shortening drugs given	31	27	26	26
In combination with drugs with possible life-shortening effect to alleviate pain or symptoms	26	20	29	23
In combination with drugs given with explicit intention to hasten death	1	8	8	8
No life-sustaining treatment withheld or withdrawn	4	3	4	5
Drugs given with possible life-shortening effect to alleviate pain or symptoms	4	3	3	4
Drugs given with the explicit intention to hasten death	0	0	1	1

*A total of 160 returned questionnaires on deaths that could have been preceded by an EoLD plus 17 sudden and unexpected deaths for which the physician did not receive a questionnaire.
†The large difference between the numbers in 1995 and 2010 can be explained by differences in number of deaths during the study period and response rate; 1995: 338 deaths in study period, response rate 96% versus 2010: 223 deaths in study period, response rate 78%.
‡Rounded and weighted percentage of all deaths of children under 1 year of age in the Netherlands in that year.

Case 1
An infant that died at a neonatal intensive care unit (NICU). Information on the child's diagnosis is missing. The involved physician indicated that artificial respiration was withdrawn with the explicit intention to hasten death. The child's future quality of life was estimated to be so poor that prolonging life was deemed futile. The child also received morphine and a benzodiazepine with the explicit intention to hasten death. The physician indicated that the drug dosages used to alleviate symptoms had not been higher than necessary. During the dying process, a neuromuscular blocker was administered to stop gasping. The child was less than a week old when it died, and its life was estimated to have been shortened by a week at most. The responding physician labelled his act as a 'non-treatment decision' and the death was reported as a natural death.

Case 2
An infant that died at a paediatric ward in a hospital. The child was born with congenital abnormalities.
It received morphine and was, during 8 weeks, continuously sedated with midazolam until death. The child had received artificial fluids and nutrition during this period. The responding physician indicated that artificial respiration and cardiovascular medication were withdrawn with the explicit intention to hasten death. The child was thought to have no realistic chance of survival. The physician indicated that death was caused by the administration of morphine with the explicit intention to hasten death. The physician indicated that the drug dosages used to alleviate symptoms had not been higher than necessary. The child was between 1 and 3 months old when it died, and its life was estimated to have been shortened by a week at most. The physician labelled his act as 'palliative sedation' and the death was reported as a natural death.

can be seen; in 2004–2006, 30% of these pregnancies were terminated, in 2007–2009, 46% were terminated and in 2010–2012, 48% were terminated.[8] Parents of children with major congenital abnormalities (diagnosed antenatally) who are born alive today are likely to have already made a decision in favour of provision of life-sustaining treatment and are thus less likely to ask for deliberate ending of life. The moment of deciding to end a child's life is shifted to pregnancy. This does not imply, however, that this decision has become easier or ethically less problematic; late termination of pregnancy has its own ethical and emotional complexities, but those are beyond the scope of this paper.

End-of-life decision-making at today's NICUs will mainly concern children who are born prematurely or who suffered from severe asphyxia during birth. In both these situations, the use of drugs with the explicit intention to hasten death is not likely to be regarded as acceptable by the expert committee. The argument to end the life of a severely asphyxiated child mainly relates to an expected poor quality of life or a future without perspective. Although some paediatricians regard this as an acceptable reason to deliberately end life, the expert committee does not. This is because the legislator has made clear that the child must suffer unbearably at the moment the decision is made, so its bleak prospects are not seen as an acceptable reason for deliberately ending life.[1 9]

For prematurely born children, life-shortening drugs will not often be used to hasten death either, since these children are likely to be dependent on life-sustaining treatment that can be withdrawn in case physicians and parents think that continuing treatment is no longer beneficial to the child. Life-shortening drugs to hasten death might then be used to end a protracted dying process.[10 11] Recently, the Royal Dutch Medical Association (KNMG) has published a report with recommendations on end-of-life decisions for newborns, in which they express the opinion that the use of lethal drugs (ie, neuromuscular blockers) to end a protracted dying process (whether to relieve the suffering of the patient or the parents) should be seen as acceptable.[12] According to the KNMG, this act should be reported to the expert committee who should review it as acceptable. Although the report—stating the official opinion of the medical profession—may be considered to have a normative status in the Dutch medicolegal context, the due care criteria of the official legal provision do not (yet) allow for the use of lethal drugs to relieve the suffering of the parents and/or without consulting an independent physician.[1 9]

Differences in interpretations of the legal provision

In addition to the finding that the frequency of the use of life-shortening drugs with the explicit intention to hasten death has decreased, the details of the cases presented in the textboxes suggest that physicians may classify their acts differently than the expert committee would. Further, the relation between the physician's reported intention and his actual acts appears to be not self-evident. In case 1, the life-shortening drug used was a neuromuscular blocker, which certainly will hasten death if not administered with artificial ventilation. According to the expert committee's definition of deliberately ending life, this act would classify as such and should be reported.[3] The KNMG also states this act should be reported as deliberately ending life, but they disagree with the expert committee about how it should be reviewed.[12] The physician in case 1, however, classified this death as a 'natural' death and did not report it to the committee. There are other paediatricians who share this viewpoint and who do not regard this act as deliberately ending life.[11]

In case 2, the physician indicated to have administered a life-shortening drug with the intention to hasten death, but the drug given was morphine, in a dose that was reported not to be higher than necessary to alleviate pain and symptoms. The use of morphine in a dose that is not higher than necessary to alleviate pain and symptoms is, at least from a legal point of view, regarded as symptom management and falls under 'normal' medical practice. This physician may have had the intention to hasten death when he used morphine (although this was probably not his sole aim, since there was also a need for alleviation of pain and symptoms), but it is questionable whether the use of morphine indeed had a life-shortening effect.[13 14]

Limitations and strengths

The limitations of this study are its retrospective design and the fact that the study is based on physicians' own perception of their actions and intentions rather than on a report of the actual drugs used and the clinical details of the patients. The strengths of this study, however, are the large number of respondents, its nationwide character, the high response rate and the fact this study has been conducted approximately every 5 years since 1995. This makes it possible to monitor the Dutch practice of end-of-life decision-making through the years and to signal changes in practice.

Conclusion

We conclude that the Dutch practice of end-of-life decision-making for children under 1 year of age has changed little between 1995 and 2010. The frequency of the use of life-shortening drugs with the explicit intention to hasten death,

however, has decreased after the introduction of ultrasound examination at 20 weeks of gestation as a routine prenatal screening procedure and of the legal provision for deliberately ending life, including the installation of an expert committee to review these cases.

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REFERENCES

1 Dutch Ministry of Security and Justice and the Dutch Ministry of Health, Welfare and Sport. Legal provision central expert committee on late termination of pregnancy (category 2) and deliberately ending the life of a newborn. *Staatscourant* 2007;51:8.
2 Verhagen E, Sauer PJ. The Groningen protocol--euthanasia in severely ill newborns. *N Engl J Med* 2005;352:959–62.
3 Annual report years 2009–2010. Expert committee on late termination of pregnancy and deliberately ending the life of a neonate, 2011.
4 Vrakking AM, van der Heide A, Onwuteaka-Philipsen BD, *et al*. Medical end-of-life decisions made for neonates and infants in the Netherlands, 1995–2001. *Lancet* 2005;365:1329–31.
5 Buiting HM, Karelse MA, Brouwers HA, *et al*. Dutch experience of monitoring active ending of life for newborns. *J Med Ethics* 2010;36:234–7.
6 Verhagen AA, Sol JJ, Brouwer OF, *et al*. Deliberate termination of life in newborns in The Netherlands; review of all 22 reported cases between 1997 and 2004. *Ned Tijdschr Geneeskd* 2005;149:183–8.
7 Eduard Verhagen AA. Neonatal euthanasia: lessons from the Groningen Protocol. *Semin Fetal Neonat Med* 2014;19:296–9.
8 Eurocat Nederland. *Eurocat update: short report congenital anomalies Northern Netherlands 1982–2012*. Groningen: University Medical Center Groningen, 2014.
9 Van de Vathorst S, Gevers JKM, Van der Heide A, *et al*. *Evaluation Legal provision central expert committee on late termination of pregnancy and deliberately ending the life of a newborn*. Den Haag: ZonMw, 2013.
10 Moratti S. Ethical and legal acceptability of the use of neuromuscular blockers (NMBs) in connection with abstention decisions in Dutch NICUs: interviews with neonatologists. *J Med Ethics* 2011;37:29–33.
11 Ten Cate K, van de Vathorst S. Dutch pediatricians' views on the use of neuromuscular blockers for dying neonates: a qualitative study. *J Perinatol* 2015;35:497–502.
12 Willems DL, Verhagen AA, van Wijlick E. Infants' best interests in end-of-life care for newborns. *Pediatrics* 2014;134:e1163–8.
13 Thorns A, Sykes N. Opioid use in last week of life and implications for end-of-life decision-making. *Lancet* 2000;356:398–9.
14 Fohr SA. The double effect of pain medication: separating myth from reality. *J Palliat Med* 1998;1:315–28.

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