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Current Concepts and Future Research on End-of-Life Decision Making in Neonatology in the Netherlands[1]

Abstract

In 1995 in the Netherlands, neonatal death was preceded by the decision to forego life-sustaining treatment in 57% of all cases. Almost 70% of pediatricians said they had withheld treatment because of no chance of survival, and 43% because of poor prognosis. For treatment withdrawal, these figures were 84% and 68%, respectively. Parents almost always participated in the decision making and had explicitly asked for it in approximately one third of cases. Some 30% of the pediatricians had at some time abandoned a decision because parents did not agree, and 30% had at some time refused a parental request for an end-of-life decision that they considered unjustified. In over 80% of the decisions, colleagues were consulted. Most pediatricians believed that end-of-life decisions should be reviewed for public control, but preferably not by the Public Prosecutor, who plays a key role in the current judicial notification procedure.

In 1998, a discussion group formed by the government concluded that deliberate ending of life should be subject to special scrutiny, since it is not inherent to normal medical practice. The group advised to design a retrospective assessment by a committee of independent doctors and judicial and ethical experts, and provided a listing of requirements for prudent medical practice relevant for end-of-life decisions in neonatal care.

Since previous research on end-of-life decisions in neonatology was retrospective in design, many questions with respect to the characteristics of the decision making process, team meetings, and communication with the parents remain unanswered. Which medical, nursing, social, religious, ethical and judicial aspects are determinant factors, and what happens to the families afterwards? The open debate on ethical issues in the Netherlands promotes future collaborative multidisciplinary and prospective research to answer these questions.

Advances in perinatal medicine have resulted not only in the survival of many more extremely sick and pre-term babies, but also in an increased risk for an adverse

[1] This paper is largely based on research work carried out by Carmen L.M. de Graaff, Agnes van der Heide, Louis A.A. Kollée, John G.C. Kester, Richard de Leeuw, Paul J. van der Maas and Gerrit van der Wal.

subsequent outcome. In some cases, life-sustaining treatment may not be in the child's best interest. In those cases, physicians have to make difficult decisions. In this review, the history of ethical discussions on neonatal intensive care in the Netherlands is briefly reviewed, and data obtained from studies on end-of-life decision making are presented. Questions arising from these empirical data will be discussed and future research topics will be addressed. Parts of this paper have been published elsewhere.[1]

History

During the rapid development of neonatal medicine in the 1970s and 1980s, Dutch pediatricians became aware of the drawbacks involved in neonatal intensive care. From 1986 onwards, a working group from the Pediatric Association of the Netherlands has been discussing the various types of end-of-life decisions. In 1989, a preliminary report was presented to the members of the Association in a special meeting. A minority of members did not accept the proposal of the working group to allow the withdrawal of life-sustaining treatment for patients who might be able to survive with continuation of treatment. The preliminary report focused on the withholding and withdrawal of treatment. Intentional ending of life was discussed extensively in the working group, but no consensus was reached at that time. In following years, the working group continued to discuss the subject, both within the group and with external experts. Finally, the definitive report *'Doen of laten? Grenzen van het medisch handelen in de neonatologie' [To do or not to do? Boundaries of medical action in neonatology]* was approved by the general assembly of the Pediatric Association of the Netherlands in November 1992.

The report 'Doen of Laten?' [*'To do or not to do?'*][2]

In the report, end-of-life decisions in neonates were categorized into three types: withholding life-sustaining treatment, withdrawing life-sustaining treatment, and intentional ending of life in exceptional cases. These decisions can be made if there is a lack of chances of survival or if there is an extremely poor prognosis for later life if the infant survives. According to the report, there is no ethical problem involved in the decision to withhold or withdraw life-sustaining treatment in cases of inevitable short-term death. This is considered to be a medical decision. If the baby has a chance of survival, the prognosis for later life must be made very carefully and should be based on medical facts. In the report, some important points were described to determine the future quality of life: the mental and physical burden of the infant's life, the infant's capability to interact with his or her environment, the self-sufficiency or dependency of the infant on caregivers and the health care system, and the expected life-span. As these points cannot be evaluated in a simple scoring system, the assessment has to be made on the basis of the overall picture of the quality of the future existence of the individual patient.

The working group was of the opinion that parents and physicians share the responsibility. The doctor takes the final decision, but the parents' wishes should be taken into account. When parents want treatment to be continued this will be done, unless it will cause the child unbearable suffering. Before taking end-of-life decisions, consultation of a team of at least two other physicians and nurses is regarded as mandatory. A minority of cases in which end-of-life decisions are considered concerns newborns who are not dependent on life-sustaining treatment, but have an extremely poor prognosis for future quality of life. Examples are newborns with very severe spina bifida and hydrocephalus, who do not meet the criteria for surgery, or newborns who have survived severe hypoxic-ischemic encephalopathy. Pediatricians in the Netherlands have different opinions on the acceptability of active termination of life in such cases. Some pediatricians feel that it may be acceptable in rare cases, but others are of the opinion that active termination of life in such babies would never be justified, because they are not receiving intensive life-sustaining treatment (any more). The working group stated that in cases in which life-sustaining treatment was withheld or withdrawn because death was inevitable, or because of very poor quality of life in case of survival, a certificate of natural death can be signed by the physician, since the disease was the natural cause of the baby's death. The working group stated that this is in accordance with the law, in contrast with the situation in a case of active termination of life, in which the doctor should not sign a certificate of natural death, since this is illegal. At the time when the working group prepared its report, no empirical research data on the practices and attitudes with respect to end-of-life decisions in the Netherlands were available, but in the 1990s the incidence of end-of-life decisions in Dutch neonatal intensive care units (NICUs) was studied.

The incidence of end-of life decisions

Early studies published articles on the frequency of end-of-life decisions taken in NICUs, which show that in the 1970s and the 1980s life-sustaining treatment had been withdrawn or withheld in between 10% and 30% of all fatal cases. [3-5] In the 1990s, the percentages found in Canada and the United States were higher; between 73% and 90%.[6-8] In 1990, in four Dutch NICUs, life-sustaining treatment was forgone in 59% of infant deaths. [9] In a similar study over the year 1993 in the same units, it was found that this figure had increased to 81%.[10] In a single NICU, from 1990 to 1994, 80 % of all deaths in that unit occurred after the withdrawal of artificial ventilation. [11] In these three Dutch studies, two-thirds of the end-of-life decisions were made because there was no chance of survival. The data published show that in the 1990s approximately 80% of deaths in neonatal intensive care units were preceded by an end-of-life decision in the Netherlands, and also in the United States and Canada.

In the Netherlands, intentional ending of life should be reported to the Coroner for judicial examination. The Coroner will discuss the case with the Public Prosecutor who decides whether or not the physician will be prosecuted. If physicians act according to the requirements for prudent medical practice, they will not be prosecuted. However, much uncertainty exists with respect to the judicial consequences of reporting the intentional ending of a newborn baby's life, and therefore cases are almost never

reported. In 1995, only three cases were reported. In 1996, two cases in which doctors were prosecuted finally resulted in acquittal, because the acts were deemed medically unavoidable. A nationwide study, commissioned by the Ministers of Health and Justice, was performed a few years ago to evaluate the current judicial notification procedure for euthanasia. [12] Parallel to this study, another nationwide study was performed to provide an overview of both practices and attitudes concerning end-of-life decisions in neonates. [13,14] The main results of this study are described below.

Study on practices and attitudes in the Netherlands

A national study on practices and attitudes in the Netherlands was performed in 1995. The study consisted of two parts. The first part was a retrospective study of all 338 consecutive deaths of infants under one year of age from August through November 1995, derived from the death certificates registered by the national statistics. A questionnaire was sent to the attending physicians. Physicians and patients remained completely anonymous to the investigators. Of the questionnaires sent, 88% were returned. Key-questions were whether life-sustaining treatment had been withheld or withdrawn, whether drugs with potentially life-shortening effects had been administered and, if so, whether there had been the explicit intention to hasten death. The second part of the study was an interview study. A random and stratified sample of 67 pediatricians was invited to participate. Only one pediatrician refused, so 66 were interviewed, of whom 31 were neonatologists or intensive care pediatricians and 35 were general pediatricians. They were asked if they had ever forgone life-sustaining treatment, and if they ever administered a drug with the explicit intention of ending a patient's life. For each of these decisions the most recent case, if any, was comprehensively discussed. At the end of the interview, personal opinions were asked on end-of-life decision-making in neonates and on the review procedures for these decisions. To obtain valid estimates for the Netherlands, weights were calculated, based on the percentage of neonatologists and intensive care pediatricians who were represented in the sample, and on the distribution of all deaths of infants under one year of age in the Netherlands per general pediatrician interviewed.

Results of the death certificate study

The incidence of end-of-life decisions in the death certificate study is shown in Table 1. In 38% of the cases no end-of-life decision was made at all, in 24% death occurred suddenly and unexpectedly, and in 14% treatment was continued until death. In the remaining 62%, an end-of-life decision preceded the death. In 57%, 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; an extremely poor prognosis for later life was the main reason in 18%. In 23% of all deaths, withholding or withdrawing treatment was followed by the administration of drugs (mostly opioids) to alleviate pain and discomfort, in doses that may have shortened life. Pain relief is generally regarded as being inherent to appropriate medical care, even if it results in shortening of life. In 8% of all deaths, forgoing life-sustaining treatment was followed

Table 1. Incidence of end-of-life decisions in infants under one year of age in the Netherlands (death certificate study).

	(n = 299) %
Death was not preceded by an end-of-life decision	
death sudden and unexpected	24
treatment continued until death	14
Death was preceded by an end-of-life decision	
life-sustaining treatment withheld/withdrawn	57
no drugs administered	26
drugs administered to alleviate pain and symptoms in doses that may have shortened life	23
drugs administered explicitly to hasten death	8
life-sustaining treatment not forgone, but	5
drugs administered to alleviate pain and symptoms in doses that may have shortened life	4
drugs administered explicitly to hasten death	1

by the administration of drugs with the explicit intention of hastening death because of severe and intolerable suffering. In 4% of all deaths, the only end-of-life decision that was made was the decision to administer potentially life-shortening drugs as palliative care to alleviate pain and symptoms. One percent of all deaths was preceded by a decision to administer a drug with the explicit intention of hastening death in infants who were not dependent on life-sustaining treatment. This percentage represents a total number of 10 to 15 such end-of-life decisions per year in the Netherlands.

Table 2. Statements of pediatricians about their practices concerning end-of-life decisions (interview study).

	Neonatologists/ intensive care pediatricians (n = 31) %	General pediatricians (n = 35) %	All %
Had at some time withheld life-sustaining treatment			
no chance of survival	67	66	67
poor prognosis for later life	55	30	43
Had at some time withdrawn life-sustaining treatment			
no chance of survival	100	68	84
poor prognosis for later life	97	40	68
*Had at some time administered drug with explicit intention to hasten death**			
yes	45	31	37
no, but could conceive of situations in which they would	29	49	39
would never administer, but would refer to another physician	21	20	20
would never administer or refer patient	4	-	2

* Whether or not after a preceding decision to forgo life sustaining treatment.

Results of the interview study

The experiences of pediatricians with end-of-life decisions in neonates are shown in Table 2. Of all pediatricians interviewed, 67% had withheld treatment because of no chance of survival, and 43% because of a poor prognosis for later life. Withdrawal of treatment at least once had been practiced by 84% because of no chance of survival, and by 68% because of a poor prognosis for later life. Neonatologists had withdrawn treatment much more often than general pediatricians. This is explained by the fact that neonatal intensive care in the Netherlands is concentrated in ten NICUs. 45% of the neonatologists and intensive care pediatricians and 31% of the general pediatricians had at some time administered drugs with the intention to hasten death, whether or not following a decision to forgo life-sustaining treatment. Furthermore, 29% of the neonatologists and intensive care pediatricians and 49% of the general pediatricians could conceive of situations in which they would, although they had never actually done so; 22% stated that they would never do so.

Congenital anomalies were the most frequently mentioned underlying diagnoses. Pre-term birth occurred in 30%, and perinatal asphyxia in approximately 25% of the cases. Congenital anomalies of the central nervous system, multiple congenital anomalies, and perinatal asphyxia were the most frequent diagnoses when drugs had been administered to hasten death.

Table 3. Practices and attitudes of pediatricians with regard to the role of parents in end-of-life decisions (interview study)

	Neonatologists/ intensive care pediatricians (n = 31) %	General pediatricians (n = 35) %	All (n = 66) %
Most recent end-of-life decision because of no chance of survival			
discussed with parents	93	92	92
parents requested decision	23	43	38
parents agreed with decision	93	92	92
parents disagreed with decision	-	-	-
Most recent end-of-life decision based on quality-of-life aspects			
discussed with parents	97	67	74
parents requested decision	28	33	32
parents agreed from the beginning	69	35	44
parents agreed after a while	28	32	30
parents disagreed with decision	-	-	-
Did not make an end-of-life decision because parents did not consent			
ever	45	26	29
never, would be willing to do so under certain conditions	36	59	55
never, would never be willing to do so	19	15	15
Did not make an end-of-life decision despite the request of parents to do so			
ever	37	21	24
never, would be willing to do so under certain conditions	53	58	57
never, would never be willing to do so	10	21	19

Pediatricians considered the involvement and approval of parents to be an important requirement for prudent decision-making (Table 3). Parents participated in the end-of-life decision making process in almost all cases attended by neonatologists, but only 67% of the cases attended by general pediatricians were discussed with the parents. End-of-life decisions were never taken against the explicit wish of parents. Parents had explicitly asked for the decision in approximately one third of all end-of-life decisions. Approximately one third of the respondents had at some time in their medical career abandoned an end-of-life decision because parents could not agree with such a decision. Most respondents were willing to refuse a parental request for an end-of-life decision if they did not consider it to be justified. Of the neonatologists, 37% had refused a parental request to end life, compared with 21% of the general pediatricians.

Table 4. Statements of pediatricians concerning review of end-of-life decisions (% replying 'yes', interview study).

	Neonatologists/ intensive care pediatricians (n = 31) %3	General pediatricians (n = 35) %
Forgoing life-sustaining treatment is a medical decision that should be reviewed in		
all cases	52	51
some cases	36	34
no cases	13	14
Administration of a drug to end life is a medical decision that should be reviewed in		
all cases	94	91
some cases	7	9
*Administration of a drug to end life is a medical decision that should be reviewed by**		
caregivers involved	20	32
independent medical professionals	55	59
committee not restricted to medical professionals	75	59
Public Prosecutor	10	5
others	10	18

* More than one answer possible.

Consultation of colleagues before making an end-of-life decision occurred in over 80% of all cases. Table 4 shows the personal opinions of the pediatricians with regard to review of end-of-life-decisions. Of the pediatricians, 52% believed that all end-of-life decisions should be reviewed in some way, and 94% believed cases of intentional ending of an infant's life with drugs should always be reviewed. Opinions varied on who should perform the review. The majority of the pediatricians thought that a committee of independent physicians, together with judicial and ethical experts, would be best qualified to perform this review. The Public Prosecutor was thought to be the appropriate reviewing authority by only 10% of the respondents,

although this is the core of the current judicial notification procedure in the Netherlands.

Review of end-of-life decisions

In 1996, the Dutch Minister of Health and the Minister of Justice established a discussion group, commissioned to make proposals for an adapted notification procedure and an assessment procedure for cases in which the life of a newborn baby with a serious medical condition is deliberately ended. It is apparent that such (rare) decisions are nearly always preceded by decisions to forgo treatment and/or decisions regarding palliative care. The group's report was issued in 1997. [15] A comprehensive survey of the requirements for prudent medical practice was given. The discussion group took the view that decisions to forgo life-sustaining treatment should, in principle, be inherent to normal medical practice, which is not subject to any special form of statutory assessment. Deliberate ending of life, however, is fundamentally different, and should accordingly be subject to special scrutiny. The group concluded that the best approach would be to design a retrospective assessment procedure in which a multidisciplinary committee plays a central role, but the law has not yet been changed. The main requirements for prudent medical practice which are relevant in the context of end-of-life decisions, derived from the report issued by the discussion group,[15] are listed below.

General requirements concerning all types of end-of-life decisions

It should be clear which doctor is primary responsible for the case. All the necessary diagnostic procedures should be performed. The prognosis should be based not only on the doctor's personal knowledge and experience, but also on published data. The team members (including the nursing staff) who are caring for the patient should discuss the diagnosis and prognosis of the patient, and there should be consensus on the diagnosis and prognosis. Parents should, from the beginning, be properly guided and fully informed about all developments in their infant's condition.

Specific requirements concerning decisions to forgo life sustaining treatment

Such a decision can only be taken if, according to the relevant medical standard, treatment is considered to be futile or to have no prospect of success. The doctor should consider the patient's overall present and future medical condition, and should not forgo life-sustaining treatment on the grounds of quality-of-life aspects without the agreement of both parents.

Specific requirements concerning palliative care

When deciding to forgo life-sustaining treatment, the patient should receive all the palliative care necessary to alleviate or prevent suffering. Other experts, such as nursing staff, home care providers and social workers, should be involved in palliative care, if necessary. Parents' needs for psychosocial care and spiritual support should

be considered. Administration of analgesic drugs that may shorten the patient's life because of the side effects must always be discussed with the parents.

Specific requirements concerning the deliberate ending of life

Before deciding to deliberately end the life of a newborn baby, the doctor must ascertain that the patient is suffering intolerably, that no alternative treatment to avoid unnecessary suffering is available, and that the parents explicitly agree with the decision. Advice should be requested from an independent and qualified doctor at another hospital. Any proposal to deliberately end the life of a patient should be discussed with the team caring for the patient, including the nursing staff, and the views expressed should be taken into account when the final decision is made.

General requirements concerning the doctor-parent relationship

Parents should be properly informed and should be stimulated to discuss the matter with other people, such as like social workers and spiritual advisors. The doctor should allow them to seek a second opinion. If the parents wish a particular type of treatment to be continued, despite the fact that the doctor believes it should be discontinued, this wish should be respected, unless continuation would lead to unacceptable suffering. If the parents wish an end-of-life decision to be taken, which is inconsistent with the doctor's personal professional responsibility, the doctor will not respect this wish. If agreement cannot be reached, the doctor should consider asking another doctor to take over the case or transferring the patient to another hospital. It is self-evident that, in addition to the medical history, diagnosis and prognosis, other details should be recorded. A record should also be made of the views of the parents and the medical and nursing staff, the advice of other doctors consulted, the decision taken, the palliative care provided, dosages of any medication given and differences of opinion within the team or between the doctor and the parents. After the life of a patient has been deliberately ended, the doctor should notify the Coroner and not complete a certificate of (natural) death.

Conclusions

In the present neonatal intensive care environment it is impossible to neglect the ethical dilemmas which caregivers face from time-to-time. Doctors are morally and legally entitled to forgo life-sustaining treatment if there is no chance of survival. However, opinions on the right of doctors to take quality-of-life aspects into account differ between cultures and within populations, based on different religious traditions and other characteristics. The majority of pediatricians in the Netherlands are of the opinion that quality-of-life considerations must be taken into consideration in the decision making. They, just as the majority of the population, accept a very poor quality of (future) life as motive to forgo life-sustaining treatment in critically ill newborn babies. The frequency with which death in a neonate in the Netherlands is preceded by a decision to forgo treatment was found to be 57%, and in NICUs as high

as 80%, which is in line with data from other countries. The administration of potentially life-shortening drugs, which are given in palliative care to alleviate pain and suffering, whether or not after forgoing life-sustaining treatment, is considered to be accepted as good clinical practice in terminal care, even if death is hastened. This probably explains the relatively large percentage of pediatricians in this study who admitted that they had administered life-shortening drugs. However, in the Netherlands the intentional ending of life of patients who are not in terminal care is very rare. Parents participate in the decision-making process in most cases. Pediatricians in the Netherlands are of the opinion that some form of public control on end-of-life decision-making in newborns is necessary. However, most pediatricians reject the current notification procedure, in which the Public Prosecutor is almost directly involved. Review by a multidisciplinary committee of independent physicians, together with judicial and ethical experts, of cases of intentional ending of life in neonates, preceding the judgement of the Public Prosecutor, is considered to be probably more effective as public control.

It is important that difficult ethical problems in neonatal care are openly discussed within both the medical profession and society. In 1997, the Royal College of Paediatrics and Child Health in the United Kingdom published a document as a framework for the practice of forgoing life-sustaining treatment in children. [16] In this document it was stressed that it is fundamental that the child's interests are served. Another important statement in this document was that 'it is unrealistic to expect complete consensus'. One should 'seek as much ethical common grounds as possible, while acknowledging sincerely held differences of opinion'.

We should maintain high standards of quality, not only with regard to the medical treatment itself, but also the way in which we handle the ethical aspects of the treatment. More research on end-of-life decision making will help to further improve these standards of quality.

Important research questions

Since previous research on end-of-life decisions in neonatology was retrospective in design, knowledge is incomplete and many questions remain unanswered. One of the key issues in establishing the prognosis for later life in critically ill infants is the predictability of poor outcome. Probably the predictability is less good than we would like it to be. Establishing the prognosis for later life includes subjective elements that should be minimized. Prospective studies on predictability of the outcome after survival might be of value for improvement of the quality of the decisions taken.The procedures of team meetings that result in end-of-life decisions may vary a lot, depending on the local structure of meetings between the various professional groups involved in neonatal care, the personal characteristics of the people involved, and the way in which such meetings are chaired. Decisions should not only be based on scientific and medical data, but also be placed in the context of moral considerations. Moral aspects should be discussed in balance with medical aspects. The author is not aware of any specific training programs for multidisciplinary meetings to discuss ethical

issues concerning individual patients. However, in the St. Radboud University Hospital neonatal intensive care unit in Nijmegen, the Netherlands, the multidisciplinary meetings on end-of-life decision making have recently been structured and formalized. Meetings are chaired by a medical ethicist and the discussion takes place according to a checklist of relevant aspects. It starts with defining the individual moral problem, followed by a discussion of the relevant medical and nursing aspects. Subsequently, social and religious aspects, consequences of the disease and treatment for the well-being of the patient, opinions and feelings of the parents, and a number of aspects concerning the responsibilities of the doctors and other caregivers is discussed. Finally, the decision is made, based on the conclusions derived from the items discussed. The chairperson makes sure that all relevant aspects are discussed in time-balance with each other. This method of 'moral deliberation' will be evaluated to determine whether or not it contributes to the quality of decision making.

Another subject for future research concerns the medical, nursing, social, religious, ethical and judicial aspects that determine the outcome of individual decision making processes. Since many of the characteristics may remain hidden if studied retrospectively, a prospective multi-center study, in which individual neonatal intensive care patients are monitored, could provide in-depth information about the decision processes. In such a study, the interaction among caregivers, and between caregivers and parents, should be monitored by independent researchers The implementation of the end-of-life decisions taken, and a follow-up of the families involved, could be included in such a study. If similar multi-center studies are performed in different countries, the differences between individual institutions and between countries can be analyzed and explained.

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