

# Medical End-of-Life Decisions for Children in the Netherlands

Astrid M. Vrakking, MSc; Agnes van der Heide, MD, PhD; Willem Frans M. Arts, MD, PhD; Rob Pieters, MD, PhD; Edwin van der Voort, MD; Judith A. C. Rietjens, MSc; Bregje D. Onwuteaka-Philipsen, PhD; Paul J. van der Maas, MD, PhD; Gerrit van der Wal, MD, PhD

**Background:** Most end-of-life decision-making studies have, until now, involved either the general population or newborn infants.

**Objective:** To assess the frequency of end-of-life decisions preceding child death and the characteristics of the decision-making process in the Netherlands.

**Methods:** Two studies were performed. The first was a death certificate study in which all 129 physicians reporting the death of a child aged between 1 and 17 years in the period August to December 2001 received a written questionnaire; the second was an interview study in which face-to-face interviews were held with 63 physicians working in pediatric hospital departments.

**Results:** Some 36% of all deaths of children between the ages of 1 and 17 years during the relevant period were preceded by an end-of-life decision: 12% by a decision to refrain from potentially life-prolonging treatment; 21%

by the alleviation of pain or symptoms with a possible life-shortening effect; and 2.7% by the use of drugs with the explicit intention of hastening death. The latter decision was made at the child's request in 0.7% and at the request of the family in 2% of cases. The interview study examined 76 cases of end-of-life decision making. End-of-life decisions were discussed with all 9 competent and 3 partly competent children, with the parents in all cases, with other physicians in 75 cases, and with nurses in 66 cases.

**Conclusions:** While not inconsiderable, the percentage of end-of-life decisions was lower for children than for adults and newborn infants. Most children are not considered to be able to participate in the decision-making process. Decisions are generally discussed with parents and other caregivers and, if possible, with the child.

*Arch Pediatr Adolesc Med.* 2005;159:802-809

## Author Affiliations:

Department of Public Health, Erasmus MC (Drs Vrakking, van der Heide, and Rietjens, and Prof van der Maas) and Erasmus MC-Sophia, Children's Hospital (Profs Arts and Pieters and Dr van der Voort), University Medical Center Rotterdam, Rotterdam, the Netherlands; Department of Public and Occupational Health and Institute for Research in Extramural Medicine, VU University Medical Center Amsterdam, Amsterdam, the Netherlands (Dr Onwuteaka-Philipsen and Prof van der Wal). Dr Vrakking is now with the Department of Intensive Care, Erasmus MC, University Medical Center Rotterdam.

UNTIL NOW, STUDIES ON end-of-life decision making have mainly focused on adults and newborn infants. In these patient groups, end-of-life care frequently involves end-of-life decisions (ELDs), that is, decisions that, whether intentionally or otherwise, hasten death.<sup>1-7</sup> A recent study in 6 European countries showed that ELDs played a role in 23% to 51% of all deaths.<sup>3</sup> In the Netherlands, about two thirds of the deaths of children younger than 1 year are preceded by an ELD.<sup>8,9</sup> Studies from other countries have shown comparably high incidences in newborns and infants.<sup>10-12</sup> Earlier studies about ELDs in older children have concentrated on specific subgroups, such as children cared for in pediatric intensive care units, or specific types of ELDs, such as forgoing life-sustaining treatments or physician-assisted dying.<sup>13-19</sup>

End-of-life decisions range from decisions to forgo potentially life-sustaining

treatments and decisions to alleviate pain or other symptoms by using drugs with a possible life-shortening effect, to decisions to give physician assistance in dying, that is, the use of drugs with the aim of ending life. End-of-life care can also involve the use of deep sedation while withholding artificial administration of food or

*For editorial comment  
see pages 887 and 889*

fluids.<sup>20</sup> In the Netherlands, the use of lethal drugs with the explicit intention of hastening death is defined as euthanasia if someone other than the patient administers the drugs at the explicit request of the patient and as physician-assisted suicide if the patient takes these drugs himself or herself. Before April 2002, physicians who observed the established rules for careful decision making could perform euthanasia or physician-assisted sui-

cide for persons who made a well-considered and voluntary request. More formal procedures were laid down in the new Euthanasia Act<sup>21</sup> that was introduced in April 2002. The new law allows physicians to grant requests for euthanasia or physician-assisted suicide from minors aged 12 to 16 years if parents agree and from minors aged 16 or 17 years if parents are informed. Neither euthanasia nor physician-assisted suicide is permitted in children younger than 12 years.

However, very little is known about the practice of end-of-life decision making for children in the Netherlands. We performed 2 retrospective, descriptive studies in an attempt to gain insight into this practice. The major objective of the studies was to quantify the practice of end-of-life decision making in children in the Netherlands.

## METHODS

Data are presented from 2 studies: the death certificate study and the interview study.

### STUDY 1: DEATH CERTIFICATE STUDY

All deaths in the Netherlands are reported to the central registry of Statistics Netherlands, Voorburg/Heerlen. In 2001, 619 children between the ages of 1 and 17 years died in the Netherlands, of whom 188 died in the 4-month period of our study. Our study focused on the 158 reported deaths occurring in the 4-month period between August 1 to December 1, 2001, for which the addresses of the reporting physicians were available. The identified physicians were sent a written questionnaire as to whether, and if so what type of, end-of-life decision making preceded death; 119 questionnaires were sent out and 90 (75%) were returned. In 39 cases, no questionnaires were sent because the children died suddenly and unexpectedly, which precluded any end-of-life decision making. Nonetheless, these cases were included in the analyses, bringing the total number of cases used for analysis to 129.

Key questions in the questionnaire were (1) Did you withhold or withdraw medical treatment while taking into account the possibility or certainty that this would hasten the patient's death or with the explicit intention of hastening the patient's death? (2) Did you intensify the alleviation of pain and suffering while taking into account the possibility or certainty that this would hasten the patient's death or partly with the intention of hastening the patient's death? (3) Was death the result of the administration, supply, or prescription of drugs with the explicit intention of hastening the patient's death?

If the answer to the third question was yes and the drugs had been administered by someone other than the patient at the patient's explicit request (written or otherwise), the case was classified as euthanasia. If the drug was self-administered, it became a case of physician-assisted suicide. If more than 1 question was answered in the affirmative, the decision with the most explicit intention prevailed. In the case of similar intentions, question 3 prevailed over question 2 and question 2 over question 1. Anonymity requirements precluded the collection of further details about patient characteristics in this study. Details about the design of this study have been published elsewhere.<sup>3,20,22</sup>

### STUDY 2: INTERVIEW STUDY

From June to December 2002, face-to-face interviews were held with physicians of specialties covering the majority of all deaths in children in the Netherlands: pediatric oncologists and he-

matologists, pediatric intensivists, and pediatric neurologists. Respondents had to have had at least 2 years' work experience, in addition to spending more than 50% of their time in their current practice. Pediatrician-oncologists and -hematologists and pediatrician-intensivists are exclusively found at departments within the 8 university hospitals in the Netherlands. A random sample was taken of half, or if only 1 or 2 physicians were working at the relevant department, all, of the physicians at each department. The sample of pediatric neurologists who also work in hospitals other than university hospitals was drawn from their professional registry. Half of the pediatric neurologists working at each hospital were randomly selected, except hospitals at which only 1 or 2 pediatric neurologists were employed, in which case all were selected. Most Dutch pediatric neurologists are neurologists with a special training in pediatric neurology according to the criteria of the International Child Neurology Association. In this article, however, the term *pediatricians* should also be taken to refer to pediatric neurologists. Of the 98 total eligible pediatricians, 69 were approached for interviews, of whom 63 (91%) (27 pediatrician-oncologists and -hematologists, 18 pediatrician-intensivists, and 18 pediatric neurologists) consented to participate.

Experienced physicians who had been trained in using the structured questionnaire conducted the interviews. In the interview study, all questions concerned end-of-life decision making for children between the ages of 3 months and 18 years. Decision making for neonates was not the subject of our study, and therefore, neonates younger than 3 months were excluded.<sup>9,23</sup> First, the physicians were asked whether they ever had performed any of 6 different ELDs and, if yes, how often. We defined these ELDs as:

1. Physician-assisted dying by the use (administration, supply, or prescription) of drugs with the explicit intention of hastening death at the explicit request of the child (that is, euthanasia or physician-assisted suicide);
2. Physician-assisted dying by the use of drugs with the explicit intention of hastening death at the explicit request of parents;
3. Physician-assisted dying by the use of drugs with the explicit intention of hastening death without the explicit request of the child or parents;
4. Deep sedation of a child with drugs such as benzodiazepines or barbiturates while forgoing artificial nutrition or hydration (that is terminal sedation);
5. Withholding or withdrawal of potentially life-sustaining treatments (that is nontreatment decisions);
6. The use of drugs to alleviate pain or other symptoms with a possible life-shortening effect.

Subsequently, questions were asked about the patient characteristics and the decision-making process in the most recent case in their practice, if any, for each of the first 5 ELDs listed. The questionnaire was based on similar studies about ELDs for adults.<sup>8,20,22</sup> Respondents were asked to describe only cases in which they acted as the primary responsible physician. In cases involving more than 1 responsible physician, respondents were asked to describe only those cases in which they had personally communicated with the parents or, if more than 1 physician had communicated with the parents, only the cases in which they had communicated with the parents after the child had died. If they never performed physician-assisted dying at the request of the child or the parents themselves, respondents were asked to describe patients for whom they had been the primary responsible physician but for whom they knew that the family doctor carried out physician-assisted dying at the request of the child or the parents. We compared all cases described by physicians working in the same department, to avoid

**Table 1. Frequencies of End-of-Life Decisions for Children Aged 1 to 17 Years (Death Certificate Study)\***

	Observed	Percentage (95% CI)	Annual
Studied deaths	129		
Sudden and unexpected death†	65	42 (35-49)	245
Nonsudden death, no end-of-life decision	22	23 (17-29)	135
Total end-of-life decisions	42	36 (29-43)	230
Nontreatment decisions	17	12 (7.8-17)	70
Administering drugs to alleviate pain or symptoms with possible life-shortening effect	21	21 (16-28)	125
Physician-assisted dying	4	2.7 (1.2-6.1)	15
Euthanasia‡	1	0.7 (0.1-3.6)	5
Physician-assisted suicide‡	0	0	0
Administering drugs with the explicit intention of hastening death without explicit request of the patient§	3	2.0 (0.8-5.2)	15
Total		100	610

Abbreviation: CI, confidence interval.

\*Observed numbers, weighted percentages for nonresponse by sex and place of death, and estimated annual numbers of all deaths for children aged 1 to 17 years between August 1 and December 1, 2001, in the Netherlands. Values are expressed as number of deaths unless otherwise indicated.

†Including all death cases in which the reporting physicians had their first contact after the person had died.

‡Euthanasia and physician-assisted suicide are defined as the use (administration, supply, or prescription) of drugs with the explicit intention of hastening death at the patient's explicit request.

§These were all performed at the explicit request of the family.

inclusion of the same case twice. One euthanasia case appeared to have been discussed with 2 physicians; in that case, the information provided by the physician most closely involved was used. In cases concerning more than 1 ELD, the use of drugs with the explicit intention of hastening death was considered to prevail over other decisions, and terminal sedation prevailed over nontreatment decisions. The average duration of the interviews was 1.45 hours (minimum 30 minutes; maximum 5 hours). Where time constraints were an issue, discussion of cases of active ending of life prevailed over discussion of other cases.

## VALIDITY

Our questionnaire was based on the validated questionnaire that was used for physicians who treat adult patients.<sup>1,2,8,22,24,25</sup> The questionnaire of study 2 was adapted for pediatric use in close cooperation with physicians from the 3 specialties we (W.F.M.A, R.P., and E.V.D.V.) interviewed. We then tested the questionnaire on 3 caregivers from the specialties involved.

## ANALYSES

Percentages derived from the death certificate study were weighted for nonresponse by sex and place of death to render them representative for all deaths of persons aged 1 to 17 years in the study period. To ensure that the percentages derived from the interview study were representative for all 98 eligible pediatricians, these were weighted for nonresponse by specialty of the respondents.<sup>1,9,22</sup> The statistical package SPSS 11.0 (SPSS Inc, Chicago, Ill) was used for the calculations in both studies, while the confidence intervals were based on the binomial errors.

The Minister of Justice ensured all physicians immunity against prosecution. Additionally, a complex mailing proce-

dures involving a notary was developed to ensure absolute anonymity for both physicians and patients in the death certificate study. The physicians in the interview study were ensured that all information would be handled with the utmost confidentiality. The Inspector General for Health Care and the chairman of the Royal Dutch Medical Association informed all physicians in writing about the purpose of the study and its privacy procedures.

## RESULTS

### STUDY 1: PREVALENCES

The death certificate study showed that 36% of all deaths of children between the ages of 1 and 17 years in the study period were preceded by an ELD (**Table 1**). Of all deaths, 12% concerned a nontreatment decision and 21%, the use of drugs to alleviate pain or other symptoms with a possible life-shortening effect. Some 2.7% of all deaths involved physician-assisted dying, of which 0.7% took place at the request of the patient (euthanasia) and 2.0% did not. The latter cases were all performed at the explicit request of the family. In 50% (n=11) of the cases of the alleviation of pain or other symptoms, the decision concurred with a nontreatment decision. All cases where physician-assisted dying was carried out without the explicit request of the patient were preceded by a nontreatment decision and by alleviation of pain or other symptoms. By contrast, euthanasia was not preceded by a nontreatment decision or alleviation of pain or other symptoms. We found no cases of physician-assisted suicide in this age group. Hence, the estimated absolute number of cases of euthanasia in 2001 in this age group based on the death certificate study is about 5, while the estimated number of cases of physician-assisted dying at the explicit request of the family is about 15.

### STUDY 2: PHYSICIANS' EXPERIENCES

Fifty percent of all the pediatricians taking part in the interview study had at some point received a request from parents to end their child's life, and 15% had ever received such a request from a child (**Table 2**). Of the 63 pediatricians, 14 had at some time in the past complied with a request from parents and 1 had granted a request from a child. Of all the pediatricians interviewed, 24% had at some time applied deep sedation while forgoing artificial nutrition and hydration in a dying child. Administering drugs to alleviate pain or symptoms with a possible life-shortening effect and decisions to forgo a potentially life-sustaining treatment (nontreatment decisions) were more common practices among pediatricians (**Table 2**).

In the interviews, 76 of the most recent cases in which an ELD had preceded the death of a child were discussed: 20 cases of physician-assisted dying where a drug was used with the explicit intention to hasten death, 12 cases of deep sedation while forgoing artificial nutrition or hydration, and 44 cases of nontreatment decisions (**Table 3**) (**Figure**). In 2 of the cases of physician-assisted dying, the decision was made at the explicit request of the child; 1 of these concerned a case of eutha-

**Table 2. Pediatricians' Reports of Requests for Physician-Assisted Dying and Their Practice of End-of-Life Decisions in Children Between 3 Months and 18 Years of Age in the Netherlands (Interview Study)\***

	Oncologists and Hematologists (n = 27)	Intensivists (n = 18)	Neurologists (n = 18)	Total† (n = 63)
Had ever received an explicit request for physician-assisted dying from child or parents‡	18	7	14	39 (62)
From parents	12	7	13	32 (50)
From a child	7	0	2	9 (15)
Had ever performed physician-assisted dying‡	6	1	9	16 (24)
Had ever granted an explicit request for physician-assisted dying from child or parents	5	1	9	15 (23)
From parents	4	1	9	14 (21)
From a child	1	0	0	1 (2)
Had ever performed physician-assisted dying without explicit request of child or parents	1	1	0	2 (3)
Had ever made a nontreatment decision	21	15	14	50 (79)
Had ever applied deep sedation while forgoing artificial nutrition or hydration	5	5	5	15 (24)
Had ever administered drugs with a possible life-shortening effect to alleviate pain or other symptoms	19	13	11	43 (71)

\*Values expressed as absolute number of physicians or absolute number (percentage) of physicians.

†Percentages are weighted for nonresponse and are representative for all pediatric oncologists and hematologists, pediatric intensivists, and pediatric neurologists in the Netherlands.

‡Physicians could have had a request from parents, a child, or both and could have performed physician-assisted dying at the request of parents, a child, without a request, or all 3.

nasia performed by a family doctor in which the respondent was involved. Another 16 cases followed an explicit request for physician-assisted death by the parents, of which 2 respondents reported having been involved in cases where a family doctor had ended a child's life. In 2 other cases, the decision was made without an explicit request from either the child or the parents. There were 3 cases in which the respondent indicated having applied deep sedation and 6 cases in which the respondent indicated having made a nontreatment decision. These were unable to be discussed because of lack of time of the respondent; the average duration of these interviews was 1.50 hours. Of the 76 children, 58 children were younger than 12 years. Thirty-six children had cancer, including leukemia and solid malignant tumors; 16 children had neurological diseases such as neurodegenerative diseases and congenital neurological abnormalities; and 24 children had other diagnoses, which included heart diseases, lung diseases, and infections. Most respondents had had the children in their medical care for longer than 1 month; the length of time in treatment was longer for cases of physician-assisted dying than for cases of deep sedation and nontreatment decisions. Fifty-three children died in the hospital, 18 in an intensive care unit. Deeply sedated children more often died in the hospital than did the other groups. Twenty-one of the 53 children who died in the hospital and 14 of the 22 children who died at home had been diagnosed with cancer (data not shown; information for 1 child diagnosed with cancer was missing). The use of (potentially) life-shortening drugs was not limited to physician-assisted dying. Physicians reported that all cases of terminal sedation involved the use of potentially life-shortening drugs, and this holds for 12 cases in which a nontreatment decision was made. The most frequently used drugs were mor-

phine or other opiates (25 cases) and sedatives (11 cases). Neuromuscular relaxants were used only in 5 of the 20 cases of physician-assisted dying. The pediatricians estimated that life had been shortened by the ELD by less than 1 week in 31 cases and by more than 1 month in 26 cases.

In 9 cases, the respondent considered the child to be fully competent, that is, able to assess his or her own situation and make an adequate decision at the moment of the decision making (**Table 4**). All of these children were 10 years or older. An additional 7 children aged 6 to 18 years were considered to be partly competent. Partly competent could mean that the child was capable of making simple choices and of communicating these or that the child was capable only of understanding simple information. Twelve of 76 children were involved in the decision-making process. The ELD was discussed with all 9 competent children and 3 of the partly or completely incompetent children. All of the children with whom the decision making was discussed were 10 years or older, except for one 5-year-old child for whom a nontreatment decision was made; at an earlier stage of the disease, a colleague of the respondent had talked to the child about his disease and discussed the possibility of forgoing treatment, despite the fact that this child was considered incompetent by the respondent. Of the 20 cases of physician-assisted dying, 4 related to competent patients, of whom 2 had explicitly requested the decision. In the other 2 cases, the request had come from both the parents and the child but that of the child was not explicit (data not shown). In 64 cases, the ELD was not discussed with the child, mainly either because the child was unconscious or, as was the case in most children younger than 12 years, the child was considered too young.

**Table 3. Characteristics of End-of-Life Decisions in Children Between the Ages of 3 Months and 18 Years in the Netherlands (Interview Study)\***

	Physician-Assisted Dying (n = 20)	Deep Sedation While Forgoing Artificial Nutrition or Hydration (n = 12)	Nontreatment Decision (n = 44)	Total
Child's age				
3 mo-5 y	8	5	17	30
6-11 y	6	4	18	28
12-17 y	6	3	9	18
Diagnosis				
Cancer	12	5	19	36
Neurological	4	2	10	16
Other	4	5	15	24
Length of time in medical care†				
<1 mo	3	3	15	21
1-12 mo	7	3	14	24
>1 y	10	4	15	29
Place of death‡				
Hospital	10	6	19	35
Hospital, intensive care unit	3	5	10	18
Home	7	1	14	22
Use of drugs§				
Morphine or other opiates (possibly in combination with other drugs [except neuromuscular relaxants])	8	7	10	25
Only sedatives	4	5	2	10
Neuromuscular relaxants (possibly in combination with other drugs)	5	0	0	5
Estimated shortening of life				
<1 wk	8	9	14	31
Between 1 wk and 1 mo	4	1	10	15
>1 mo	8	2	16	26

\*Values are expressed as absolute number of instances. In 2 of the cases of physician-assisted dying, the decision was made at the explicit request of the child; in 1 of these cases, the respondent had solely been involved in a case where a family doctor had performed euthanasia. In 16 cases, the parents had made an explicit request; 2 of these respondents had solely been involved in cases where a family doctor had ended a child's life. In 2 other cases, the decision was made without a request being made by the child or the parents. Furthermore, 3 cases in which the respondent indicated having applied deep sedation and 6 cases in which the respondent indicated having made a nontreatment decision were not discussed because of lack of time of the respondent.

†In 2 cases of deep sedation while forgoing artificial nutrition and hydration, information on the length of time in treatment was missing.

‡Information on place of death of 1 case of a nontreatment decision was missing.

§In cases of physician-assisted dying, the drugs refer to the drugs that were used to end the child's life; in cases of deep sedation or a nontreatment decision they refer to drugs that possibly had a life-shortening effect.

||In 4 cases of a nontreatment decision, information on the estimated shortening of life was missing.

The ELDs were discussed with the parents in all cases; in 34 cases, the ELD had been requested by the parents. In most cases of physician-assisted dying, the request came from the parents, unlike the majority of cases of deep sedation and nontreatment decisions where the parents usually had not requested the decision. In virtually all cases, the respondents had also discussed their decisions with other physicians. Nurses were involved in the decision-making process in 66 cases. In 2 cases, no request was made by either the child or the parents; instead the decision followed from extensive discussion with the team and with the parents. In both cases, all treatment options had been exhausted and the child's suffering was both hopeless and unbearable. The ELD was taken together with the parents because the decision was seen as the only possibility to relieve the child's suffering.

#### COMMENT

To our knowledge, this study is the first nationwide study on ELDs in Dutch children. In the Netherlands, childhood mortality is very low and mainly concerns chil-

dren younger than 5 years. The main causes of death in children between the ages of 1 and 17 years in 2001 were accidents (29%), cancer (18%), neurological diseases (11%), congenital abnormalities (8%), and infectious diseases (6%)<sup>26</sup>; causes of death during the study period were similar. In study 1, we found the proportion of sudden and unexpected deaths among children to be somewhat higher than for all deaths.<sup>3</sup> The proportion of ELDs was lower than in neonates and infants and somewhat lower than in adults.<sup>3,8-12,22</sup> In children, nontreatment decisions occurred less frequently than in other age groups.<sup>3,8,9,22</sup> This can partly be explained by the fact that death in younger age groups occurs more often suddenly and unexpectedly than in older age groups, so that decisions whether to apply potentially life-prolonging treatment are less often required. Furthermore, treatment may more often be continued in nonsudden deaths up to the time the child dies. The proportion of decisions to administer drugs to alleviate pain and symptoms with a possible life-shortening effect was comparable with the proportion in adults.<sup>3</sup> Apparently, the choices made regarding the relief of suffering in the ter-

minal phase are similar for both children and adults. The practice of active life ending occurs as frequently in children as in adults, but a patient request is rare in children.<sup>3,8,9,22</sup> This may be because, predominantly, most deaths in children occur before age 5 years.

The frequency of ELDs in our interview study was higher compared with other studies in Canada and Europe, where percentages of ELDs of between 34% and 41% were reported. However, these studies solely addressed the decision to forgo life-sustaining treatments in pediatric intensive care units.<sup>14,17,19</sup> In the Dutch Medical Treatment Contract Act<sup>27</sup> and the Dutch Euthanasia Act, children 12 years and older are permitted to decide about their medical treatment or to request hastening of their death. Although any legal cut-off point for age seems arbitrary, our study found that pediatricians indeed feel that children from around the ages of 10 or 12 years onward are often able to participate in an important medical decision. Children 10 years or older were often considered to be partly or fully competent and hence were involved in the decision-making process.

A study in the United States, Canada, and the United Kingdom found that of a group of 228 pediatric oncologists, 26% had at some point received a request for euthanasia and 20%, a request for physician-assisted suicide from parents or children, and that 9% and 4%, respectively, had ever granted such a request.<sup>13</sup> In our interview study, the proportion of requests from parents and children for physician-assisted dying and the proportion of requests granted were higher (62% and 24%, respectively). Rarely among these cases did the request come from the child himself or herself, even when only the deaths of children who were old enough to ask for physician-assisted dying were taken into account. The active ending of life at the parents' request is more commonly practiced. Elsewhere, it was shown that more than half of all pediatricians in the Netherlands are willing to perform active ending of life if the child explicitly requests this and parents agree; when parents do not agree, they are considerably less willing to do so.<sup>28</sup>

Two thirds of all children for whom clinical specialists made an ELD died in the hospital; the remaining one third died at home. Of the children who were diagnosed with cancer, about 60% died in the hospital. In a study of the end of life of children with cancer in the United States, about 50% of the children died in the hospital; nearly half of these deaths occurred in the intensive care unit.<sup>29</sup> The somewhat larger proportion of children with cancer who died in the hospital in our study may be because we only included cases where an ELD had been made. Ending the life of a terminally ill child at home is a rare practice in the Netherlands; this is in accordance with another study in which family doctors reported that they virtually never receive requests for euthanasia or physician-assisted suicide from children younger than 18 years.<sup>8</sup>

Specific problems relate to the medical care and decision making for severely ill children, not in the least because death and dying are usually so far away in this stage of life. Parents are often assigned an important role in the decision making, but there are different opinions on whether parents should make decisions themselves, should be consulted before the physician makes a deci-

#### **1. Physician-assisted dying at the explicit request of the child (euthanasia)**

A 16-year-old child had an autoimmune disease for which no treatment options were left. The child had relapses, infections, cough, fatigue, and loss of appetite and experienced the situation as unbearable. The child was capable of assessing the situation and of making an adequate decision and repeatedly expressed a wish to receive assistance in dying. Parents agreed with the request. Four independent physicians and the medical ethical review board were consulted and also agreed. The pediatrician administered a neuromuscular relaxant after inducing a coma. The parents and a nurse were present at the moment of dying. The physician estimated the shortening of life to be 6 months at maximum. The euthanasia was reported to the Public Prosecutor.

#### **2. Physician-assisted dying at the explicit request of parents**

A child 18 months of age had a progressive neurodegenerative disease. There were no treatment options left. The child was very ill. The child was treated for epilepsy and received artificial nutrition. The parents asked for physician-assisted dying because they felt their child suffered unbearably and hopelessly and because they wanted to shorten the dying process. The request was discussed in a multidisciplinary team. The pediatrician also consulted colleague pediatricians, the nursing staff, the family doctor, and an independent pediatrician from another hospital. The discussion partners all agreed to comply with the request. The child received sedatives and opiates and died within a few hours. The parents and a nurse were present at the moment of dying. The physician estimated the shortening of life to be 4 weeks at maximum.

#### **3. Physician-assisted dying without the request of the child or parents**

A 13-year-old child had acute myeloid leukemia for which no treatment options were left. The child developed multiorgan failure and a subcoma. The lack of treatment alternatives and the possibility of ending the child's suffering by ending life were extensively discussed with the parents. The parents agreed with the ending of life. The child received opiates and died within a few days. The parents and a nurse were present at the moment of dying. The physician estimated the shortening of life to be no more than 1 week.

#### **4. Deep sedation**

A child 14 years of age had a congenital heart disease. When the child was much younger it was decided that surgery would not be beneficial. The child had developed endocarditis, pulmonary embolisms, and respiratory insufficiency, which required artificial ventilation. The physicians concluded that further treatment and ventilation would be in vain, because the child's recovery was not possible. All treatment, including artificial ventilation and nutrition and hydration, was stopped. To avoid severe shortness of breath and to make the dying process more acceptable for the family, the child, who was already in a subcoma, received opiates and was deeply sedated with barbiturates. The physician estimated the shortening of life to be less than 24 hours.

#### **5. Nontreatment decision**

A 5-year-old child had a progressive metabolic encephalopathy, which led to therapy-resistant epilepsy. Different types of drugs, including opiates to induce a coma, were not effective. In the end, it was decided on request of the parents not to start artificial ventilation and to withhold all opiates. One of the attending pediatricians discussed details about prognosis and medical management with the child. The child died shortly afterward. The physician estimated the shortening of life to be about 6 months.

**Figure.** Case descriptions of 5 end-of-life decisions.

sion, or should be protected from participating in such emotionally charged decision making.<sup>13,18,29-31</sup>

The parents were involved in the decision making in all cases, and the decision was made at the explicit request in about half of the cases. In the Netherlands, physicians are trained to involve the patient or the patient's relatives in medical decisions, but in the end, it is the physician who is responsible for the decision that is made (Dutch Medical Treatment Contract Act). Because we only interviewed pediatricians, we do not know what the parents themselves thought about their involvement in the decision making. A qualitative study in hospitals showed that physicians and parents did not always agree on the way decisions for children with cancer were made and that parents were often involved only after the physicians had made their decisions.<sup>32</sup> Furthermore, older children may want to participate in the decision process themselves. Their ability to do so, however, is questionable, especially because end-of-life care may involve decisions that have far-

**Table 4. Discussion of End-of-Life Decisions for Children Between the Ages of 3 Months and 18 Years in the Netherlands (Interview Study)\***

	Physician-Assisted Dying (n = 20)	Deep Sedation While Forgoing Artificial Nutrition or Hydration (n = 12)	Nontreatment Decision (n = 44)	Total (n = 76)
<b>Child</b>				
Child was competent†	4	1	4	9
Child was (partly or completely) incompetent	16	11	39	66
Decision was discussed with child	4	1	7	12
Decision taken at the explicit request of child	2	1	2	5
Decision was not discussed with child	16	11	37	64
<b>Reasons for not discussing the decision with child‡</b>				
Child was too young	9	5	16	30
Child was unconscious	4	5	15	24
Child was mentally handicapped	1	0	8	9
Emotional state of the child	2	1	1	4
Other reason(s)	1	2	2	5
<b>Parents</b>				
Decision was discussed with the child's parents	20	12	44	76
Decision made at the request of the parents	16	3	15	34
<b>Other caregivers decision was discussed with‡</b>				
Other physicians	20	12	43	75
Nursing staff	18	8	40	66

\*Values are expressed as absolute number of instances.

†In 1 case of a nontreatment decision, information on the child's competence was missing.

‡More than 1 answer was possible.

reaching and irreversible consequences. It is often difficult to decide whether and when it is possible or desirable to discuss these decisions with the patient and how to address, for example, children's requests to forgo treatment or to receive assistance in dying.<sup>19,30,31,33</sup>

In almost all cases, the physicians involved colleague-physicians and nurses in the decision making. Apparently, a consultative model is dominant in Dutch pediatric practice. This also holds for the Dutch neonatology practice.<sup>9,23</sup>

Our study has a number of limitations. Because of the retrospective design of the study, there is the possibility of recall bias. However, the validity of our death certificate questionnaire has been shown in several studies.<sup>1,3,9,24</sup> It sometimes appeared to be difficult for physicians to distinguish between the different ELDs, even though the interviewers always mentioned the exact definitions and ordering of different types of ELDs. For example, when pain or other symptoms can only be alleviated with drugs that may hasten death, it can be difficult to distinguish whether hastening of death was taken into account or an appreciated goal when using these drugs. Study 2 is not fully representative of the entire population of physicians who may take ELDs for children because physicians who are rarely involved with dying children, such as family doctors, were not interviewed. Furthermore, no firm comparison can be made between pediatrician-oncologists, pediatrician-intensivists, and pediatric neurologists because the numbers were too small.

## CONCLUSION

End-of-life decision making is an important aspect of end-of-life care for children younger than 18 years. An ELD

is made in about one third of the deaths in this age group, although physician-assisted dying is rare in this age group, especially for older children. In most cases, pediatricians consider children unable to participate in the decision-making process because they are unconscious or because they are too young. Communication about end-of-life decision making for children typically involves caregivers, parents, and, if possible, the child. To gain more insight into the end-of-life decision-making process, experiences and opinions of parents and other caregivers, such as nursing staff, should be studied as well.

**Accepted for Publication:** March 9, 2005.

**Correspondence:** Astrid M. Vrakking, MSc, Department of Intensive Care, Office H1026, Erasmus MC, University Medical Center Rotterdam, PO Box 2040, 3000 CA Rotterdam, the Netherlands (a.vrakking@erasmusmc.nl).

**Author Contributions:** All authors participated in the design and revision of the manuscript and have seen and approved the final version.

**Funding/Support:** This study was supported by a grant from the Ministry of Health, Welfare and Sport and the Ministry of Justice, Den Haag, the Netherlands.

**Additional Information:** The study sponsor approved the study design but was not involved in the data collection, data analysis, or data interpretation.

**Acknowledgment:** We thank Ingeborg Keij-Deerenberg, MSc, of Statistics Netherlands, Voorburg/Heerlen, for contributions to the study; Hanny Groenewoud, PhD, for critical comments on earlier drafts of this article; the members of the steering committee for continuous support throughout the study; the physicians who participated; the interviewers; the research assistants; and the

chairman of the Netherlands Society of Child Neurology, the chairman of the Royal Dutch Medical Association, Utrecht, and the Inspector General for Health Care, Den Haag, for support to the study.

## REFERENCES

1. 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;335:1699-1705.
2. van der Maas PJ, van Delden JJ, Pijnenborg L, Looman CW. Euthanasia and other medical decisions concerning the end of life. *Lancet.* 1991;338:669-674.
3. van der Heide A, Deliens L, Faisst K, et al. End-of-life decision-making in six European countries: descriptive study. *Lancet.* 2003;362:345-350.
4. Pijnenborg L, van der Maas PJ, van Delden JJ, Looman CW. Life-terminating acts without explicit request of patient. *Lancet.* 1993;341:1196-1199.
5. Kuhse H, Singer P, Baume P, Clark M, Rickard M. End-of-life decisions in Australian medical practice. *Med J Aust.* 1997;166:191-196.
6. Meier DE, Emmons CA, Wallenstein S, Quill T, Morrison RS, Cassel CK. A national survey of physician-assisted suicide and euthanasia in the United States. *N Engl J Med.* 1998;338:1193-1201.
7. Deliens L, Mortier F, Bilsen J, et al. End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey. *Lancet.* 2000;356:1806-1811.
8. van der Wal G, van der Heide A, Ontwuteaka-Philipsen BD, van der Maas PJ. *Medical Decision Making at the End of Life: The Practice and the Euthanasia Notification Procedure.* Utrecht, the Netherlands: De Tijdstroom; 2003.
9. van der Heide A, van der Maas PJ, van der Wal G, et al. Medical end-of-life decisions made for neonates and infants in the Netherlands. *Lancet.* 1997;350:251-255.
10. Cuttini M, Nadai M, Kaminski M, et al. End-of-life decisions in neonatal intensive care: physicians' self-reported practices in seven European countries. EURONIC Study Group. *Lancet.* 2000;355:2112-2118.
11. Rebagliato M, Cuttini M, Broggin L, et al. Neonatal end-of-life decision making: physicians' attitudes and relationship with self-reported practices in 10 European countries. *JAMA.* 2000;284:2451-2459.
12. Wall SN, Partridge JC. Death in the intensive care nursery: physician practice of withdrawing and withholding life support. *Pediatrics.* 1997;99:64-70.
13. Hilden JM, Emanuel EJ, Fairclough DL, et al. Attitudes and practices among pediatric oncologists regarding end-of-life care: results of the 1998 American Society of Clinical Oncology survey. *J Clin Oncol.* 2001;19:205-212.
14. Ryan CA, Byrne P, Kuhn S, Tyebkhan J. No resuscitation and withdrawal of therapy in a neonatal and a pediatric intensive care unit in Canada. *J Pediatr.* 1993;123:534-538.
15. Burns JP, Mitchell C, Griffith JL, Truog RD. End-of-life care in the pediatric intensive care unit: attitudes and practices of pediatric critical care physicians and nurses. *Crit Care Med.* 2001;29:658-664.
16. Althabe M, Cardigni G, Vassallo JC, et al. Dying in the intensive care unit: collaborative multicenter study about forgoing life-sustaining treatment in Argentine pediatric intensive care units. *Pediatr Crit Care Med.* 2003;4:164-169.
17. Devictor DJ, Nguyen DT. Forgoing life-sustaining treatments: how the decision is made in French pediatric intensive care units. *Crit Care Med.* 2001;29:1356-1359.
18. Contro N, Larson J, Scofield S, Sourkes B, Cohen H. Family perspectives on the quality of pediatric palliative care. *Arch Pediatr Adolesc Med.* 2002;156:14-19.
19. Garros D, Rosychuk RJ, Cox PN. Circumstances surrounding end of life in a pediatric intensive care unit. *Pediatrics.* 2003;112:e371 Available at: <http://pediatrics.aappublications.org/cgi/content/full/112/5/e371>.
20. Rietjens JA, van der Heide A, Vrakking AM, Onwuteaka-Philipsen BD, van der Maas PJ, van der Wal G. Physician reports of terminal sedation without hydration or nutrition for patients nearing death in the Netherlands. *Ann Intern Med.* 2004;141:178-185.
21. Act of April 12, 2001: review procedures of termination of life on request and assisted suicide and amendment to the penal code and the Burial and Cremation Act (The Termination of Life on Request and Assistance With Suicide [Review Procedures] Act). *Staatsblad.* 2001:1-8.
22. Onwuteaka-Philipsen BD, van der Heide A, Koper D, et al. Euthanasia and other end-of-life decisions in the Netherlands in 1990, 1995, and 2001. *Lancet.* 2003;362:395-399.
23. van der Heide A, van der Maas PJ, van der Wal G, Kollee LA, de Leeuw R, Holl RA. The role of parents in end-of-life decisions in neonatology: physicians' views and practices. *Pediatrics.* 1998;101:413-418.
24. van der Maas PJ, van Delden JJM, Pijnenborg L. *Euthanasia and Other Medical Decisions Concerning the End of Life.* 's-Gravenhage, the Netherlands: Sdu; 1991.
25. van der Wal G, van der Maas PJ, Bosma JM, et al. Evaluation of the notification procedure for physician-assisted death in the Netherlands. *N Engl J Med.* 1996;335:1706-1711.
26. Statistics Netherlands. Statline: main primary causes of death for children from one to 17 years old in the Netherlands in 2001. Available at: <http://statline.cbs.nl/StatWeb/start.asp?LA=en&DM=SLEN&Ip=Search/Search>. Accessed January 5, 2005.
27. Act of 17 November 1994 amending the civil code and other legislation in connection with the incorporation of provisions concerning the contract to provide medical treatment (Medical Treatment Contract Act). *Staatsblad.* 1994:837.
28. Vrakking AM, van der Heide A, Looman CWN, et al. Physicians' willingness to grant requests for assistance in dying for children: a study of hypothetical cases. *J Pediatr.* 2005;146:611-617.
29. Wolfe J, Grier HE, Klar N, et al. Symptoms and suffering at the end of life in children with cancer. *N Engl J Med.* 2000;342:326-333.
30. Foreman DM. The family rule: a framework for obtaining ethical consent for medical interventions from children. *J Med Ethics.* 1999;25:491-496, discussion 497-500.
31. Meyer EC, Burns JP, Griffith JL, Truog RD. Parental perspectives on end-of-life care in the pediatric intensive care unit. *Crit Care Med.* 2002;30:226-231.
32. *Tates K. Parents' Perspectives on Interdisciplinary Attuning of Information and Role Attributions in Child Oncological Care: Conference Book Shared Decision-Making; September 2-4, 2003.* Swansea, Wales: University of Wales; 2003:98-99.
33. Sahler OJ, Frager G, Levetown M, Cohn FG, Lipson MA. Medical education about end-of-life care in the pediatric setting: principles, challenges, and opportunities. *Pediatrics.* 2000;105:575-584.