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.

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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. A recent study in 6 European countries showed that ELDs played a role in 23% to 51% of all deaths. In the Netherlands, about two thirds of the deaths of children younger than 1 year are preceded by an ELD. Studies from other countries have shown comparably high incidences in newborns and infants. 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.

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 fluids. In the Netherlands, the use of lethal drugs with the explicit intention of hastening death is defined as euthanasia if someone other than the physician 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\(^1\) 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.

**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.\(^3\),\(^20\),\(^22\)

**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 hematologists, 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.\(^3\),\(^22\) 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 without 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.\(^3\),\(^20\),\(^22\) 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...
 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. 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 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. 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 procedure 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.

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 euta-
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)*

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

*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-

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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 children 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%). 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. The proportion of ELDs was lower than in neonates and infants and somewhat lower than in adults. 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. Apparently, the choices made regarding the relief of suffering in the ter-

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

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

*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.
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.3,8,9,22 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.14,17,10 In the Dutch Medical Treatment Contract Act27 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.13 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.28

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.29 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.8

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 decision, or should be protected from participating in such emotionally charged decision making.13,18,20-31

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.23 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-reaching consequences for parents, and health care providers. Therefore, informed consent should be given if possible, but if not, the physician should discuss the situation with the parents and usually make the decision.
reaching and irreversible consequences. It is often diffi-
cult to decide whether and when it is possible or desirable
to discuss these decisions with the patient and how to ad-
dress, for example, children’s requests to forgo treatment
or to receive assistance in dying.19,30,31,33

In almost all cases, the physicians involved colleague-
physicians and nurses in the decision making. Appar-
ently, a consultative model is dominant in Dutch pedi-
atrie practice. This also holds for the Dutch neonatology
practice.9,23

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 certifi-
cate questionnaire has been shown in several stud-
ies.1,3,9,24 It sometimes appeared to be difficult for physi-
cians to distinguish between the different ELDs, even
though the interviewers always mentioned the exact defi-
nitions and ordering of different types of ELDs. For ex-
ample, when pain or other symptoms can only be allevi-
ed 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 popula-
tion of physicians who may take ELDs for children be-
cause physicians who are rarely involved with dying chil-
dren, such as family doctors, were not interviewed.
Furthermore, no firm comparison can be made between
pediatric-oncologists, pediatric-intensivists, and pe-
diatric neurologists because the numbers were too small.

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, pediatri-
cians consider children unable to participate in the de-
cision-making process because they are unconscious or
because they are too young. Communication about end-
of-life decision making for children typically involves care-
givers, parents, and, if possible, the child. To gain more
insight into the end-of-life decision-making process, ex-
periences and opinions of parents and other caregivers,
such as nursing staff, should be studied as well.

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

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

*Values are expressed as absolute number of instances.
†1 case of a nontreatment decision, information on the child’s competence was missing.
‡More than 1 answer was possible.

CONCLUSION

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