ARTICLE

Medical End-of-Life Decisions in Children in Flanders, Belgium

A Population-Based Postmortem Survey

Geert Pousset, MA; Johan Bilsen, PhD; Joachim Cohen, PhD; Kenneth Chambaere, MA; Luc Deliens, PhD; Freddy Mortier, PhD

Objectives: To estimate the prevalence of end-of-life decisions and to describe their characteristics and the preceding decision-making process in minors in Belgium.

Design: Population-based postmortem anonymous physician survey.

Setting: Flanders, Belgium.

Participants: All physicians signing the death certificates of all patients (N = 250) aged 1 to 17 years who died between June 2007 and November 2008 in Flanders, Belgium.

Outcome Measures: Prevalence and characteristics of end-of-life decisions and the preceding decision-making process.

Results: For 165 of the 250 deaths, a physician questionnaire was returned (70.5%). In 36.4%, death was preceded by an end-of-life decision. Drugs were administered to alleviate pain and symptoms with a possible life-shortening effect in 18.2% of all deaths, nontreatment decisions were made in 10.3%, and lethal drugs without the patient's explicit request were used in 7.9%. No cases of euthanasia, ie, the use of drugs with the explicit intention to hasten death at the patient's explicit request, were reported. Poor clinical prospects (84.6%) and low quality of life expectations (61.5%) were important reasons for the physicians to engage in end-of-life decisions. Parents were involved in decision making in 85.2% of these decisions, patients in 15.4%.

Conclusions: Medical end-of-life decisions are frequent in minors in Flanders, Belgium. Whereas parents were involved in most end-of-life decisions, the patients themselves were involved much less frequently, even when the ending of their lives was intended. At the time of decision making, patients were often comatose or the physicians deemed them incompetent or too young to be involved.

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Author Affiliations: End-of-Life Care Research Group, Vrije Universiteit Brussel, Brussels, Belgium (Mssrs Pousset and Chambaere, and Drs Bilsen, Cohen, and Deliens); Bioethics Institute Ghent, Ghent University, Ghent, Belgium (Mr Pousset and Dr Mortier); and Department of Public and Occupational Health, Extramuraal Geneeskundig Onderzoek (EMGO) Institute for Health and Care Research, Expertise Center for Palliative Care, VU University Medical Center, Amsterdam, the Netherlands (Drs Cohen and Deliens).

MEDICAL END-OF-LIFE decisions with a possible or certain life-shortening effect have become frequently used options at the end of a patient's life, and their prevalence has been extensively studied in adults.[1-4] In minors (aged <18 years), end-of-life decisions have received less attention, and studies have mostly been limited to specific care settings or patient groups.[5-12] However, end-of-life decisions in minors pose specific clinical and ethical challenges for professional caregivers. Because parents function as advocates for their child, they are the primary communicators with professional caregivers.[13] The involvement of minor patients in the decision-making process is not always straightforward and depends on their age, level of competence, the nature of the decisions concerned, and experience with chronic illness.[14,15] The 3-way interaction between caregivers, parents, and patients makes decision making complex.[16] Furthermore, on an ethical level, the interplay between the parents' representative function and the patient's decision-making capacity raises important questions about the rights of minors to self-determination, the limits of parental advocacy, and balancing best interest considerations with the minor patient's wishes.[17]

Whereas nontreatment decisions and the administration of drugs to alleviate pain and symptoms with a possible life-shortening effect are generally regarded as part of common and sound medical practice, physician-assisted death, ie, the administration, prescription, or supply of drugs by a physician with the explicit intention of ending the patient's life, is much less so.[18-20] If drugs are administrated by a physician to end a pa-

tient's life at the patient's explicit request, the decision is termed *euthanasia* in the 3 countries where laws on this practice have been enacted in recent years: Belgium, the Netherlands, and Luxemburg. In other countries, this practice is commonly referred to as *voluntary euthanasia*. Additionally, physician-assisted suicide, ie, lethal drugs provided by a physician but administered by the patient, has been legally accepted in the Netherlands, Luxemburg, Switzerland, and the states of Oregon, Montana, and Washington in the United States.[21-23] Only in the Netherlands is the law on euthanasia or physician-assisted suicide applicable to minors; they can legitimately request assistance in dying from the age of 12 years with parental consent and from the age of 16 years when parents are informed. For neonates, the Groningen Protocol was developed to facilitate reporting of cases for legal control and to enhance quality of decision making.[24] Debates are taking place in Belgian society and politics to extend the application of the law on euthanasia to include minors, and legal propositions on the subject are under consideration.[25,26] However, little empirical evidence on these end-of-life decisions is available in minors, and in Belgium no population-based data have so far been collected.

This study aims to (1) estimate the prevalence of end-of-life decisions with a possible or certain life-shortening effect in minors across care settings in Flanders, Belgium, (2) describe clinical and demographic characteristics of patients involved, (3) describe characteristics of end-of-life decisions (estimated life-shortening effect and reasons for deciding to perform an end-of-life decision), and (4) describe the decision-making process preceding these end-of-life decisions.

METHODS

In Flanders, the largest region of Belgium with approximately 6 million inhabitants, all deaths are to be reported to the Flemish Ministry of Health. From June 2007 until November 2008 (18-month period), 250 patients residing in Belgium aged 1 to 17 years died in Flanders. The focus was on patients from this age group, because these had not been previously studied in Flanders and only once in the Netherlands.[11] An anonymous questionnaire was mailed by the Flemish Ministry of Health to all physicians who signed the death certificates in each of these cases. There was generally a 2- to 3-month delay between the death of the patient and receipt of the questionnaire. Some physicians signed more than 1 death certificate, but no physician signed more than 5 during the 18-month study period. To enhance response, the total design method was followed, with a maximum of 3 reminders per case.[27] A complex mailing procedure, separating data collection and data analyses with a lawyer serving as an intermediary between physicians and the Flemish Ministry of Health, was used to ensure strict anonymity of both the physician and patient. In an appendix to the questionnaire, physicians were informed about the mailing procedure. The anonymity procedure was identical to that of a study on medical end-of-life decisions in all deaths in Flanders described elsewhere.[28]

The questionnaire was similar to those used in previous studies in adults and neonates,[1-3,6,7,11] but it was adapted to fit pediatric practice by including questions on the decision-making capacity of patients and the involvement of parents. All questions were closed and contained different answer categories for which 1 or more answers were possible.

If, according to the physician, a death was not sudden and unexpected, he or she was asked about end-of-life decisions that may have had a possible or certain life-shortening effect. Instead of using terms with a different connotation, like euthanasia, descriptions of the decisions concerned were used: withholding or withdrawing treatment (nontreatment decisions); administration of drugs to alleviate pain and symptoms (taking a possible hastening of death into account); and the administration, prescription, or supply of drugs by the physician with the explicit intention of hastening the patient's death (physician-assisted death). The latter was further divided according to who administered the drugs and whether or not there was an explicit patient request. If the drugs were administered by the physician at the patient's explicit request, we categorized the decision as *euthanasia*; if the drugs were administered by the patient him or herself, the decision was categorized as *physician-assisted suicide*; a final category contained cases in which drugs were administered by someone other than the patient, with the explicit intention of hastening the patient's death, without explicit patient request. The exact wordings of the questions are described elsewhere.[28] If more than 1 decision was made for 1 patient, the decision with the most explicit life-shortening intention was used to classify the decision. If different decisions with a similar intention cooccurred, the administration of drugs prevailed over the withdrawal or withholding of treatment.

Additional questions were aimed at gathering information on the characteristics of these end-of-life decisions (estimated life-shortening effect or main reasons for the decision) and the care provided (length and goal of treatment for terminal illness). Others focused on the decision-making process preceding the end-of-life decision: discussion with patient, parents, or other professional caregivers and the reasons that the decision was not discussed with the patient. Clinical and demographic information as recorded on the death certificate (age, sex, and cause and place of death) was provided by the Flemish Ministry of Health. The lawyer linked data from the questionnaires case by case to clinical and demographic information of the corresponding deaths, after which the data were made anonymous.

The study, including the anonymity procedure, was approved by the ethical review board of the University Hospital of the Vrije Universiteit Brussel and the ethics committee of Ghent University Hospital. Positive recommendations were received from the Belgian National Disciplinary Board of Physicians and the Belgian Federal Privacy Commission.

Standard descriptive statistics (frequencies and 95% confidence intervals corrected for finite population size [N = 250]) were used to analyze the data. χ^2 Statistics were used to investigate representativeness of the response sample for the population and the association between patient characteristics and end-of-life decisions. Version 15.0 of SPSS was used for all analyses. Significance was set at $P < .05$.

RESULTS

In 16 of the 250 cases, the physician received the questionnaire but was unable to provide information, according to an additional nonresponse survey, because the patient could not be identified or because they had not been involved in the treatment of the patient themselves and the treating physician was not known and/or could not be reached. For 165 of the 234 remaining cases, a questionnaire was returned (response rate of 70.5%).

Of the 165 studied deaths, 92 patients were male (55.8%); 71 died at ages 12 to 17 years (43.0%); external causes of death were the most common (eg, traffic

accidents and suicide [44.8%]); 25 patients died from cancer (15.2%); and the hospital was the most frequent place of death (40.0%). The response sample did not differ from the nonresponse sample by sex, age, or cause of death.

Table 1. Frequencies of Medical End-of-Life Decisions (N=165)[a]

Characteristic	Cases, No. (%)	95% CI
Sudden and unexpected death[b]	88 (53.3)	48.8-57.8
Nonsudden death, no end-of-life decision	17 (10.3)	7.9-13.4
Total end-of-life decisions	60 (36.4)	32.2-40.8
Withholding or withdrawing of life-sustaining treatment	17 (10.3)	7.9-13.4
Without intention of shortening the patient's life	6 (3.6)	2.3-5.7
With intention of shortening the patient's life	11 (6.7)	4.7-9.3
Alleviation of pain and symptoms with a possible life-shortening effect	30 (18.2)	15.0-21.9
Without intention of shortening the patient's life	27 (16.4)	13.3-20.0
With intention of shortening the patient's life	3 (1.8)	0.9-3.5
Use of drugs with the explicit intention of hastening the patient's death	13 (7.9)	5.8-10.7
Euthanasia	0	
Physician-assisted suicide	0	
Life-ending acts without explicit patient request	13 (7.9)	5.8-10.7

Abbreviation: CI, confidence interval.
[a]Number of observed cases, percentage, and 95% confidence intervals were calculated via a complex samples procedure (Monte Carlo) and corrected for finite population size (N = 250).
[b]Including cases in which the physician's first contact was after the child's death.

The proportion of hospital deaths was significantly higher in the response sample than in the nonresponse sample (56.5% vs 40.0%). When the response sample was compared with the total population, demographic and clinical characteristics did not differ (data not shown).

Of all 165 deaths studied, 53.3% were indicated by the physician to have been sudden and unexpected, thus an end-of-life decision was not possible (**Table 1**). In 10.3% of all deaths, death was expected, but no end-of-life decision was made. In total, 36.4% of all deaths were preceded by an end-of-life decision. Administration of drugs to alleviate pain and symptoms with a possible life-shortening effect were the most frequent, involving 18.2% of all deaths. Nontreatment decisions were made in 10.3% of all deaths. Physicians administered, prescribed, or supplied drugs with an explicit intention of hastening the patient's death in 7.9% of all deaths (13 cases), all of which occurred without an explicit patient request. These lethal drugs were muscle relaxants (curare) combined with barbiturates in 1 case, morphine in 8 cases (as the sole drug in 3 and combined with benzodiazepine in 5 cases), and barbiturates in 4 cases (as the sole drug in 2 and combined with benzodiazepine in 2 cases). The drugs were administered by the attending physician in 7 of the 13 cases, by a nurse in 3 instances, and by both in 3 cases. Physicians estimated that death had been hastened by 1 week or less in 90.4% of cases. In 8 of the 13 cases, the main goal of treatment in the last week of life was comfort; in 5 of 13 cases, an expert in palliative care was consulted by the physician. In 6 of 13 cases, the physician had been treating the patient for the fatal illness for more than a year, in 2 cases for 1 week or less. Patients aged younger than 6 years died in 7 of 13 cases, 3 patients were aged 12 years or older.

Table 2. Type of Medical End-of-Life Decision According to Patient Characteristics (N=165)

Characteristic	Study Sample, No. (%)	Nontreatment Decisions (n=17)		Alleviation of Pain and Symptoms[a] (n=30)		Physician-Assisted Death (n=13)		All End-of-Life Decisions (n=60)	
		%	*P* Value[b]	%	*P* Value[b]	%	*P* Value[b]	%	*P* Value[b]
Sex									
M	92 (55.8)	58.8	.79	60.0	.60	53.8	.88	58.3	.62
F	73 (44.2)	41.2		40.0		46.2		41.7	
Age, y									
1-5	62 (37.6)	41.2	.39	46.7	.13	53.8	.30	46.7	.005
6-11	32 (19.4)	29.4		26.7		23.1		26.7	
12-17	71 (43.0)	29.4		26.7		23.1		26.7	
Cause of death									
Cancer	25 (15.2)	11.8	.48	33.3	<.001	30.8	.18	26.7	<.001
External	74 (44.8)	41.2		10.0		15.4		20.0	
Diseases of the CNS	16 (9.7)	11.8		16.7		15.4		15.0	
Congenital diseases	14 (8.5)	0		13.3		15.4		10.0	
Other	36 (21.8)	35.3		26.7		23.1		18.3	
Place of death									
Home	53 (32.1)	11.8	.001	43.3	.21	30.8	.03	31.7	<.001
Hospital	66 (40.0)	82.4		40.0		69.2		58.3	
Other	46 (27.9)	5.9		16.7		0		10.0	

Abbreviation: CNS, central nervous system.
[a]Administration of drugs to alleviate pain and symptoms with a possible life-shortening effect.
[b]*P* value for χ^2 statistic testing differences between patient groups in incidence of end-of-life decisions. The Fisher exact test was used when expected cell counts were less than 5.

Table 3. Characteristics of End-of-Life Decisions

Characteristic	%			
	Nontreatment Decisions (n=17)	Alleviation of Pain and Symptoms[a] (n=30)	Physician-Assisted Death (n=13)	All End-of-Life Decisions (n=60)
Estimated shortening of life[b]				
≥1 wk	13.3	7.7	9.1	9.6
1-7 d	26.7	7.7	45.5	21.2
<24 h	20.0	19.2	45.5	25.0
No shortening	40.0	65.4	0	44.2
Reason for end-of-life decision[b,c]				
No improvement to be expected	87.5	78.3	92.3	84.6
Low expected quality of life	56.3	52.2	84.6	61.5
Not needlessly prolonging life	25.0	39.1	76.9	50.0
Severe symptoms of patient	25.0	17.4	69.2	44.2
Expected suffering of the patient	43.8	47.8	61.5	44.2
Wish of the parents	18.8	52.2	61.5	32.7
Time treated for fatal illness				
1-7 d	47.1	13.3	15.4	23.3
1-4 wk	5.9	13.3	15.4	11.7
1-12 mo	5.9	16.7	23.1	15.0
≥1 y	41.2	56.7	46.2	50.0
Main goal of treatment in last week				
Cure	47.1	13.3	30.8	26.7
Prolonging of life	5.9	3.3	7.7	5.0
Comfort	47.1	83.3	61.5	68.3

[a] Administration of drugs to alleviate pain and symptoms with a possible life-shortening effect.
[b] Data were missing for 2 to 8 cases.
[c] Because multiple answers were possible, percentages may add up to more than 100.

End-of-life decisions were relatively more frequent in children younger than 12 years (46.8% vs 22.5% in children aged 12-17 years). Of children in whom end-of-life decisions were made, 58.3% died in the hospital compared with 31.7% at home and 10.0% in other locations (**Table 2**).

Estimated life shortening was less than 24 hours in 69.2% of cases in which an end-of-life decision was performed and less than 24 hours in 45.5% of physician-assisted deaths (**Table 3**). No improvement prospects and low quality of life expectations were the most common reasons physicians cited in all 3 end-of-life decisions. Not needlessly prolonging life, severe symptoms, expected suffering, and the wish of the parents were other frequently cited reasons in cases of physician-assisted death, but were less frequent in nontreatment decisions and administration of drugs to alleviate pain and symptoms with a possible life-shortening effect. In 50% of cases in which an end-of-life decision was made, the patient had been treated for his or her terminal illness for more than 1 year. The main goal of treatment in the last week of life was comfort in 47.1% of cases of nontreatment decisions and 83.3% in cases of administration of drugs to alleviate pain and symptoms with a possible life-shortening effect.

All nontreatment decisions and cases of physician-assisted death were discussed with the parents, as were 68.0% of cases of administration of drugs to alleviate pain and symptoms with a possible life-shortening effect (**Table 4**). Discussion with parents was aimed at reaching a joint decision in 77.8% of cases. The decision was requested by the parents in 30.4% of nontreatment decisions, in 33.3% of cases of administration of drugs to alleviate pain and symptoms with a possible life-shortening effect, and in 75% of cases of physician-assisted death. Decisions were discussed with the patient in 7.7% of cases of physician-assisted death, 12.5% of nontreatment decisions, and 21.7% of cases of administration of drugs to alleviate pain and symptoms with a possible life-shortening effect. In cases in which an end-of-life decision was made, patients were found not to have decision-making capacity by the physician at the time of decision-making in all cases but 1. As reasons for not discussing the decision with the patient, physicians most frequently cited the patient being comatose (64.3%) or too young (59.5%). Decisions were discussed with other professional caregivers in 92.3% of cases. Rates of involvement of other physicians (92.3%) and nurses (84.6%) were highest in cases of physician-assisted death.

COMMENT

Medical end-of-life decisions preceded 36.4% of all deaths of minors aged 1 to 17 years in Flanders. If sudden and unexpected deaths were excluded, end-of-life decisions preceded 78% of deaths. The administration of drugs to alleviate pain and symptoms with a possible life-shortening effect was the most frequent end-of-life decision. Nontreatment decisions were less frequent. The prevalence of physician-assisted death was high. No case of euthanasia was reported. Poor clinical prospects and low quality of life expectations were important reasons for the physicians to make an end-of-life decision. Shared

Table 4. Decision-Making Process Preceding End-of-Life Decisions[a]

Characteristic	%			
	Nontreatment Decisions (n=17)	Alleviation of Pain and Symptoms[b] (n=30)	Physician-Assisted Death (n=13)	All End-of-Life Decisions (n=60)
Decision discussed with parents	100.0	68.0	100.0	85.2
Aim of discussion with parents[c]				
Reaching a decision together	66.7	82.4	84.6	77.8
Obtaining parental consent	6.7	17.6	23.1	15.6
Informing parents of a decision	13.3	11.8	7.7	11.1
Decision requested by parents	33.3	30.4	75.0	41.2
Decision discussed with patient	12.5	21.7	7.7	15.4
Decision requested by patient	0	4.3	0	1.9
Reasons for not discussing with patient[c]				
Patient was comatose	92.3	41.2	66.7	64.3
Patient was too young	38.5	76.5	58.3	59.5
Patient was mentally disabled	30.8	35.3	50.0	35.7
Patient was found competent	0	0	7.7	2.1
Decision discussed with other caregivers[c]				
Physicians	75.0	69.6	92.3	76.9
Nurses	43.8	43.5	84.6	53.8
Other	6.3	26.1	7.7	15.4
Not discussed with other caregivers	12.5	8.7	0	7.7

[a] Percentages do not always add up to 100 because of rounding. Data were missing for 3 (reasons for not discussing with patient), 6 (discussion with parents), 8 (discussion with patient and other caregivers), 9 (request by parents), and 13 (patient competence) cases.
[b] Administration of drugs to alleviate pain and symptoms with a possible life-shortening effect.
[c] Because multiple answers were possible, percentages may add up to more than 100.

decision making with parents was reached in 85.2% of cases, but patients were seldom involved in the process themselves. Physicians reported the patient being comatose or too young as the most important reasons for not involving them.

To our knowledge, this study was only the second in the world to investigate end-of-life decisions in children across different care settings and causes of death.[11] Although our response rate was slightly lower than studies in the Netherlands, which reported response rates of 75%[11] to 78%,[3] and a study in neonates in Flanders in which a response rate of 87% was reported,[6] a good response rate of 70.5% was attained. Patients in our response group were representative of the total population. The method we used has been successfully applied in previous studies and allows for making reliable estimates of end-of-life decisions.[1-3,6,7,11] However, only the physician's perspective was studied; the valuable perspective of parents was not included. Our study was retrospective and descriptive, thus less suitable for providing in-depth explanations of its findings.

Medical end-of-life decisions are frequent in children dying in Flanders, as could be expected from previous studies in limited patient groups (eg, neonates) and settings (eg, intensive care units), where medical end-of-life decisions were also frequent.[5-10] The overall prevalence of end-of-life decisions in the present study was lower than in Flemish adults (48%)[4] and in neonates in Flanders and the Netherlands[6,7] but consistent with the only comparable population-based study in children aged 1 to 17 years in the Netherlands (36%).[11] However, the finding that Flemish physicians frequently intended to hasten death (in 7.9% of all deaths) was remarkable and different from findings in the United States, where hastening of death is rather a foreseen but unintended adverse effect of medical end-of-life decisions.[5] The prevalence in our study was higher than that of physician-assisted death in Flemish adults (3.8%) and was similar to that found in Flemish neonates (7%).[4,6] The prevalence of physician-assisted death in children is notably higher in Belgium than in the Netherlands (7.9% vs 2.7%), but in Belgium there was no case of a patient explicitly requesting physician-assisted death (euthanasia), compared with 5 cases per year in the Netherlands.[11] The finding that ending a patient's life without his or her request was more frequent in Belgium than in the Netherlands is consistent with findings of previous studies among adults.[2,3] This may be caused by differences in actual practices of Flemish and Dutch physicians. Flemish physicians in fact acted more often with an explicit life-shortening intention than their Dutch colleagues. They also differ by reported intentions; physicians may have acted in a similar way in both countries, but Flemish physicians ascribed a more explicit life-shortening intention to their acts than their Dutch colleagues. The present findings further suggest that physician-assisted death is not an isolated practice in Flanders but is part of a broader process of care and symptom control. In this study, physician-assisted death mostly occurred after a long period of illness, often by increasing dosages of morphine in discussion with the parents, and—given the limited estimated life-shortening effect—often at the very last moments of life.

All nontreatment decisions and physician-assisted cases of death were previously discussed with the parents of the minors, and physicians mostly indicated that they reached a decision together with the parents, indicating that physicians predominantly followed a model of shared decision making in these cases. Unfortunately, the study

does not allow for comparison of physician and parental perspectives on this matter, which could have provided a greater depth of understanding. The results concur with the results from the nationwide study in the Netherlands, where end-of-life decisions were always discussed with the parents of the child,[11] and with the findings in Flemish neonates, where decisions were discussed with parents in 84% of cases.[29] In cases of the administration of drugs to alleviate pain and symptoms with a possible life-shortening effect, discussion with parents occurred less often. It may be that physicians find it less necessary to discuss this decision with the parents, considering it a duty and part of standard practice to relieve their patients' suffering irrespective of the opinion of others, even if a possible life-shortening adverse effect cannot be precluded.[30,31] On the other hand, administration of drugs to alleviate pain and symptoms with a possible life-shortening effect was relatively more often discussed with or requested by the patient. It seems more often to be patient initiated, possibly with the patient indicating to the physician a worsening of his or her symptoms. Nontreatment decisions and physician-assisted death generally occurred in different clinical circumstances than administration of drugs to alleviate pain and symptoms with a possible life-shortening effect, with poorer clinical prospects for patients, which made it more difficult to discuss the decisions with them. Given the clear life-shortening effect of both decisions, it is thus not surprising that parents were consulted in all of these cases.

End-of-life decisions were generally not discussed with minor patients, and only 1 patient was considered to have the capacity for decision making by the attending physician. This was in line with a Dutch interview study, in which pediatricians found minor patients incompetent for end-of-life decision making in 12% of cases and consequently did not discuss the decision with minor patients in 84% of cases.[11] In about two-thirds of cases, the patient's comatose condition was cited by the physician as a reason for not discussing the end-of-life decision. In nearly 60% of cases, physicians deemed the patients too young to discuss possible end-of-life decisions. These patients were younger than 6 years in more than 70% of cases. In 7 of 10 cases in which a decision was not discussed with a patient aged 12 years or older, the patient was comatose. These reasons were the same as those for not discussing a decision with a minor patient reported by Dutch pediatricians: in 71%, patients were unconscious or deemed too young.[11] The present data are limited in providing a full understanding of what factors determine physicians' assessment of minor patients' decision-making capacity. Additional research is needed to comprehend why decisions are not discussed with minor patients and how physicians assess their decision-making capacity.

Medical end-of-life decisions are frequent in minors in Flanders. Although the legal representatives of the minors were involved in most end-of-life decisions, patients themselves were involved very rarely, even when life ending was intended. At the time of decision making, patients were often comatose or the physicians deemed them incompetent or too young to be involved.

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Correspondence: Geert Pousset, MA, Department of Medical Sociology, End-of-life Care Research Group, Laarbeeklaan 103, 1090 Brussels, Belgium (geert.pousset@ugent.be).
Author Contributions: *Study concept and design:* Pousset, Bilsen, Cohen, Chambaere, Deliens, and Mortier. *Acquisition of data:* Pousset, Bilsen, Cohen, Chambaere, Deliens, and Mortier. *Analysis and interpretation of data:* Pousset, Bilsen, Cohen, Chambaere, Deliens, and Mortier. *Drafting of the manuscript:* Pousset. *Critical revision of the manuscript for important intellectual content:* Pousset, Bilsen, Cohen, Chambaere, Deliens, and Mortier. *Statistical analysis:* Pousset, Bilsen, Cohen, Chambaere, Deliens, and Mortier. *Obtained funding:* Bilsen, Cohen, Deliens, and Mortier. *Administrative, technical, and material support:* Pousset and Chambaere. *Study supervision:* Pousset, Bilsen, Cohen, Deliens, and Mortier.
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Correction

Error in Text. In the Article titled "Primary Operative Management for Pediatric Empyema: Decreases in Hospital Length of Stay and Charges in a National Sample" by Li and Gates, published in the January 2008 issue of the *Archives* (2008;162[1]:44-48), an error occurred in the text on page 46. The fourth sentence of the second paragraph in the left column should have read, "An estimated 10 or fewer patients died during their empyema hospitalization, all in the NM [nonoperative management] arm."