

Reporting of euthanasia in medical practice in Flanders, Belgium: cross sectional analysis of reported and unreported cases

Tinne Smets, junior researcher,¹ Johan Bilsen, professor of public health,¹ Joachim Cohen, senior researcher,¹ Mette L Rurup, senior researcher,² Freddy Mortier, professor of bioethics,³ Luc Deliens, professor of public health and palliative care^{1,2}

¹End of Life Care Research Group, Vrije Universiteit Brussel, Brussels, Belgium

²Department of Public and Occupational Health, EMGO Institute for Health and Care Research, Expertise Center for Palliative Care, VU University Medical Centre, Amsterdam, Netherlands

³Bioethics Institute Ghent, Ghent University, Ghent, Belgium

Correspondence to: T Smets, End of Life Care Research Group, Faculty of Medicine and Pharmacy, Laarbeeklaan 103, 1090 Brussels, Belgium tinne.smets@vub.ac.be

Cite this as: *BMJ* 2010;341:c5174
doi:10.1136/bmj.c5174

ABSTRACT

Objectives To estimate the rate of reporting of euthanasia cases to the Federal Control and Evaluation Committee and to compare the characteristics of reported and unreported cases of euthanasia.

Design Cross sectional analysis.

Setting Flanders, Belgium.

Participants A stratified at random sample was drawn of people who died between 1 June 2007 and 30 November 2007. The certifying physician of each death was sent a questionnaire on end of life decision making in the death concerned.

Main outcome measures The rate of euthanasia cases reported to the Federal Control and Evaluation Committee; physicians' reasons for not reporting cases of euthanasia; the relation between reporting and non-reporting and the characteristics of the physician and patient; the time by which life was shortened according to the physician; the labelling of the end of life decision by the physician involved; and differences in characteristics of due care between reported and unreported euthanasia cases.

Results The survey response rate was 58.4% (3623/6202 eligible cases). The estimated total number of cases of euthanasia in Flanders in 2007 was 1040 (95% CI 970 to 1109), thus the incidence of euthanasia was estimated as 1.9% of all deaths (95% CI 1.6% to 2.3%). Approximately half (549/1040 (52.8%, 95% CI 43.9% to 60.5%)) of all estimated cases of euthanasia were reported to the Federal Control and Evaluation Committee. Physicians who perceived their case as euthanasia reported it in 93.1% (67/72) of cases. Cases of euthanasia were reported less often when the time by which life was shortened was less than one week compared with when the perceived life shortening was greater (37.3% v 74.1%; $P<0.001$).

Unreported cases were generally dealt with less carefully than reported cases: a written request for euthanasia was more often absent (87.7% v 17.6% verbal request only; $P<0.001$), other physicians and caregivers specialised in palliative care were consulted less often (54.6% v 97.5%; 33.0% v 63.9%; $P<0.001$ for both), the life ending act was more often performed with opioids or sedatives (92.1% v

4.4%; $P<0.001$), and the drugs were more often administered by a nurse (41.3% v 0.0%; $P<0.001$).

Conclusions One out of two euthanasia cases is reported to the Federal Control and Evaluation Committee. Most non-reporting physicians do not perceive their act as euthanasia. Countries debating legalisation of euthanasia should simultaneously consider developing a policy facilitating the due care and reporting obligations of physicians.

INTRODUCTION

Medical end of life decisions including euthanasia, are known to occur in several countries.^{1,2} Belgium is, along with the Netherlands and Luxembourg, one of the few places in the world where euthanasia is legal. Questions concerning efficient societal control over euthanasia and the prevention of abuse are at the forefront of the debate over euthanasia.³⁻⁶ The secrecy in which euthanasia takes place in countries where it is illegal prevents the development of standards for careful practice and makes societal control difficult.^{7,8} However, legalisation of euthanasia usually involves defining a standard for careful medical practice and a system for societal control.⁹⁻¹² Due care criteria were embedded in the law when euthanasia was legalised in Belgium in 2002.^{9,10} To make societal control over euthanasia possible, the law also requires physicians who perform euthanasia to report each case to the Federal Control and Evaluation Committee (review committee). This review committee determines whether or not the due care criteria of the law were respected and sends the case to the judicial authorities when irregularities are found.^{9,13}

Since legalisation of euthanasia in Belgium, the review committee has published three biennial reports covering all reported cases of euthanasia.¹⁴⁻¹⁷ According to these documents, physicians who reported cases practised euthanasia carefully and in compliance with the law, and no cases of abuse have been found. However, concerns exist that only cases of euthanasia that are dealt with carefully are being reported.¹⁸ Whether cases that are not reported to the official review system are dealt with equally carefully is uncertain.

In the Netherlands, surveys on end of life decisions have been conducted using a representative sample of death certificates to identify instances where a definition of euthanasia was met but the case was not reported to the authorities. These studies have shown that although reported and unreported cases of euthanasia did not differ according to patient characteristics and clinical conditions, physicians responsible for the unreported cases were less likely to have consulted a second physician or written a report on the decision.^{19,20} The reporting rate in the Netherlands has gradually increased from 18% in 1990 to 80.2% in 2005, indicating a trend towards more societal control over the practice.²¹ Most euthanasia cases that are not reported in the Netherlands are performed with opioids or sedatives and are often not perceived as euthanasia by the physicians themselves.^{20,21}

The rate at which physicians in Belgium report cases of euthanasia is unknown, and differences between reported and unreported cases have not been investigated. In this large scale study of death certificates, we estimate the rate of reporting of euthanasia cases in Flanders, the Dutch speaking part of Belgium, to the federal review committee. We investigate the relation between reporting and non-reporting of euthanasia and the characteristics of the physician and patient, the time by which life was shortened as estimated by the physician, and the labelling of the end of life decision by the physician involved. Finally, we study the reasons for non-reporting, and compare due care characteristics of reported and unreported cases.

METHODS

Study design

We performed a study of death certificates in Flanders, Belgium, with the principal aim of estimating the incidence of medical end of life decisions with a possible or certain life shortening effect.²² All deaths in Flanders must be reported to the proper government authorities and death certificates issued. By studying death certificates we were able to use death as the unit of measurement and reliably estimate the incidence and characteristics of end of life decisions.²³ A stratified at random sample of persons deceased in Flanders was drawn by the Flemish Agency for Care and Health, the central administration authority that handles death certificates. All deaths of Flemish residents aged 1 year or more that took place in Flanders between 1 June 2007 and 30 November 2007 were included. Deaths of Flemish persons that occurred outside of Flanders, deaths that occurred in Flanders of persons who were temporarily in Flanders but did not reside there on a permanent basis (mainly deaths by accident), and deaths of persons younger than 1 year were excluded.

To increase the reliability of the estimate of the total number of euthanasia cases, we oversampled cases where an end of life decision was more likely. Deaths were grouped into one of four strata according to the underlying cause of death on the death certificate and the corresponding probability of an end of life decision

being made. Stratum one contained all deaths where an end of life decision was certain (that is, euthanasia indicated as the immediate cause of death); stratum two contained all deaths from neoplasms (international classification of diseases, 10th revision (ICD-10) codes C and D00-D48) where medical assistance in dying was probable; stratum three contained all deaths from causes where medical assistance in dying was possible (ICD-10 codes E, F, G, J, K, and N); and stratum four contained all deaths where medical assistance in dying was improbable. All deaths in stratum one were retained in the sample, whereas 50% of the deaths in stratum two, 25% in stratum three, and 12.5% in stratum four were included. This resulted in a sample of 6927 death certificates, which represents about 25% of all deaths in the sampling period and about 12% of all deaths in the whole of 2007. Data were weighted afterwards to correct for the disproportionate stratification of the underlying causes of death.²²

Every physician who had reported a death was sent a five page questionnaire. If the physician who received the questionnaire was not the main treating physician, he or she was asked to pass the questionnaire on to the treating physician. To guarantee total anonymity of physicians and patients, a lawyer was used as intermediary between responding physicians, researchers, and the Flemish Agency for Care and Health. We used the total design method to optimise the response rate.²⁴ An intensive follow-up mailing was conducted in cases of non-response.

Deaths where physician response to the questionnaire was impossible were excluded—for example, cases where the physician could not identify the patient on the basis of the information in the letter or did not have access to the patient file; cases where the certifying physician was not the treating physician for the patient in question; and cases where the identity of the treating physician was unknown.

Positive recommendations for the anonymity procedure and study protocol were obtained from the ethical review board of the University Hospital of the Vrije Universiteit Brussel, the ethics committee of the University Hospital of Ghent University, the Belgian National Disciplinary Board of Physicians, and the Belgian Federal Privacy Commission. The study design, sampling, and mailing procedure are described in detail elsewhere,²² and the first results of this study have previously been published.²⁵

Questionnaire

The questionnaire focused on the characteristics of the end of life decision making that preceded the patient's death. Terms such as "euthanasia" were not used because they are subject to ambiguous and multidimensional definition. Instead, four key questions were used to more validly determine the types of decision in end of life care. The questions assessed whether the physician had taken any of the following measures: withholding or withdrawing medical treatment taking into account a possible life shortening effect; intensifying the alleviation of pain or other symptoms with a

possible life shortening effect; withholding or withdrawing medical treatment with the explicit intention of hastening the patient's death; or administering, supplying, or prescribing drugs with the explicit intention of hastening the patient's death. The act was classified as euthanasia if the last of the four key questions was answered affirmatively, the act was performed in response to an explicit request of the patient, and the physician or another person other than the patient himself or herself had administered the drug. This definition of euthanasia corresponds to the legal definitions of euthanasia in Belgium,⁹ the Netherlands,²⁶ and Luxembourg,²⁷ and to the definition of euthanasia used by the European Association for Palliative Care in its official position statement on euthanasia.²⁸ For cases in which physicians responded affirmatively to more than one of the four key questions, the act that involved the most explicit intention with regard to the hastening of the patient's death was used to classify the act. When classifying cases of euthanasia, the administration of drugs prevailed over the withholding or withdrawing of medical treatment for cases in which there was no single most explicit intention.

The questionnaire also contained questions about the decision making process, the type of drugs used, and the life shortening effect of the act, as estimated by the physician. We also asked whether or not the physician had reported the case to the review committee, and, if appropriate, their reasons for non-reporting. Physicians were further asked to choose the term that they thought best described their act: alleviation of symptoms; non-treatment decision; palliative or terminal sedation; or euthanasia.

Analysis

To estimate the reporting rate for euthanasia in Flanders, two numbers are needed:

- 1) An estimate of the number of euthanasia cases reported to the review committee (numerator)
- 2) An estimate of the total number of euthanasia cases performed (denominator).

The survey of death certificates allowed us to estimate the total number of euthanasia cases in Flanders in 2007. To estimate the number of euthanasia cases reported to the review committee, we used the question that asked whether or not the physician had reported the case to the review committee. The total number of euthanasia cases reported to the review committee in Belgium is actually known from the committee reports,¹⁴⁻¹⁶ but we chose not to use the official data to calculate the reporting rate because they do not allow us to distinguish with certainty the euthanasia cases performed in Flanders from those performed in Brussels or Wallonia, the other two parts of Belgium. The classification "reported" or "unreported" was made using the question whether or not the physician had reported the case to the review committee.

The total number of euthanasia cases and the total number of reported euthanasia cases were estimated by weighting the sample for the disproportionate

stratification procedure and for non-response bias with regard to age, sex, province, place, and cause of death, making the numbers representative for all deaths in Flanders in the study year. The weighting procedure was done in three steps. In the first step, the data were corrected for the disproportionate stratification procedure by assigning to the cases a weight that was the inverse of the sampling fraction of the stratum they had been assigned to. We found proportionally less hospital deaths and more cancer deaths in the sample than in the population ($P < 0.000$). To correct for this difference, in a second step the sample was weighted on the basis of place of death and cause of death by dividing the number of cases in the population by the sampled number for each combination of these characteristics. Finally, we found significant differences between responding physicians and non-responding physicians in the age, province, and place of death of their patients. We therefore calculated an additional weight by dividing the sampled number of cases by the responding number for every specific combination of these three variables. The different weights resulting from the three steps were combined into one overall weight. After this procedure no significant differences were found between the cases from responding physicians and the population for sex, age, province, place, and cause of death. The data are therefore representative of the entire population. The weighting procedure was done using binary logistic regression.

Differences in the distribution of characteristics between reported and unreported cases of euthanasia were tested by Fisher's Exact test. P values that were less than or equal to 0.05 were considered to indicate statistical significance. Statistical calculations were performed with SPSS software version 16.0. Reliable multivariate models could not be made because of multicollinearity.

RESULTS

Reporting rate for euthanasia

The survey response rate was 58.4 (3623/6202 eligible cases). There were 6927 deaths in the sample, of which 725 were excluded because response for these cases was impossible. There were thus 6202 eligible deaths in the sample. The number of cases of euthanasia in the sample according to the death certificates was 137. Extrapolation on the basis of these 137 cases gave an estimated total number of cases of euthanasia in Flanders in 2007 of 1040 (95% CI 970 to 1109; table 1). The incidence of euthanasia in Flanders in 2007 was thus estimated as 1.9% of all deaths (95% CI 1.6% to 2.3%).²⁵ Approximately half (549/1040 (52.8%, 95% CI 43.9% to 60.5%)) of euthanasia cases were reported to the review committee (that is, an estimated yearly number of 549, 95% CI 426 to 672).

Reasons for not reporting a case of euthanasia

The physicians who specified that they had not reported a case that the study defined as euthanasia (n=64 cases) were asked about the reasons for non-reporting. For 76.7% of these cases, physicians answered that they

Table 1 Reporting rates for euthanasia in Flanders, Belgium, in 2007

	Number of cases	Rate
Estimated number of cases of euthanasia	137	—
Estimated number of reported cases of euthanasia	549	—
Estimated weighted total number of cases of euthanasia*	1040	1.9% (1.6% to 2.3%)†
Overall reporting rate for euthanasia‡		52.8% (43.9% to 60.5%)†
Reporting rates for euthanasia according to drug use§		
Recommended drugs¶	70	92.9% (84.3% to 96.5%)
Non-recommended drugs**	61	4.8% (1.1% to 16.9%)

*The estimated total rate of euthanasia was calculated by weighting for stratification and for patient and mortality characteristics of all deaths in 2007.²⁵ The original number of euthanasia cases in the sample was 137. One case was missing data on the variable "reporting of end of life decision."

†Percent of all deaths in Flanders, Belgium, 2007.²⁵

‡Weighted percentage.

§Five "missings" on the variable "drugs used for euthanasia."

¶Barbiturates, neuromuscular relaxants, or both.

**Opioids, benzodiazepines, or other drugs other than barbiturates or neuromuscular relaxants.

did not perceive their act as euthanasia, whereas for 17.9% they gave the reason that reporting is too much of an administrative burden, 11.9% that the legal due care requirements had possibly not all been met, and 9% that euthanasia is a private matter between physician and patient (8.7%). A small proportion (2.3%) did not report the case because of possible legal consequences (multiple answers were possible, not in tables).

Reporting of euthanasia according to characteristics of physician and patient, time by which life was shortened, and labelling of the end of life decision

General practitioners and specialists were equally likely to report their cases of euthanasia to the review committee (43/80 (53.8%) *v* 29/56 (51.8%); table 2).

We found no relation between reporting of euthanasia and the patient's sex, educational attainment, living situation, or place of death (table 2). However, in a bivariate analysis there was a significant relation between reporting of euthanasia and the patient's age, with deaths of patients aged 80 years or older reported significantly less often than deaths of younger patients (6/28 (21.4%) *v* 67/109 (61.5%); $P=0.001$). Cases were also reported less often when the time by which life was shortened was less than one week compared with when the life shortening effect was greater (27/73 (37.0%) *v* 42/57 (73.7%); $P<0.001$). These bivariate relations did not hold after controlling for labelling of the end of life decision (data not shown).

We asked all physicians who performed an act of euthanasia as defined in our study to choose the term that they thought best described the act. In 53.2% (72/136 (one case missing data on this variable)) of all cases, physicians chose the term "euthanasia." In the remaining cases the physicians chose a different label. The reporting rate for cases that were labelled "euthanasia" by the physician was 93.1%, whereas the reporting rate for cases labelled with a term other than euthanasia was much lower (7.8% overall). A large majority of the unreported cases (92.2%) involved acts of euthanasia as defined in our study but were not perceived or labelled as "euthanasia" by the physician (data not shown).

Differences between reported and unreported cases

A verbal as well as a written request for euthanasia was present in 73.1% of all reported cases, whereas a legally required written request was absent in the majority of unreported cases (87.7% verbal request only; $P<0.001$; table 3). In reported cases, the decision to perform euthanasia was always discussed with others, which was not always the case in unreported cases (100% *v* 85.2%; $P=0.001$). Other physicians and care givers specialised in palliative care were consulted more often in reported cases than in unreported cases (97.5% *v* 54.6%; $P<0.001$ and 63.9% *v* 33.0%; $P<0.001$, respectively). No differences were found between reported and unreported cases for discussion of the decision to end the patient's life with nursing staff, relatives, or other persons ($P=0.864$, $P=0.841$, and $P=0.068$, respectively).

Reported cases of euthanasia were almost always performed with barbiturates, neuromuscular relaxants, or both (95.6%), whereas the majority of unreported cases (90.5%) were performed with other drugs, mainly opioids, sedatives, or both ($P<0.001$). However, in about half (52.7%) of the unreported cases in which opioids were used with the explicit goal of hastening death, physicians indicated that they did not administer a higher dose than necessary for pain and symptom alleviation. In reported cases of euthanasia, the drugs were almost always administered by a physician (97.7% of cases); in unreported cases, the drugs were often administered by a nurse alone (41.3%; $P<0.001$). When drugs were administered by a nurse alone, the agents used were always opioids or sedatives (not in tables).

DISCUSSION

The reporting rate for euthanasia in Flanders in 2007 is estimated to be 52.8%. This means that only one out of two cases of actual euthanasia is reported to and reviewed by the Federal Control and Evaluation Committee, and one in two is not. The most important reason given by physicians for not reporting a case to the review committee was that the physician did not perceive the act to be euthanasia (76.7%). A large majority of the unreported cases (92.2%) were in fact acts of euthanasia as defined in our study but were not perceived or labelled as "euthanasia" by the physician involved. Unreported cases of euthanasia were generally dealt with less carefully than reported cases: a written request for euthanasia was absent more often; other physicians and care givers specialised in palliative care were consulted less often; the life ending act was more often performed with opioids, sedatives, or both; and the life ending drugs were more often administered by a nurse instead of a physician.

Strengths and limitations of study

This study is the first in Belgium to estimate the rate at which euthanasia is reported to the federal authorities and to study the differences between reported and unreported cases. We followed the same robust study design as in our previous studies^{29,30}: we drew a large representative sample of death certificates; used

Table 2 | Reporting of euthanasia according to characteristics of physician and patient, time by which life was shortened, and labelling of the end of life decision*

	All cases (n=137; weighted n)†	Cases reported to review committee (n=72)		P value‡
		Weighted n	Weighted percentage of cases (95% CI)	
Physician characteristic				
Type of physician				
General practitioner	80	43	53.8 (41.5 to 65.4)	0.863
Specialist	56	29	51.8 (34.3 to 69.1)	
Patient characteristic				
Sex				
Male	83	43	51.8 (38.3 to 64.9)	0.727
Female	54	30	55.6 (39.3 to 70.0)	
Age				
18-49	12	8	66.7 (31.7 to 90.0)	0.001§
50-64	37	23	62.2 (42.2 to 77.8)	
65-79	60	36	60.0 (45.3 to 72.8)	
≥80	28	6	21.4 (9.1 to 40.4)	
Educational attainment				
Primary school	20	7	35.0 (13.1 to 64.4)	0.309
Lower secondary school	40	24	60.0 (41.2 to 75.8)	
Higher secondary school or higher	37	21	58.8 (37.5 to 75.0)	
Unknown	41	21	51.2 (35.1 to 67.9)	
Living situation				
Alone	24	15	62.5 (40.6 to 80.5)	0.432
In private household	98	50	51.0 (39.1 to 63.0)	
In institution	10	4	40.0 (9.9 to 83.3)	
Place of death				
Home	66	37	56.1 (43.3 to 68.3)	0.874
Hospital	59	30	50.8 (34.1 to 67.6)	
Care home	5	2	40.0 (13.3 to 77.8)	
Other	6	3	50.0 (7.6 to 91.4)	
Diagnosis				
Malignant disease	111	58	52.3 (42.3 to 61.9)	0.002§
Cardiovascular disease	5	0	0.0 (0.0 to 0.0)	
Disease of the nervous system	7	6	85.7 (34.3 to 98.1)	
Disease of the respiratory system	6	2	33.3 (4.5 to 85.9)	
Other disease	5	5	100.0 (100 to 100)	
Shortening of life				
<24 hours	13	2	15.4 (4.8 to 40.1)	<0.001§
1-7 days	60	25	41.7 (27.6 to 57.5)	
1-4 weeks	35	21	60.0 (35.1 to 80.5)	
1-6 months	16	16	100.0 (100 to 100)	
>6 months	6	5	83.3 (44.0 to 98.8)	
Labelling of the end of life decision				
Euthanasia	72	67	93.1 (85.1 to 96.6)	<0.001§
Palliative or terminal sedation	48	2	6.3 (1.5 to 21.6)	
Non-treatment decision	8	2	25.0 (1.8 to 78.6)	
Alleviation of symptoms	8	0	0.0 (0.0 to 30.1)	

*Percentages are row percentages. All percentages and total numbers are adjusted for stratification, and to patient/mortality characteristics of all deaths in 2007, which makes the percentages representative for all deaths in Flanders in 2007. Total numbers may not always amount to 137 because of rounding or missing values on variables. Percentages may not always amount to 100 because of rounding.

†One case was missing data on the variable "reporting of end of life decision."

‡P value for reported cases versus cases not reported.

§P<0.05 using Fisher's Exact (Monte Carlo).

identical key questions; and applied the same mailing procedure to guarantee total anonymity for patients and physicians.

This study also has some limitations. The response rate was only 58%, so the possibility that the results

could have been different had the response rate been higher cannot be excluded. We therefore urge caution in interpreting the results. Furthermore, the study is based on self reporting by physicians. It is possible that they did not remember all aspects of a case well, and we cannot exclude a social desirability bias, especially for the question of whether or not the physician had reported the case to the review committee. Unfortunately, because death certificate data for 2007 are not yet available for Wallonia, the French speaking part of Belgium, we could not estimate a reporting rate for the whole country. Our findings cannot be extrapolated to the French speaking part of Belgium, in particular because research has shown that end of life practices differ in the French speaking and the Flemish speaking regions and because there may be a difference in willingness to report cases of euthanasia owing to cultural differences.^{31,32} A non-response bias cannot be completely excluded, although our non-response survey did not point to that possibility.

Study interpretation

Five years after the enactment of the euthanasia law in 2002, half of all euthanasia cases in Flanders were reported to the review committee. A similar reporting procedure exists in the Netherlands, where the current reporting rate is estimated at 80.2%.²¹ However, the Netherlands had already experienced two decades of relatively open euthanasia practice before euthanasia was officially legalised in 2002, and a reporting procedure has been in place since the early 1990s.^{13,33} Compared to the Netherlands, bringing life ending acts into the open is a relatively new experience for physicians in Flanders (and in Belgium as a whole) because physicians have only been required to report cases since the enactment of the euthanasia law.^{13,34} This may, at least in part, explain the lower reporting rate in Flanders compared with in the Netherlands. Another possible explanation could be that a higher number of unclear cases of euthanasia—in which opioids, sedatives, or both are used to hasten death instead of neuromuscular relaxants—occur in Flanders than in the Netherlands and that there are more cases in which the estimated term of life shortening is small.²¹ These less clear cut cases of euthanasia are often not perceived as euthanasia by the physicians and are consequently not being reported.

The considerable distance between the legal definition of euthanasia and the perception of the physician of whether an act was euthanasia could be explained by three possible coinciding hypotheses.

A first hypothesis suggests that when a patient requests that their life be ended and the physician in response disproportionately increases the opioid or sedative dose instead of administering neuromuscular relaxants, the distinction between euthanasia and normal compassionate intensification of symptom treatment is blurred. The confusion that may arise might mean that physicians do not perceive the life ending decision as euthanasia.³⁵ This would also explain why drugs are in these cases often administered by a nurse

Table 3 | Characteristics of due care for reported and unreported cases of euthanasia*

	All cases (n=137)‡		Cases reported to review committee (n=72)		Unreported cases (n=64)		P value
	Weighted n	Weighted percentage of cases (95% CI)	Weighted n	Weighted percentage of cases (95% CI)	Weighted n	Weighted percentage of cases (95% CI)	
Type of request for euthanasia							
Verbal request only	68	50.0 (40.1 to 60.5)	13	17.6 (9.1 to 31.5)	55	87.7 (76.6 to 93.9)	<0.001†
Written request only	9	6.6 (2.3 to 18.0)	7	9.3 (2.4 to 29.9)	2	3.7 (0.9 to 14.5)	
Verbal and written request	58	43.3 (33.5 to 53.1)	53	73.1 (56.8 to 84.9)	5	8.6 (3.9 to 18.0)	
Decision discussed with others‡							
Total	126	93.3 (80.2 to 97.8)	72	100 (100 to 100)	54	85.2 (63.0 to 95.1)	0.001†
Other physician	106	77.0 (66.2 to 85.7)	71	97.5 (88.1 to 99.5)	35	54.6 (38.7 to 69.6)	<0.001†
Caregiver specialised in palliative care	67	49.1 (39.2 to 59.6)	46	63.9 (49.6 to 76.2)	21	33.0 (21.3 to 47.2)	<0.001†
Nursing staff	72	53.5 (42.8 to 63.3)	39	54.3 (40.5 to 67.5)	33	51.9 (36.6 to 66.9)	0.864
Relative	106	77.5 (66.0 to 85.8)	57	78.4 (63.6 to 88.4)	49	76.2 (57.4 to 88.4)	0.841
Other persons	8	5.9 (2.9 to 11.9)	7	9.1 (4.2 to 18.7)	1	2.3 (0.3 to 15.0)	0.068
Drug used for euthanasia							
Neuromuscular relaxant§	15	11.2 (6.5 to 18.9)	15	22.1 (12.8 to 35.0)	0	—	<0.001†
Barbiturate¶	21	15.7 (10.5 to 23.2)	18	26.5 (16.6 to 38.5)	3	4.8 (1.8 to 13.0)	
Neuromuscular relaxant and barbiturate**	34	26.6 (17.7 to 36.8)	32	47.1 (34.0 to 61.9)	2	3.2 (1.0 to 10.3)	
Opioids††	60	45.5 (35.5 to 56.4)	3	4.4 (1.0 to 15.4)	57	90.5 (80.2 to 94.8)	
Other drug	1	1.0 (0.2 to 4.1)	0	—	1	1.6 (0.5 to 8.3)	
Person who administered the drug							
Physician	96	72.2 (60.8 to 81.0)	69	97.9 (86.5 to 99.7)	27	43.0 (29.0 to 58.3)	<0.001†
Nurse	26	19.3 (11.7 to 30.4)	0	—	26	41.3 (26.3 to 57.5)	
Physician and nurse	9	7.4 (3.2 to 16.2)	1	2.1 (0.3 to 13.5)	8	13.4 (5.3 to 29.7)	
Physician and other person	2	1.2 (0.3 to 4.8)	0	—	2	2.6 (0.6 to 10.0)	

*All percentages are adjusted for stratification and for patient and mortality characteristics of all deaths in 2007, which makes the percentages representative for all deaths in Flanders in 2007.

†P<0.05, using Fisher's Exact (Monte Carlo).

‡One case was missing data on the variable "reporting of end of life decision." Total numbers may not always amount to 137 because of rounding or missing values on variables. Percentages may not always amount to 100 because of rounding.

§ Neuromuscular relaxant alone or in conjunction with benzodiazepine, opioids, or other drug other than barbiturate.

¶Barbiturate alone or in conjunction with benzodiazepine, opioids, or other drug other than muscle relaxant.

**Neuromuscular relaxant and barbiturate, alone or in conjunction with benzodiazepine, opioids, or other drug.

††Opioids alone or in conjunction with benzodiazepine or other drug other than barbiturate or neuromuscular relaxant.

*All percentages are adjusted for stratification and for patient and mortality characteristics of all deaths in 2007, which makes the percentages representative for all deaths in Flanders in 2007.

†P<0.05, using Fisher's Exact (Monte Carlo).

‡One case was missing data on the variable "reporting of end of life decision." Total numbers may not always amount to 137 because of rounding or missing values on variables. Percentages may not always amount to 100 because of rounding.

§ Neuromuscular relaxant alone or in conjunction with benzodiazepine, opioids, or other drug other than barbiturate.

¶ Barbiturate alone or in conjunction with benzodiazepine, opioids, or other drug other than muscle relaxant.

**Neuromuscular relaxant and barbiturate, alone or in conjunction with benzodiazepine, opioids, or other drug.

††Opioids alone or in conjunction with benzodiazepine or other drug other than barbiturate or neuromuscular relaxant.

and not according to the requirements of the euthanasia law. This hypothesis is supported by findings from another study that has shown that some physicians see a "grey area," or continuum, between palliation and euthanasia and find that the distinctions between the two are not always clear cut.³⁵ The fact that some of the physicians in our study indicated that their use of opioids, sedatives, or both had the explicit intention of hastening death, yet at the same time indicated they had not used a higher dose than necessary to alleviate pain and other symptoms, may be an indication of the confusion that can arise in these situations. Although the physicians in our study had the intention of hastening death and believed that death was the result of using these drugs, it is possible that some may have overestimated the actual life shortening effect of the drugs they administered.

A second proposed hypothesis is one of reducing cognitive dissonance. Some physicians may on the one hand feel reluctant to perform euthanasia or follow the requirements of the euthanasia law, while on the other hand want to help the patient who requests euthanasia. To reduce this cognitive dissonance, they may

choose to use opioids or sedatives because these drugs are not normally associated with euthanasia. Research has also shown that this kind of life ending practice might be more psychologically acceptable to physicians than euthanasia by bolus injection.³⁶ By disguising the end of life decision as normal medical practice, whether deliberately or not, physicians might feel they have granted their patient's wish without in their eyes having performed real euthanasia and without having to comply with the euthanasia law.

Opioids and sedatives are used to perform euthanasia more often in patients older than 80 than in younger patients, which may indicate that physicians are perhaps more reluctant to perform euthanasia in elderly patients. Research from the Netherlands has shown that requests for euthanasia from older patients are often refused.³⁷ There are strong positive associations with refusing a request where the patient is not fully competent and where there is a lesser degree of unbearable and hopeless suffering.³⁷ It is possible that physicians find that older patients' requests or suffering are not explicit enough to merit what is in their eyes real euthanasia by bolus injection.

WHAT IS ALREADY KNOWN ON THIS TOPIC

Medical end of life decisions, including euthanasia, are known to occur in several countries; Belgium legalised euthanasia in 2002

To provide societal control over the practice of euthanasia, physicians in Belgium are required by law to report each case to the Federal Control and Evaluation Committee

The rate at which physicians in Belgium report cases of euthanasia is unknown, and possible differences between reported and unreported cases have not been investigated

WHAT THIS STUDY ADDS

The reporting rate for euthanasia in Flanders, the Dutch speaking part of Belgium, in 2007 is estimated at 52.8%

Most physicians who did not report cases of euthanasia did not perceive their act as euthanasia

Unreported cases of euthanasia were generally dealt with less carefully than reported cases

A third hypothesis has to do with perceived time pressure. Our results indicate that unreported cases involved a shorter period by which life was shortened. It is plausible that, in cases in which the patient is obviously in a lot of pain and then requests euthanasia, the physician may feel under pressure to help the patient as soon as possible. He or she could then begin the process of euthanasia, but this process can be experienced as too time consuming or burdensome. The physician may in these circumstances prefer to use opioids or sedatives because these drugs are more readily available and there is less control over their distribution than with neuromuscular relaxants. By disguising euthanasia as pain alleviation, physicians can proceed with the euthanasia process without having to comply with the stringent, and in their perception time consuming, procedures of the euthanasia law.

We found a strong relation between a priori consultation of other physicians and the reporting of euthanasia. Consultation occurred in almost all reported cases, whereas it occurred in only half of all unreported cases. This association was also found in the Netherlands,^{38,39} where the most important reason for not consulting was that the physician did not intend to report the case. Physicians who intend to report a case seem to consult another physician and comply with the other requirements of the law, whereas physicians who do not intend to report a case appear to consult a physician only when they feel the need for the opinion of a colleague.³⁹ In the Netherlands, the availability of a service of expert consultants has had a positive influence on the reporting rate of euthanasia.³⁸ A similar service was developed in Flanders,⁴⁰⁻⁴² and it is likely that such services, in increasing physicians' knowledge of euthanasia, may help increase the reporting rate.

Conclusions and policy implications

The quality of medical practice at the end of life needs monitoring in any kind of society, and certainly in countries that have legalised euthanasia. To provide better societal control over euthanasia and safeguard the quality of the practice, it is necessary that all cases of euthanasia are reported. The transparency in reporting that

was envisaged by the architects of the euthanasia law in Belgium extends especially to those cases in which the time by which life is shortened is greater than one week and to those cases in which it is more certain that life is shortened by the drugs administered. However, this study estimated that in 2007 only half of all cases of euthanasia in Flanders and around three in four where life was shortened by more than one week were reported to the review committee.

As such legalisation alone does not seem sufficient to reach the goal of transparency ("total" or a 100% transparency seems to be a rather utopian ideal) and to guarantee the careful practice of euthanasia. It seems warranted that a policy be developed to facilitate physicians in complying correctly with a request for euthanasia, including their obligation to report. Education in medical schools and adequate support for treating physicians who are confronted with an explicit request for euthanasia will be pivotal in reaching that goal.

The possibility of societal control over the euthanasia practice is an important prerequisite for effective euthanasia legislation. By estimating the reporting rate for euthanasia in a country that has legalised the practice and by investigating reasons for non-reporting, our study offers valuable data driven information that can inform the debates about the legalisation of euthanasia that are currently going on in the United Kingdom and in many other countries.

We thank Herwin De Kind, Anne Kongs, the team of the Flemish Agency for Care and Health, lawyer Wim De Brock, and Kenneth Chambaere and Geert Pousset for their cooperation in the data collection. We thank Johan Vanoverloop and Steven Gorié for their statistical advice and Jane Ruthven for her linguistic help. We thank the Belgian National Disciplinary Board of Physicians for their approval of the study and Koen Matthijs for supporting the study. Especially we thank the thousands of physicians who provided the study data.

Contributors: LD and FM were project supervisors. TS analysed the data and wrote the manuscript. All authors contributed to data analysis and commented critically on several drafts of the manuscript, including the final version. All authors had full access to all of the data (including statistical reports and tables) in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis. LD is guarantor of the study.

Funding: This study is part of the Monitoring Quality of End of Life Care (MELC) study, a collaboration between the Vrije Universiteit Brussel, Ghent University, Antwerp University, the Scientific Institute of Public Health, all in Belgium, and VU University Medical Center Amsterdam, The Netherlands. This study is supported by a grant from the Institute for the Promotion of Innovation by Science and Technology in Flanders (Instituut voor de aanmoediging van Innovatie door Wetenschap en Technologie in Vlaanderen; SBO IWT nr. 050158). The funders had no role in study design; in the collection, analysis and interpretation of the data; in the writing of the manuscript; or in the decision to submit for publication.

Competing interests: All authors have completed the Unified Competing Interest form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous 3 years; no other relationships or activities that could appear to have influenced the submitted work.

Ethical approval: The ethical review board of the University Hospital of the Vrije Universiteit Brussel, the ethics committee of the University Hospital of Ghent University, the Belgian National Disciplinary Board of Physicians, and the Belgian Federal Privacy Commission approved the study protocol.

Data sharing: No additional data available.

- 1 Van der Heide A, Deliens L, Faisst K, Nilstun T, Norup M, Paci E, et al, on behalf of the EURELD consortium. End-of-life decision-making in six European countries: descriptive study. *Lancet* 2003;362:345-50.
- 2 Meier D, 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;338:1193-201.
- 3 George RJD, Finlay IG, Jeffrey D. Legalised euthanasia will violate the rights of vulnerable patients. *BMJ* 2005;331:684-5.
- 4 Materstvedt LJ, Clark D, Ellershaw J, Reidun F, Boeck Gravgard AM, Müller-Busch HC, et al. Euthanasia and physician-assisted suicide: a view from an EAPC Task Force. *Palliat Med* 2003;17:97-101.
- 5 Magnusson RS. Euthanasia: above ground, below ground. *JME* 2004;30:441-6.
- 6 Van der Heide A, Van Delden JIM, van der Wal G. Doctor-assisted dying: what difference does legalisation make? *Lancet* 2004;364:24-5.
- 7 Pollard BJ. Can euthanasia be safely legalized? *Palliat Med* 2001;15:61-5.
- 8 New York State Task Force on Life and the Law. *When death is sought. Assisted suicide and euthanasia in the medical context*. New York State Task Force on Life and the Law, 1994.
- 9 Belgisch Staatsblad. Wet betreffende euthanasie 28 mei 2002. [Law concerning euthanasia 28 May 2002] [Dutch]. Bill number 2002009590. 22 June 2002. <http://www.health.belgium.be/internet2Prd/groups/public/@public/@dg1/@acutecare/documents/ie2law/14888539.pdf>.
- 10 Deliens L, van der Wal G. The euthanasia law in Belgium and the Netherlands. *Lancet* 2003;362:1239-40.
- 11 Regionale Toetsingscommissies Euthanasie. Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding 1 april, 2002. [Termination of Life on Request and Assisted Suicide (Review Procedures) Act, 1 April 2002] [Dutch]. 2005. www.toetsingscommissies euthanasie.nl/wetgeving.
- 12 Service Central de Legislation. Loi du 16 mars 2009 sur l'euthanasie et l'assistance au suicide. [Law of 16 March 2009 on euthanasia and assisted suicide] [French]. 2009. www.legilux.public.lu/leg/a/archives/2009/0046/a046.pdf.
- 13 Smets T, Bilsen J, Cohen J, Rurup ML, De Keyser E, Deliens L. The medical practice of euthanasia in Belgium and the Netherlands: legal notification, control, and evaluation procedures. *Health Policy* 2009;90:181-7.
- 14 Federale Controle—en Evaluatiecommissie voor euthanasie. Eerste verslag aan de wetgevende kamers 22 september 2002-31 december 2003 [Federal Control and Evaluation Committee on Euthanasia. First report to Parliament, 22 September 2002-31 December 2003] [Dutch]. 2003. <http://www.health.belgium.be/internet2Prd/groups/public/@public/@dg1/@acutecare/documents/ie2divers/14276508.pdf>.
- 15 Federale Controle—en Evaluatiecommissie voor Euthanasie. Tweede verslag aan de wetgevende kamers 1 januari 2004-31 december 2005, 2006 [Federal Control and Evaluation Committee on Euthanasia. Second report to Parliament, 1 January 2004-31 December 2005] [Dutch]. 2006. <http://www.health.belgium.be/internet2Prd/groups/public/@public/@dg1/@acutecare/documents/ie2divers/14088500.pdf>.
- 16 Federale Controle—en Evaluatiecommissie voor Euthanasie. Derde verslag aan de wetgevende kamers 1 januari 2006-31 december 2007, 2008 [Federal Control and Evaluation Committee on Euthanasia. Second report to Parliament, 1 January 2006-31 December 2007] [Dutch]. 2008. <http://www.health.belgium.be/internet2Prd/groups/public/@public/@dg1/@acutecare/documents/ie2divers/14280500.pdf>.
- 17 Smets T, Bilsen J, Cohen J, Rurup ML, Deliens L. Legal euthanasia in Belgium. Characteristics of all reported euthanasia cases. *Med Care* 2010;48:187-92.
- 18 Keown J. Mr Marty's muddle: a superficial and selective case for euthanasia in Europe. *JME* 2006;32:29-33.
- 19 Van der Wal G, van der Maas PJ, Bosma JM, Onwuteaka-Philipsen BD, Willems DL, Haverkate I, et al. Evaluation of the notification procedure for physician-assisted death in the Netherlands. *N Engl J Med* 1996;335:1706-11.
- 20 Rurup M, Buiting HM, Pasman RHW, van der Maas PJ, van der Heide A, Onwuteaka-Philipsen BD. The reporting rate of euthanasia and physicians-assisted suicide. A study of the trends. *Med Care* 2008;46:1198-202.
- 21 Van der Heide A, Onwuteaka-Philipsen BD, Rurup M, Buiting HM, Van Delden JIM, Hanssen-de Wolf JE. End-of-life practices in the Netherlands under the Euthanasia Act. *N Engl J Med* 2007;356:1957-65.
- 22 Chambaere K, Bilsen J, Cohen J, Pousset G, Onwuteaka-Philipsen BD, Mortier F, et al. A post-mortem survey on end-of-life decisions using a representative sample of death certificates in Flanders, Belgium: research protocol. *BMC Public Health* 2008;8:299.
- 23 Teno JM. Measuring end-of-life care outcomes retrospectively. *J Palliat Med* 2005;8:42-9.
- 24 Dillman T. Mail and telephone surveys. The total design method. Wiley, 1978.
- 25 Bilsen J, Cohen J, Chambaere K, Pousset G, Onwuteaka-Philipsen BD, Mortier F, et al. Medical end-of-life practices under the euthanasia law in Belgium. A nationwide post-mortem survey. *N Engl J Med* 2009;361:1119-21.
- 26 Regionale Toetsingscommissies Euthanasie. Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding 1 april, 2002 [Termination of Life on Request and Assisted Suicide (Review Procedures) Act, 1 April 2002] [Dutch]. 2005. www.toetsingscommissies euthanasie.nl/wetgeving.
- 27 Service Central de Legislation. Loi du 16 mars 2009 sur l'euthanasie et l'assistance au suicide. [Law of 16 March 2009 on euthanasia and assisted suicide] [French]. 2009. www.legilux.public.lu/leg/a/archives/2009/0046/a046.pdf.
- 28 Materstvedt LJ, Clark D, Ellershaw J, Forde R, Boeck Gravgard A-M, Müller-Bosch HC, et al. Euthanasia and physician-assisted suicide: a view from an EAPC Ethics Task Force. *Palliat Med* 2003;17:97-101.
- 29 Mortier F, Deliens L, Bilsen J, Cosyns M, Ingels K, Vander Stichele R. End-of-life decisions of physicians in the city of Hasselt (Flanders, Belgium). *Bioethics* 2000;14:254-67.
- 30 Deliens L, Mortier F, Bilsen J, Cosyns M, Vander Stichele R, Vanoverloop J, et al. End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey. *Lancet* 2000;356:1806-11.
- 31 Chambaere K, Bilsen J, Cohen J, Raman E, Deliens L. Differences in performance of euthanasia and continuous deep sedation by French- and Dutch-speaking physicians in Brussels, Belgium. *J Pain Symptom Manage* 2010;39:e5-7.
- 32 Van den Block L, Deschepper R, Bilsen J, Bossuyt N, Van Casteren V, Deliens L. Euthanasia and other end-of-life decisions: a mortality follow-back study in Belgium. *BMC Public Health* 2009;9:79.
- 33 Weyers H. Explaining the emergence of euthanasia law in the Netherlands: how the sociology of law can help the sociology of bioethics. *Social Health Illn* 2006;28:802-16.
- 34 Adams M. Euthanasia: the process of legal change in Belgium. In: Klijn A, Otłowski M, Trappenburg M, eds. *Regulating physician-negotiated death*. Elsevier, 2001. p. 29-48.
- 35 Sprung CL, Ledoux D, Bulow HR, Lippert A, Wennberg E, Baras M, et al. Relieving suffering or intentionally hastening death: where do you draw the line? *Crit Care Med* 2008;36:8-13.
- 36 Douglas C, Kerridge I, Ankeny R. Managing intentions: the end-of-life administration of analgesics and sedatives, and the possibility of slow euthanasia. *Bioethics* 2008;22:388-96.
- 37 Jansen-van der Weide MC, Onwuteaka-Philipsen BD, van der Wal G. Granted, undecided, withdrawn, and refused requests for euthanasia and physician-assisted suicide. *Arch Intern Med* 2005;165:1698-704.
- 38 Jansen-van der Weide MC, Onwuteaka-Philipsen BD, van der Wal G. Implementation of the project "Support and Consultation on Euthanasia in the Netherlands (SCEN)." *Health Policy* 2004;69:365-73.
- 39 Onwuteaka-Philipsen BD, van der Wal G, Kostense PJ, van der Maas PJ. Consultation with another physician on euthanasia and assisted suicide in the Netherlands. *Soc Sci Med* 2000;51:429-38.
- 40 Van Wesemael Y, Cohen J, Onwuteaka-Philipsen BD, Bilsen J, Distelmans W, Deliens L. Role and involvement of LEIF-physicians (Life End Information Forum) in euthanasia and other end-of-life care decisions in Flanders, Belgium. *Health Serv Res* 2009;44:2180-92.
- 41 Distelmans W, Destrooper P, Bauwens S, De Maegd M, Van de Gaer K. Life End Information Forum (LEIF): professional advice and support at end-of-life issues. *Psycho Oncology* 2008;17:222.
- 42 Distelmans W, Bauwens S, Destrooper P. Life End Information Forum-physicians (LEIFartsen): improvement of communication skills in end-of-life issues among physicians. *Psycho Oncology* 2006;15(suppl 2):226-75.

Accepted: 26 July 2010