# The incidence and characteristics of end-of-life decisions by GPs in Belgium

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**Background.** Medical end-of-life decisions (ELDs) have been discussed for several years in different countries, but little is known about the involvement of GPs in these ELDs.

**Objectives.** The aim of the present study was to establish the incidence and characteristics of ELDs by GPs.

**Method.** We selected 3999 deaths, a 20% random sample of all registered deaths during the first 4 months of 1998 in Flanders, Belgium, and mailed anonymous questionnaires to the attesting physicians. Here we focus exclusively on the 1647 deaths certified by GPs.

**Results.** The GPs returned 1067 questionnaires (response rate of 64.8%). At least one ELD was made in 39.5% [95% confidence interval (CI) 37.8–41.2] of all primary care deaths. The incidence of euthanasia (including physician-assisted suicide) was 1.5% (95% CI 0.9–2.3) (incidence higher among more educated patients and at home), of administration of lethal drugs without the patient's explicit request 3.8% (95% CI 2.9–5.0) (higher among cancer patients), of alleviation of pain and symptoms with possibly life-shortening effect 18.6% (95% CI 17.0–20.2) (higher among cancer patients and married patients) and of non-treatment decisions 15.6% (95% CI 14.2–17.2) (higher among cancer patients and in nursing homes). The decision was not discussed with the patient in three out of four of the ELDs. A colleague was consulted in one in four ELD cases.

**Conclusion.** ELDs are common in general practice in Flanders, Belgium, despite the restrictive law concerning euthanasia at the time of this study. The incidence of these ELDs varies with cause and place of death, the patient's education and the GP's religion and age. Requirements of prudent practice regarding ELDs are rather poorly met by GPs. Further international research and debate is needed to highlight the GPs' important role in end-of-life care.

**Keywords.** Euthanasia, family physicians, medical futility, physician's practice patterns, primary health care, terminal care.

## Introduction

Medical developments and an ageing population increasingly confront physicians with end-of-life decisions (ELDs) potentially affecting the duration of the patient's survival. Robust incidence studies in The Netherlands, Australia, the USA and Belgium have shown that ELDs are common in medical practice.<sup>1–5</sup> In these studies, the main results are given for all medical practitioners, including specialists and GPs. Separate analyses for general practice were only performed in The Netherlands, a country with a legal regulation for euthanasia.<sup>6–11</sup>

This study is the first report on the incidence and characteristics of ELDs made by GPs in a country where euthanasia was illegal, namely the Dutch-speaking part of Belgium (Flanders). The data in this study stem from a death certificate study performed in 1998. In a death certificate study, a sample is taken from the official death certificates of a recent period, and a questionnaire is sent by mail to the physician who signed the certificate. The overall results of this study (concatenated for GPs and specialists) were published in 2000 in the *Lancet.*<sup>5</sup> Here we present a subanalysis restricted to the GPs. The interest in this separate focus on ELDs by GPs lies in the

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uniqueness of the data set from a country where euthanasia was a clandestine act and in the robustness of the data due to a high response rate of the GPs. End-of-life care is of special interest for GPs. Research has confirmed the preference of patients to die at home among their family members.<sup>12</sup> However, in Belgium, as in many industrialized countries with a strong hospital care sector, more patients die in hospital than at home.<sup>13</sup> Continuity of care in the terminal phase of life is often problematic for the attending GP. This often leads to frustration among patients, relatives and GPs themselves. Moreover, hospital costs are increasing, and many governments now have explicit programmes for palliative home care.<sup>14</sup> It is important for GPs to redefine their proper role in end-of-life care, backed by credible data on incidence and characteristics of ELDs in primary care. GPs usually have a longstanding relationship with their patients and a good knowledge of the family context.<sup>15</sup> Compared with hospital care, they have fewer technical options for life-prolonging treatment, and their work is less subject to social guidance by peers and scrutiny by regulatory authorities. This rather traditional setting may influence the incidence and type of ELDs as well as the preceding decision-making process.

### Methods

In 1998, we performed a death certificate study in Flanders, the northern Dutch-speaking region of Belgium with 6 million inhabitants and 56 354 deaths in 1998. The overall results of this death certificate study were reported elsewhere.<sup>5</sup> Here we report on the results of new analyses of a subset of the original data set of 3999 sampled death certificates and 1925 cases. We identified the speciality of the attesting physicians (GP or specialist) for each of the 3999 sampled death certificates and selected only the cases in the data set for which a GP returned the questionnaire. For the sake of comprehensiveness, we summarize here the main features of the method of the study, and refer for more details to the overall study.<sup>5</sup>

#### Death certificate study

All deaths in Flanders are reported to the Preventive and Public Health Division of the Ministry of Flanders by means of a detailed death certificate signed by the attending physician. A 20% random sample was taken from all death certificates signed between January 1 and April 30, 1998. The involved physicians received a selfadministered postal questionnaire, together with some essential anonymous patient data, allowing them to identify the deceased. A complex mailing procedure ensured total anonymity<sup>16</sup> and was approved by the Belgian Medical Disciplinary Board.<sup>17</sup> The survey was performed according to the total design method.<sup>18</sup> For this subanalysis, the death certificates attested by GPs and the questionnaires completed by GPs were selected.

#### Questionnaire and terminology

The 51 questions of the questionnaire inquired about medical interventions with a possible life-shortening effect, whether a life-shortening intention was explicit, secondary or absent, about the decision-making process that preceded the ELD and about some background characteristics of the physician. Upon receipt of the completed questionnaire, patient data from the death certificates were linked anonymously to the questionnaire data.<sup>16</sup> Based on a combination of answers to the questions, we classified the cases in the following pre-defined categories of ELDs. (i) Euthanasia (EUTH): the administration of (lethal) drugs with the explicit intention of hastening the patient's death, at his/her explicit request. (ii) Physicianassisted suicide (PAS): the prescription or supply of (lethal) drugs with the intention of enabling the patient to end his/her life. (iii) Life-ending acts without the patient's explicit request (LAWER): the administration of (lethal) drugs with the explicit intention of hastening the patient's death, without his/her explicit request. (iv) Alleviation of pain and symptoms (APS): intensifying the use of drugs to alleviate pain and symptoms in a potentially life-shortening way. (v) Non-treatment decisions (NTD): withholding or withdrawing (potentially life-prolonging) treatment, with or without the explicit intention of hastening the patient's death.

#### Analysis of data

After comparison with the national mortality statistics, the results were adjusted for underlying disease and place of death. Additionally, the results were seasonally adjusted and extrapolated to estimates of frequencies for all deaths in 1998, with 95% confidence intervals (CIs) calculated by multinomial logistic regression.<sup>19</sup> For comparisons of incidence rates, we used Fisher's exact test (alpha level at P < 0.05).<sup>20</sup> Results for EUTH and PAS were concatenated (EUTHPAS) because PAS was limited to three observed cases

#### Results

Of the 3999 sampled death certificates, 1647 were attested by 1329 GPs, of which 864 (65%) returned at least one questionnaire. In total, we received 1067 useful questionnaires, which represents 64.8% of the 1647 questionnaires sent to the GPs.

#### Incidence estimates (Table 1)

Death under the care of a GP in Flanders in 1998 was preceded by at least one ELD in two out of five cases. Excluding the sudden deaths, an ELD was reported in 60.3%. More than 5% of all deaths in general practice resulted from the use of drugs with the explicit intention of shortening the patient's life. LAWER was three times more frequent (3.8%) than EUTH (1.3%). APS (18.6%) and NTD (15.6%) were the most frequently reported,

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ELDs	Weighted% <sup>a</sup> (95% CI) <sup>b</sup> ( <i>n</i> = 1067)	Estimates for all deaths certified by GPs in 1998 $(n = 23931)^{\circ}$
Administration, prescription or supply of drugs with the explicit intention of shortening the patient's life	5.3% (4.5-6.4)	1275
Euthanasia (EUTH)	1.3% (0.7–2.0)	304
Physician-assisted suicide (PAS)	0.3% (0.1–0.7)	65
Life-ending acts without the patient's explicit request (LAWER)	3.8% (2.9–5.0)	906
Alleviation of pain and symptoms with drugs with a potentially life-shortening effect (APS)	18.6% (17.0–20.2)	4440
Life shortening was not intended	12.9% (11.2–15.0)	3096
Life shortening was partly intended	5.6% (4.5–7.1)	1344
Non-treatment decision (withholding or withdrawing a treatment) (NTD)	15.6% (14.2–17.2)	3735
Life shortening was not intended	7.2% (5.9–8.8)	1717
Life shortening was partly intended	4.0% (3.1–5.3)	959
Life shortening was the explicit intention	4.4% (3.4–5.7)	1059
All sudden-deaths where an ELD was not possible	34.6% (33.0–36.3)	8283
All deaths where an ELD was possible, but was not made	25.9% (24.4–27.5)	6198
All deaths with an ELD	39.5% (37.8–41.2)	9450

#### TABLE 1 Incidence of end-of-life decisions (ELDs) in general practice in Flanders, 1998

<sup>a</sup> The percentages are adjusted to patient/mortality characteristics of all deaths in 1998.

<sup>b</sup> Asymptotic confidence intervals for multinomial distribution, using the statistical package StatXact v. 4.0.

<sup>c</sup> The estimates are adjusted to patient/mortality characteristics and extrapolated to all deaths in 1998 (source: Ministry of Flanders, Preventive and Social Health Care Division).

the former mostly without and the latter mostly with a partial or explicit life-shortening intention.

# *Incidence of ELDs according to patient characteristics* (*Table 2*)

The incidence of all ELDs varied significantly according to cause of death. EUTHPAS is practised more often among patients with a higher level of education and patients who died at home. LAWER was practised more among cancer patients. APS was more frequent among cancer patients and married patients. NTD occurred more among cancer patients and patients dying in nursing homes.

# *Incidence of ELDs according to GP characteristics* (*Table 3*)

The incidence of all ELDs in general was greatest among patients treated by GPs between 35 and 44 years old and by GPs with 11–20 years experience in direct patient care. EUTHPAS did not vary according to physician characteristics. LAWER was practised more often among patients treated by GPs who were younger than 35 years old and by non-Catholic GPs, while APS occurred more frequently among patients treated by Catholic GPs. NTD was more frequent among patients treated by non-religious GPs and GPs who were between 35 and 55 years old. The incidence of ELDs did not vary according to actual postgraduate training of the GP in palliative or terminal care.

# *Estimated survival-shortening effect by ELDs in general practice (Table 4)*

In most cases, the duration by which the patient's life was shortened due to the ELD was estimated to be nil or 1-7 days. The estimated survival shortening exceeded 1 month in only 2.5% of cases. In about half of EUTHPAS, LAWER and NTD cases, the survival duration was estimated as shortened by 1-7 days while in half of the APS cases it was estimated to be <1 day. Survival shortening of >1 month was most frequent for NTD and LAWER and rare for EUTHPAS and APS.

#### *Characteristics of the decision-making process preceding the ELD (Table 5)*

EUTHPAS, by definition always at the explicit request of a competent patient, was rarely practised without any previous discussion with at least one colleague, nurse or relative. In LAWER cases, without an explicit request by the patient, most patients were incompetent at the time of the decision and there was often a previous wish by the patient or a request by the family. Nevertheless, 16.1% of these cases were competent and only some discussion (no explicit request) with these patients took place. In a quarter of all LAWER cases, no wish or request whatsoever had been stated. For APS and NTD, no wish or request was reported in almost half of the cases, despite much more competent patients. The ELD was made without any previous discussion with a colleague, nurse or relative in about one-fifth of all LAWER, APS and NTD cases.

	Deaths studied	ELD in 1998 among all deaths in general practice (weighted %) <sup>a</sup>							
Overall results (weighted%) <sup>a</sup>	( <i>n</i> = 1067)	EUTH + PAS n = 16 1.5	LAWER <i>n</i> = 38 3.8	APS n = 188 18.6	NTD n = 164 15.6	All n = 406 39.5			
Socio-demographic data									
1_64	142	3.6	54	22.5	99	41 4			
65–79	311	1.7	5.0	18.7	14.1	39.5			
≥80	614	1.1	2.8	17.6	17.8	39.3			
<i>P</i> -value <sup>b</sup>		0.155	0.189	0.474	0.089	0.932			
Sex									
Male	489	1.8	4.0	20.8	13.5	40.1			
Female	578	1.4	3.6	16.7	17.4	39.2			
<i>P</i> -value		0.591	0.856	0.149	0.146	0.774			
Marital status									
Single	121	1.1	2.2	16.7	15.7	35.7			
Married	385	2.0	4.6	24.0	13.8	44.4			
Widowed	516	1.0	2.8	15.4	17.2	36.4			
Divorced	45	2.9	11.4	8.8	14.3	37.4			
<i>P</i> -value		0.453	0.070	0.015	0.689	0.135			
Educational level									
Primary school	544	0.5	3.4	17.3	16.8	38.0			
High school (not graduated)	179	2.2	3.6	18.2	16.8	40.8			
High school or college	125	5.2	4.1	27.8	10.3	47.4			
Not known <sup>c</sup>	219	1.2	4.2	16.9	14.5	36.8			
<i>P</i> -value		0.003	0.863	0.071	0.260	0.190			
Mortality patient data									
Place of death									
At home	538	2.7	3.9	19.7	11.8	38.1			
In nursing home	457	0.6	2.7	17.2	20.2	40.7			
Other/not known <sup>c</sup>	72	-	7.5	18.8	15.0	41.3			
<i>P</i> -value		0.027	0.417	0.447	0.002	0.449			
Cause of death									
Cancer	282	3.3	6.5	35.5	18.8	64.1			
Cardiovascular disease	325	0.4	1.6	7.6	8.8	18.4			
Disease of the nervous system	124	1.2	3.6	14.5	15.7	35.0			
Other	336	1.3	3.3	13.8	19.2	37.6			
<i>P</i> -value		0.072	0.038	< 0.001	0.003	< 0.001			

TABLE 2 End-of-life decisions in general practice according to patient socio-demographic and mortality characteristics

APS = alleviation of pain and symptoms in a potentially life-shortening way; EUTH = euthanasia; LAWER = the administration of (lethal) drugs with the explicit intention of hastening the end of life of the patient without his explicit request. NTD = non-treatment decisions [withholding or withdrawing a (potential life-prolonging) treatment]; PAS = physician-assisted suicide.

<sup>a</sup> The percentages are adjusted to patient/mortality characteristics of all deaths in 1998.

<sup>b</sup> Significance of difference in distribution between cases with and without the considered ELD category, Fisher's exact test, using the statistical package StatXact v. 4.0.

<sup>c</sup> Not included in test.

## Discussion

This is the first incidence study reporting on ELDs by GPs in a country with a restrictive approach towards euthanasia and physician-assisted suicide and without formal guidelines for ELDs. At the time of the study, the use of lethal drugs in medical practice in Flanders, Belgium, was legally likened to first-degree murder, although cases were rarely prosecuted.<sup>21</sup> Conditions of strict anonymity and ethics clearance from the National Medical Disciplinary Board made it possible to conduct a nationwide study about ELDs. The interest in this study, focusing on GPs, lies in the high response rate among the GPs, resulting in robust results.

This study shows that ELDs are common in general practice in Flanders. Despite large differences between

	Non- sudden	ELD in 1998 among all non-sudden deaths in general practice (weighted %) <sup>a</sup>							
Overall results (weighted%) <sup>a</sup>	deaths studied $(n = 680)$	EUTH + PAS $n = 16$ $2.4$	LAWER <i>n</i> = 38 5.8	APS n = 188 28.4	NTD n = 164 23.9	All  n = 406  60.3			
Physician characteristics									
Age									
≤34	85	0.0	13.2	32.9	17.1	63.2			
35–44	203	3.2	5.1	29.9	28.0	66.2			
45–54	251	2.6	5.1	27.2	28.2	63.1			
≥55	141	2.8	2.8	25.2	14.0	44.9			
<i>P</i> -value <sup>b</sup>		0.511	0.041	0.657	0.010	0.004			
Sex									
Male	588	2.4	5.7	28.3	23.2	59.6			
Female	92	2.5	6.3	29.1	27.8	65.7			
<i>P</i> -value		1.000	0.795	0.893	0.392	0.456			
Religion $(n = 675)$									
Non-practising Catholics	276	3.3	3.7	32.7	18.7	58.4			
Practising Catholics	173	2.2	2.9	27.7	28.5	61.3			
Not religious	156	0.8	10.7	18.9	31.1	61.5			
Other <sup>c</sup>	70	1.8	10.7	30.4	19.6	62.5			
<i>P</i> -value		0.425	0.014	0.025	0.017	0.840			
Years in direct patient care $(n = 672)$									
1–10	119	1.0	10.6	29.8	19.2	60.6			
11-20	253	2.6	4.1	33.0	28.4	68.1			
>20	300	2.6	4.8	23.9	23.0	54.3			
<i>P</i> -value		0.748	0.074	0.115	0.195	0.014			
Any postgraduate training in palliative or terminal care									
Yes	522	2.1	5.9	28.7	24.8	61.9			
No	158	1.6	5.5	27.3	21.1	55.5			
P-value		0.740	1.000	0.823	0.409	0.214			

Physician characteristics were only available in cases of non-sudden death, as in cases of sudden death, the physician was asked to return the questionnaire unanswered.

APS = alleviation of pain and symptoms in a potentially life-shortening way; EUTH = euthanasia; LAWER = the administration of (lethal) drugs with the explicit intention of hastening the end of life of the patient without his explicit request. NTD = non-treatment decisions [withholding or withdrawing a (potential life-prolonging) treatment]; PAS = physician-assisted suicide.

<sup>a</sup> The percentages are adjusted to patient/mortality characteristics of all deaths in 1998; percentages shown here are percentages of number of cases studied in which end-of-life decision making was possible for the physician; excluding all sudden death situations.

<sup>b</sup> Significance of difference in distribution between cases with and without the ELD-category under consideration, Fisher's exact test, using the statistical package StatXact v. 4.0.

<sup>c</sup> Not included in test.

primary health care and hospital care in our country, this study unexpectedly shows that the overall frequencies of the different categories of ELDs by GPs are similar to the overall results as reported in our previous publication.<sup>5</sup> We estimate that the 8000 active GPs in Flanders<sup>22</sup> made at least one ELD for about two out of five deaths of patients under their care (three out of five non-sudden deaths), mostly in extremis, as indicated by the small estimated survival-shortening effect. The incidence of ELDs with the explicit intention to shorten life is considerable (one in 10 deaths certified). Using drugs with the explicit intention of shortening the patient's life occurs in one in 20 deaths, which means that an estimated 1200 ELDs in general practice were made illegally. Strikingly, LAWER was three times more frequent than EUTH. For the 65% of these LAWER cases where the physician perceived the patient as incompetent, this decision probably can be seen as beneficence towards a patient with whom communication was (or had become) impossible (e.g. because of the sudden deterioration of the illness or because communication on ELDs had been deferred for too long). It is difficult to understand why there was only a previous discussion but no explicit request by the patient in the 16% of competent LAWER cases. Fear of legal complications in the case of an open discussion about ending life is one possible explanation for this objectionable situation, as it is also for deferring communication.<sup>23</sup> Another explanation can be a lack of communication skills. In addition, paternalistic attitudes have also to be considered.

Estimated amount of time by which life was shortened	Observed cases ( <i>n</i> = 406)	Weighted <sup>a</sup> percentages of ELDs							
		EUTH + PAS n = 16	LAWER <i>n</i> = 38	APS n = 188	NTD <i>n</i> = 164	All $n = 406$			
>1 month	11	_	3.2	1.4	4.6	2.5			
1–4 weeks	50	16.7	6.5	9.9	15	11.8			
1–7 days	159	58.3	64.5	27.8	46.5	39.6			
<24 h	63	16.7	25.8	19.2	7.9	15.5			
Probably not shortened	109	8.3	_	37.1	23.6	27.2			
Not known	14	-	-	4.6	2.4	3.4			

Table 4	Estimated	l survival	shortening	effect c	f end	l-of-life	decisions in	n general	l practice,	Flanders,	1998
				55	2			0	1 /		

APS = alleviation of pain and symptoms in a potentially life-shortening way; EUTH = euthanasia; LAWER = the administration of (lethal) drugs with the explicit intention of hastening the end of life of the patient without his explicit request. NTD = non-treatment decisions [withholding or withdrawing a (potential life-prolonging) treatment]; PAS = physician-assisted suicide. <sup>a</sup> The percentages are adjusted to patient/mortality characteristics of all deaths in 1998.

 TABLE 5
 Characteristics of the end-of-life decision-making process in general practice in Flanders, 1998

Characteristics of end-of-life decision-making process	Observed cases	ELD in among all deaths in general practice (weighted %) <sup>a</sup>					
	( <i>n</i> = 406)	EUTH + PAS $n = 16$	LAWER $n = 38$	APS <i>n</i> = 188	NTD <i>n</i> = 164	All $n = 406$	
Request by/discussion with the patient/family							
Explicit request by the patient	74	100	_	17.1	17.3	18.6	
No explicit request, but discussed with the patient	26	-	16.1	4.6	7.1	6.5	
No request, no discussion, but previous wish ever stated by the patient	60	-	25.8	17.1	10.2	14.6	
No request, no discussion, no previous wish, but request by relative(s)	57	-	32.3	9.2	16.5	13.7	
No request, no discussion, no previous wish and no request by relative(s)	179	-	25.8	48	48	44.1	
Not known	10	-	_	3.9	0.8	2.5	
Patient competent at time of decision							
Yes	127	100	16.1	39.3	24.6	33.4	
No	203	-	64.5	41.4	60.3	49.8	
Unknown	76	_	19.4	19.3	15.1	16.8	
Explicit request made by close relative(s)							
Yes	112	50.0	58.1	20.5	24.4	26.9	
No	284	50.0	41.9	75.5	74.8	70.6	
Unknown	10	_	_	4.0	0.8	2.5	
Decision discussed with others <sup>b</sup>							
Colleague(s)	103	50	25.8	24.5	29.9	27.2	
Nursing staff	167	33.3	25.8	39.7	45.7	40.3	
Relative(s)	236	75.0	61.3	54.9	60.6	57.9	
No	85	8.3	19.4	25.8	15.8	20.4	

APS = alleviation of pain and symptoms in a potentially life-shortening way; EUTH = euthanasia; LAWER = the administration of (lethal) drugs with the explicit intention of hastening the end of life of the patient without his explicit request. NTD = non-treatment decisions [withholding or withdrawing a (potential life-prolonging) treatment]; PAS = physician-assisted suicide.

<sup>a</sup> The percentages are adjusted to patient/mortality characteristics of all deaths in 1998.

<sup>b</sup> Multiple responses possible.

The incidence of ELDs by GPs correlates foremost with the primary disease contributing to the patients' death. The increased likelihood of cancer due to expected further increases in longevity will probably increase ELDs in the future. Interestingly, we found more euthanasia and physician-assisted suicide (EUTHPAS) among the patients with a higher level of education. Perhaps these patients (and their close relatives) demand more participation in health care decisions. They are probably more capable of formulating explicit requests and more able to convince the physician that the conditions for the safe performance of an illegal act are fulfilled. In the present cohort of the old and the very old, the educational status is mainly low. As the post-war highly educated baby boomers reach old age, this situation will change dramatically, presumably with considerable impact on the incidence and nature of ELDs. Another interesting observation is the higher incidence of EUTH among patients dying at home than in nursing homes, while for NTD the reverse is true. This may be related to different characteristics of patients dying at home versus in a nursing home. However, the interpersonal and social context also has to be considered. Possibly, physician-assisted death is facilitated by the presence of family members and the more intimate and private home setting. Alternatively, for those living alone, the home situation may also entail more loneliness and requests for EUTH. In nursing homes, there may be a dissuasive effect on patients because of better nursing care possibilities and on physicians because of institutional control. Further studies in both settings can bring more insight.

With regard to physician characteristics, most types of ELDs varied significantly according to the religion of the GP. Catholic GPs were far less involved in LAWER than their non-religious colleagues, while for APS it is quite the reverse. It is difficult to interpret these findings. The high frequency of APS by Catholic GPs may be explained by its accordance with the Catholic position, which rejects intentional life ending but accepts the alleviation of pain with life shortening as a non-intended side effect.<sup>24</sup> This rejection of intentional life ending by Catholics also appears to translate into a significantly lower frequency of non-requested intentional life ending (although life ending with an explicit request is performed at least as frequently by Catholic as by non-Catholic GPs). Longitudinal observational studies are needed to shed more light on these observations.

Requirements for prudent practice regarding ELDs in general practice are rather poorly met. In a quarter of the LAWER cases and in half of the APS and NTD cases, the GPs made the decision on their own. During the decision-making process preceding the ELD, colleagues were not consulted in half of the EUTHPAS and in three-quarters of all the other ELD categories. The predominantly solo work setting of the Flemish GP may explain this lack of peer review, but it surely does not explain the low level of involvement of the patient in decision making. Neither does it throw light on the 40% of cases where there was no communication about ELDs with relatives, despite the frequency of family contacts and house calls by GPs in Flanders.<sup>15</sup> Probably the illegal character of some ELDs does not contribute to openness in this matter. Whatever the reasons, this lack of consultation is medically undesirable and ethically unacceptable. It is a clear indication that the situation, prevailing up to now, needs change.

The new euthanasia legislation in Belgium, which officially came into force in September 2002, clearly

stipulates the conditions under which medical life ending with lethal drugs is no longer looked upon as a crime.<sup>25</sup> There has to be an explicit, unambiguous, repeated and persistent request by a competent, well-informed and incurably ill patient, aged 18 years or more whose 'unbearable' suffering cannot be alleviated otherwise. The physicians previously have to consult at least one colleague (two colleagues in the case of a non-terminally ill patient) and, if applicable, to inform the nurses. After carrying out the ELD, they have to report it to a Federal Control and Evaluation Commission, which will evaluate the conditions and decide whether or not to notify legal authorities. Because these conditions focus directly on the decision-making process, a positive effect on actual prudent medical practice concerning ELDs can be expected, as often suggested in the literature about differences between countries with and without a legal regulation. However, since the new Belgian law only relates to euthanasia, it leaves the other and far more frequent ELDs unregulated. Furthermore, the legal regulation was not initiated by physicians nor supported by medical associations and is viewed by many as a political top-down intrusion in medical practice. Even in the case of euthanasia, it is uncertain whether legal change alone will bring about substantial improvement in the field. For this to happen, both the government and the medical organizations must support the implementation of the law by establishing clear guidelines for good medical practices and by improving the quality of training in end-of-life care. Preferably this must be done taking into account a reliable estimation of the incidences and specific characteristics of ELDs by GPs. Besides constantly monitoring and evaluating concrete practices, long-term follow up studies are also needed to evaluate and, if necessary, to modify the implementation.

In most countries, GPs play a key role in the population's health care. This study shows, moreover, their important role in end-of-life care, at least in Belgium. Up to now, comparisons with other countries about this topic have been difficult to make because of scarcity of data and the use of different study designs. We hope this study will contribute to further international research and will stimulate GPs to take part in the growing international debate about euthanasia and other ELDs.

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