

End-of-Life Decisions Among Cancer Patients Compared With Noncancer Patients in Flanders, Belgium

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A B S T R A C T

Purpose

Incidence studies reported more end-of-life decisions with possible/certain life-shortening effect (ELDs) among cancer patients than among noncancer patients. These studies did not correct for the different proportions of sudden/unexpected deaths of cancer versus noncancer patients, which could have biased the results. We investigated incidences and characteristics of ELDs among nonsudden cancer and noncancer deaths.

Methods

We sampled 5,005 certificates of all deaths in 2001 (Flanders, Belgium) stratified for ELD likelihood. Questionnaires were mailed to the certifying physicians. Data were corrected for stratification and nonresponse.

Results

The response rate was 59%. Among 2,128 nonsudden deaths included, ELDs occurred in 74% of cancer versus 50% of noncancer patients ($P < .001$). Symptom alleviation with possible life-shortening effect occurred more frequently among cancer patients ($P < .001$); nontreatment decisions occurred less frequently ($P < .001$). The higher incidence of lethal drug use among cancer patients did not hold after correcting for patient age. Half of the cancer patients who died after an ELD were incompetent to make decisions compared with 76% of noncancer patients ($P < .001$). Discussion with patients and relatives was similar in both groups. In one fifth of all patients the ELD was not discussed.

Conclusion

ELDs are common in nonsudden deaths. The different incidences for symptom alleviation with possible life-shortening effect and nontreatment decisions among cancer versus noncancer patients may be related to differences in dying trajectories and in timely recognition of patient needs. The end-of-life decision-making process is similar for both groups: consultation of patients and relatives can be improved in a significant minority of patients.

J Clin Oncol 24:2842-2848. © 2006 by American Society of Clinical Oncology

INTRODUCTION

Robust incidence studies in Europe, the United States, and Australia have shown that end-of-life decisions with a possible or certain life-shortening effect (ELDs) are common in medical practice. Death is preceded by at least one such ELD in approximately 40% of all patients.¹⁻⁷ These ELDs can be classified as nontreatment decisions, symptom alleviation with possible life-shortening effect, and physician-assisted dying (including euthanasia, physician-assisted suicide, and life-ending acts without patient's explicit request).

Cancer as a cause of death stands out in these studies, because physician-assisted dying and symptom alleviation with a possible life-shortening effect occur more frequently among patients who die as a

result of cancer than among other patients.^{2,5,7} Furthermore, cancer was the cause of death in more than 70% of the legal cases of physician-assisted suicide in 1999 in Oregon⁸ and in 82.5% and 88% of the legally reported cases of euthanasia or physician-assisted suicide from 2002 to 2003 in Belgium and the Netherlands, respectively.^{9,10} Studies reporting that oncologists receive more requests for and have performed euthanasia and physician-assisted suicide more often compared with other physicians further support the epidemiologic data.¹¹⁻¹³

However, when comparing incidences of ELDs among cancer versus noncancer patients in these studies, all sudden and nonsudden deaths were included. From an epidemiologic or public health viewpoint, these comparisons can be methodologically problematic. An ELD is not likely to have been

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Submitted August 5, 2005; accepted March 10, 2006.

Supported by a grant from the Fifth Framework Programme of the European Commission (contract QLRT-1999-30859). L.V.d.B. received a student grant from the Fund for Scientific Research, Flanders, Belgium.

Presented in part at the Ninth Congress of the European Association for Palliative Care, April 6-10, 2005, Aachen, Germany.

Authors' disclosures of potential conflicts of interest and author contributions are found at the end of this article.

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0732-183X/06/2418-2842/\$20.00

DOI: 10.1200/JCO.2005.03.7531

made before sudden deaths, whereas among nonsudden deaths the planning of ELDs is more feasible. Cancer patients die less suddenly and most often have a linear and more predictable dying process compared with that of other diseases, where the rate of sudden and unexpected deaths is much higher (eg, cardiovascular diseases).¹⁴⁻¹⁸ To investigate whether ELDs are as probable for patients dying from cancer as for those dying from other chronic nonmalignant diseases, we need to select only the patients in which an ELD was possible in both patient groups.

Furthermore, in existing publications on ELDs, the decision-making processes for cancer and noncancer patients have never been reported separately nor compared. These analyses can provide oncologists and other physicians with important information regarding communication with patients, relatives, and other caregivers at the end of life.

In this study we focus exclusively on all nonsudden deaths and address the following two research questions. Does the incidence of end-of-life decisions differ between cancer and noncancer patients? Are there differences in the characteristics of the end-of-life decision-making process between cancer and noncancer patients?

METHODS

Study Design

A nationwide death certificate study was conducted in 2001 in Flanders, the Dutch-speaking part of Belgium, which has approximately 56,000 deaths per year. All deaths are reported to the Health Care Division of the Ministry of Flanders by means of death certificates. We selected a random sample ($N = 5,005$) of all deaths (aged 1 year or older) occurring between June and December 2001, stratified for the likelihood that an ELD was made. Larger samples of deaths were taken for strata in which the cause of death made an ELD more likely. For example, we sampled one in three cases of patients with malignancies compared to one in nine cases of patients who died after a car accident. We mailed questionnaires to the physicians who signed the death certificates. A complex mailing procedure, approved by the Ethical Review Board of the Academic Hospital of the Vrije Universiteit Brussel (Brussels, Belgium) and the Belgian National Disciplinary Board of Physicians, ensured the anonymity of the physician and patient. More details on this methodology and mailing procedure are published elsewhere.⁷ This study was part of a European study of ELDs in six European countries.⁷ At the time the study was performed, euthanasia was not legal in Belgium, but a law allowing it under certain conditions was under discussion.¹⁹

Questionnaire

To identify the cases in which an ELD was not possible, we asked the physician in the first part of the questionnaire if the patient had died "suddenly and completely unexpectedly." If the answer was "no," we asked the following questions to investigate the incidences of ELDs. (A) Did you withhold or withdraw medical treatment while taking into account the possibility or certainty that this would hasten the patient's death or with the explicit intention of hastening the patient's death? (B) Did you intensify the alleviation of pain and suffering while taking into account the possibility or certainty that this would hasten the patient's death or partly with the intention of hastening the patient's death? (C) Was death the result of the administration, supply, or prescription of drugs with the explicit intention of hastening the patient's death?

In the second part of the questionnaire, we surveyed the decision-making process of the ELD, if made. We asked the physician if the patient was competent to make decisions (incompetence was defined as "not or not entirely able to judge his or her situation and to make adequate decisions accordingly"), whether he or she made an explicit request, whether the decision was discussed with the patient without him or her making an explicit request, and whether the decision was discussed with the patients' relatives and other professional

caregivers. We also asked the physician to estimate by how much time the patient's life had been shortened as a consequence of the ELD.

ELDs are medical decisions aimed at hastening the patient's death or in which the physician takes into account a possible hastening of death. In accordance with other ELD studies,^{1,2,5,7,20} we classified the case as a nontreatment decision when at least one of the questions under (A) was answered "yes." When at least one of the questions under (B) was answered "yes," we classified it as intensification of pain and symptom alleviation with a possible life-shortening effect. When question (C) was answered "yes," we classified it as physician-assisted dying, subdivided between euthanasia when the drug was given by the physician at the patient's explicit request, or as physician-assisted suicide when the patient had taken the drug him or herself, or as life-ending acts without the patient's explicit request when the drug was administered without the patient's explicit request. To classify cases in which more than one ELD was scored, the decision with the most explicit intention prevailed over other ELDs. When the same life-shortening intentions were scored, physician-assisted dying prevailed over symptom alleviation with possible life-shortening effect, which prevailed over nontreatment decisions (eg, when symptom alleviation and nontreatment decisions were scored, each time taking into account a possible life-shortening effect, symptom alleviation prevailed).

Afterward, the information about the deceased patients on the death certificates (age, sex, educational level, occupational class, living situation, civil status, place of death, and cause of death according to International Classification of Diseases [10th revision]) was anonymously linked to the questionnaires completed by the physicians.

Data Analysis

Data were corrected for stratification and weighted for sex, age, place of death, and cause of death according to all deaths during the study period. Details on stratification and weighting procedure have been described elsewhere.⁷ Results for euthanasia and physician-assisted suicide were combined because the latter was limited to one patient.

To compare incidences and characteristics of ELDs in general and for all ELD types separately (nontreatment decisions, symptom alleviation with possible life-shortening effect, and physician-assisted dying) among cancer versus noncancer patients, we used Fisher's exact tests (5% α level). We performed logistic regression analyses to adjust for patient age, sex, place of death, educational level, occupational class, living situation and civil status, and type of physician (general practitioner *v* specialist), to isolate the effect of cause of death as a predictor. In the logistic regression analyses, the models were adjusted for stratification and unequal weighting.

Analyses were performed using StatXact6 version 6 (Cytel Software Corporation, Cambridge, MA) and SAS version 9.1.3 (SAS Institute, Cary, NC).

RESULTS

The response rate was 59% (unweighted $n = 2,950$). Cancer was the cause of death in 25.7% of the cases. Noncancer causes of death were cardiovascular diseases (26.4%), diseases of the nervous system (14.0%), respiratory diseases (13.3%), and other (20.6%). Of all deaths, 76.6% were considered nonsudden. Among cancer patients, 94.6% (unweighted $n = 1,140$) died nonsuddenly compared with 69.8% (unweighted $n = 988$) among noncancer patients ($P < .001$).

Patient Characteristics

Table 1 indicates that cancer patients died younger than noncancer patients, were more often male, had a higher educational level, and more had been employed. They lived more often in a private household, more were married, and they died more often at home. Noncancer patients died more often in a home for the elderly.

Incidence of ELDs

Bivariate analyses in Table 2 indicate that an ELD was made in 74.1% of the cancer patients, compared with 50.1% of the noncancer

Table 1. Cancer Versus Noncancer Patients Who Died Nonsuddenly in Flanders, Belgium, 2001 (N = 2,128)

Patient Characteristic*	Cancer (n = 1,140)		Noncancer (n = 988)	
	No. of Patients	Weighted %†	No. of Patients	Weighted %†
Age, years				
1-64	301	26.1	81	8.2
65-79	498	45.2	248	26.8
≥ 80	341	28.7	656	65.0
Sex				
Male	671	59.7	422	42.8
Female	469	40.3	566	57.2
Educational level				
Primary education or lower	400	44.9	495	66.1
Lower secondary education	264	29.8	154	21.3
Higher secondary education	163	18.2	60	8.2
Higher education or university	64	7.1	32	4.4
Occupational class				
Service class	109	10.8	50	6.5
Intermediate class	244	24.6	137	17.5
Workers class	363	38.2	236	30.3
Had never been employed	253	26.4	349	45.7
Living situation				
Living alone	191	18.9	144	15.9
Living in a private household	793	69.6	412	45.2
Living in an institution	142	11.1	417	38.8
Other‡	5	0.5	1	0.1
Civil status				
Unmarried	103	9.0	93	8.7
Married	661	57.2	314	32.4
Widow(er)	310	27.8	542	54.8
Divorced	66	6.0	36	4.0
Place of death				
Home	530	36.3	155	14.1
Hospital	478	54.5	467	54.5
Home for the elderly	126	8.8	360	31.1
Other‡	6	0.5	3	0.2

*For all patient characteristics, difference in distribution among cancer versus noncancer patients was significant with $P < .001$ (Fisher's exact test).

†The percentages are weighted for stratification and adjusted for patient mortality characteristics of all deaths in Flanders, Belgium, 2001.

‡Not included in significance testing.

patients. Symptom alleviation with a possible life-shortening effect was reported in 53% of the cancer patients, which is twice as frequent as that among noncancer patients. Nontreatment decisions were reported 1.5 times less frequently among cancer patients. Physician-assisted dying occurred in 4.6% of the cancer deaths, which is almost three times higher than for noncancer patients. Euthanasia/physician-assisted suicide preceded death in 1.2% of cancer patients and was not found among noncancer patients. Life-ending without explicit request occurred twice as often among cancer patients.

The odds ratios (ORs) for nontreatment decisions and symptom alleviation with possible life-shortening effect in the logistic regression analysis (Table 2) show analog results regarding the differences between cancer and noncancer patients. Calculation of the OR for euthanasia/physician-assisted suicide was not possible because no occurrences were reported in the noncancer group. When correcting for the patient's age, the ORs for physician-assisted dying and life-ending without explicit request were no longer significant. Patients older than 80 years were almost five times less likely to die as a result of physician-assisted dying or life-ending without explicit request than younger

patients (adjusted OR of age for physician-assisted dying, 0.25; 95% CI, 0.14 to 0.46; adjusted OR of age for life-ending without explicit request, 0.34; 95% CI, 0.18 to 0.64). Additional subanalysis of the latter cases showed no difference in the patient's competence between those younger and those older than 80 years ($P = .301$).

End-of-Life Decision-Making Process

Table 3 shows that ELDs most often related to patients judged to be incompetent. This was more pronounced for noncancer (76.1%) than for cancer (51.8%) patients ($P < .001$), and higher for nontreatment decisions and life-ending without explicit request than for symptom alleviation with possible life-shortening effect. Inherent to the definition of euthanasia/physician-assisted suicide, all patients in this group were competent. For life-ending without explicit request, we found no difference between cancer and noncancer deaths regarding the proportion of (in)competent patients.

For competent patients, ELDs among cancer and noncancer patients were similar with regard to prior discussion with the patient and his or her relatives, except for life-ending without explicit request.

Table 2. ELDs Among Nonsudden Cancer Versus Noncancer Deaths in Flanders, Belgium, 2001 (N = 2,128)

Type of ELD	Cancer (n = 1,140)		Noncancer (n = 988)		P‡	Odds Ratio*	
	No. of Patients	Weighted %†	No. of Patients	Weighted %†		Adjusted	95% CI
At least one ELD was made	844	74.1	501	50.1	< .001	2.791	2.313 to 3.367
Nontreatment decisions	183	16.4	248	25.1	< .001	0.574	0.461 to 0.716
Life shortening taken into account	62	5.8	109	11.1	< .001	0.489	0.350 to 0.682
Life shortening explicitly intended	121	10.6	139	14.0	.037	0.712	0.544 to 0.932
Intensification of pain and/or symptom alleviation with a possible life-shortening effect	606	53.1	234	23.2	< .001	3.688	3.040 to 4.474
Life shortening taken into account	525	46.2	200	20.2	< .001	3.398	2.781 to 4.151
Life shortening partly intended	81	6.9	34	3.0	< .001	2.156	1.413 to 3.289
Administration, prescription or supply of drugs with the explicit intention of shortening the patient's life	55	4.6	19	1.8	.001	NS§	
Euthanasia or physician-assisted suicide	16	1.2	—		< .001	—	
Life-ending acts without the patient's explicit request	39	3.4	19	1.8	.037	NS§	

Abbreviations: ELD, end-of-life decision with possible/certain life-shortening effect; NS, not significant; LR, logistic regression.

*Odds ratio of LR with noncancer patients as reference group, adjusted for patient characteristics (age, sex, place of death, educational level, occupational class, living situation, civil status) and for type of physician (general practitioner v specialist); LR was adjusted for stratification and unequal weighting.

†Percentages are weighted for stratification and adjusted for patient mortality characteristics of all deaths in Flanders, Belgium, 2001.

‡Bivariate differences between cancer and noncancer are calculated using Fisher's exact test (exact *P*) 5% α level.

§The only significant predictor of physician-assisted dying and life-ending without explicit request is the age of the patient, with younger patients having greater odds of dying as a consequence of these ELDs.

||Calculation of odds ratios for euthanasia/physician-assisted suicide was not possible because no occurrences were reported in the noncancer group.

On average, in one of five patients the ELD was not discussed with the patient or his or her relatives. Symptom alleviation with a possible life-shortening effect in particular was the least often discussed. Life-ending without explicit request was always discussed with competent cancer patients, and never with competent noncancer patients (only three such patients).

For incompetent patients, ELDs were discussed in four of five cases with patients' relatives, with no differences found for cancer and noncancer patients. Physicians consulted relatives least often for symptom alleviation with possible life-shortening effect compared with other ELDs.

Consultation of other professional caregivers mainly differed for cancer and noncancer patients with regard to symptom alleviation with possible life-shortening effect. They were discussed less often with nursing staff in the cancer group (*P* = .007). In both groups, this ELD type was discussed less often with other caregivers than all other ELDs.

We found no differences between cancer and noncancer deaths regarding the estimated duration by which the patient's life was shortened due to an ELD. In three of four cases the estimated duration was less than 1 week.

DISCUSSION

Life-shortening ELDs are common in nonsudden deaths in Flanders, Belgium, with a higher incidence among cancer than noncancer patients, especially regarding symptom alleviation with a possible life-shortening effect. Nontreatment decisions occur more frequently among noncancer patients. The use of lethal drugs without explicit request is not related to having cancer or not. ELDs mostly relate to

incompetent patients and the decision-making process preceding the ELDs is similar for cancer and noncancer patients.

To our knowledge, this is the first study of ELDs among nonsudden deaths, comparing the incidences as well as the ELD characteristics among cancer and noncancer patients. The higher incidence of nonsudden deaths among cancer patients emphasizes the importance of selecting the nonsudden deaths to make meaningful comparisons. The death certificate study was judged a highly reliable method to estimate ELD incidences in a population.^{2,3,5,7}

This study also has some limitations. First, although the response rate was satisfying, we cannot fully exclude the possibility of a response bias, especially an under-reporting of specific ELDs such as physician-assisted dying. However, because the weighted sample was representative for the population and anonymity was guaranteed, we believe that the results are valid estimations of the true frequency of ELDs in Flanders. Second, the results of our study are based on self-reports of physicians and therefore cannot fully exclude errors in the perceptions of their acts. For example, physicians might have overestimated the actual life-shortening effect of symptom-alleviating medication such as opioids.²¹ Third, causes of death are recorded solely from the information on the death certificates and additional information about the patient's disease trajectory, which might explain the results more fully, was not gathered.

A major finding is that even after selection of the nonsudden deaths, cancer and noncancer patients differ considerably in the frequency of different ELD types. Symptom alleviation with a possible life-shortening effect in particular was substantially higher for cancer patients. A possible explanation is a higher amount of pain among cancer patients compared with other diseases,²² which can lead to

Table 3. Characteristics of the End-of-Life Decision-Making Process for Nonsudden Cancer Versus Noncancer Deaths (N = 1,345) *

Characteristic	ELD			NTD			APS			EUTH/PAS			LAWER		
No. of deaths studied															
Cancer Deaths	844			183			606			16			39		
Noncancer deaths	501			248			234			0			19		
Characteristics of ELD	Weighted %			Weighted %			Weighted %			Weighted %			Weighted %		
	Cancer Deaths	Noncancer Deaths	P†	Cancer Deaths	Noncancer Deaths	P†	Cancer Deaths	Noncancer Deaths	P†	Cancer Deaths	Noncancer Deaths	P†	Cancer Deaths	Noncancer Deaths	P†
Discussion of decision with patient and relatives															
Patient was competent	35.4	13.0	< .001	29.2	9.6	< .001	36.1	16.8	< .001	100.0	—	—	36.4	8.7	.083
Discussed with patient	69.8	60.2	.156	75.0	74.2	.99	65.6	52.0	.121	100.0	—	—	100.0	0.0	.028
Discussed with patient's relatives	73.4	70.4	.652	77.4	83.9	.749	69.1	62.5	.469	100.0	—	—	100.0	50.0	.200
Not discussed with patient nor relatives	18.2	24.7	.244	9.7	12.9	.99	22.6	31.3	.245	—	—	—	0.0	50.0	.200
Patient was incompetent	51.8	76.1	< .001	66.0	83.9	< .001	47.7	66.8	< .001	—	—	—	63.6	91.3	.083
Discussed with patient's relatives	77.2	78.7	.637	87.1	82.2	.374	72.7	71.1	.813	—	—	—	78.6	100.0	.056
Unknown whether patient was competent‡	12.8	10.9		4.7	6.5		16.2	16.4		—	—	—	—	—	—
Discussion with other caregivers§															
Other physicians	42.4	44.3	.575	55.1	46.1	.117	37.0	40.8	.209	62.5	—	—	59.1	65.2	.763
Nursing staff	50.4	62.5	< .001	57.9	67.2	.074	47.5	56.4	.007	62.5	—	—	57.1	73.9	.342
No discussion with other caregivers	19.7	12.7	.002	13.1	10.2	.474	22.3	15.8	.053	11.1	—	—	18.2	8.3	.405
Unknown if decision was discussed with other caregivers‡	7.0	6.4	—	1.9	2.5	—	9.0	11.0	—	—	—	—	—	—	—
Estimated shortening of life															
Less than 1 week	78.3	75.8		72.6	77.1		80.1	74.2		75.0	—	—	81.8	78.3	
1 week to 1 month	7.9	9.3		17.0	9.9		4.3	8.4		25.0	—	—	13.5	13.0	
More than 1 month	2.9	3.7		6.6	5.9		1.7	1.0		0.0	—	—	4.5	8.7	
Unknown‡	11.0	11.2		3.8	7.1		13.8	16.4		—	—	—	—	—	

Abbreviations: ELD, at least one end-of-life decision with possible/certain life-shortening effect was made; NTD, nontreatment decisions; APS, intensification of pain and symptom alleviation with possible life-shortening effect; EUTH/PAS, euthanasia and physician-assisted suicide; LAWER, life-ending acts without the patient's explicit request.

*The percentages are weighted for stratification and adjusted for patient mortality characteristics of all deaths in Flanders, Belgium, 2001.

†Differences between cancer deaths and noncancer deaths are calculated using Fisher's exact test (exact *P*), 5% α level. Significant differences are indicated in bold.

‡Category not included in significance testing.

§Multiple responses possible.

more complaints and an increase of pain medication in the terminal phase. However, several studies^{17,23} show that noncancer patients often under-reported pain and that physicians underassess and undertreat it.^{17,24} A complementary explanation may be that palliative care services—specializing in symptom treatment—are more readily available to cancer patients than to other patients.^{14,17,25,26}

The higher incidence of life-ending without explicit request in the cancer group could be attributed to age differences between cancer and noncancer patients, with patients older than 80 years receiving fewer lethal drugs without their explicit request than patients younger than 80 years. Physicians seem to hold different attitudes and behaviors toward younger patients versus the elderly, which needs to be investigated further.

Regarding euthanasia/physician-assisted suicide, we could not evaluate if patient characteristics could explain the difference in incidence rates between cancer and noncancer patients. However, it is

plausible that cancer patients are still more likely to die after euthanasia/physician-assisted suicide because they are on average younger and thus probably more assertive, and because their prognosis is more certain, making them more aware of the terminal nature of their illness.¹⁸ Therefore, explicit requests for euthanasia or physician-assisted suicide can probably be expected more often in this group.

Contrary to all other ELDs, decisions to withhold or withdraw treatments at the end of life occurred less often among cancer patients and were the most frequently reported ELD among noncancer patients. A possible explanation related to differences in dying trajectory and population characteristics^{17,26} is that noncancer patients are often elderly, who suffer from several comorbid conditions, and gradually become physically and cognitively impaired. When the physician believes that the end of life is approaching, questions will arise regarding the effect and utility of beginning or continuing life-prolonging therapies, probably without improving the patient's quality of life.

Physicians may therefore need to make decisions to forgo possible (futile) treatments among these patients. A complementary explanation for the lower frequency of these decisions in the cancer group is a possible therapeutic persistence among specialist physicians treating cancer patients (eg, continuing with chemotherapy regimens that have a low likelihood of beneficial effect for the patient).

Half of the cancer patients who died after an ELD and even more (three of four) noncancer patients were judged as incompetent. The higher amount of incompetence found in the noncancer group is probably a reflection of the higher number of elderly patients in the noncancer population, who often have several serious chronic illnesses, including dementia and other cognitive impairments.^{17,26} The high number of incompetent patients found for both groups is striking. Physicians seem to be confronted with many patients with whom conversation is judged difficult at the end of life. A possible explanation

is that ELDs are made late in the dying process when a lot of patients experience impaired cognitive function. Therefore, we believe that communication with patients about possible ELDs could start earlier in the disease process, before its terminal stages.

Furthermore, for both groups, the ELD was not discussed with competent patients nor with relatives of incompetent patients in one fifth of the cases. In particular, symptom alleviation with possible life-shortening effect could be discussed more often with all actors involved.

In conclusion, after correcting for the sudden/unexpected deaths, the most frequently reported ELD types are strongly related to having cancer or not, whereas the characteristics of the end-of-life decision-making process are similar for both groups. Patients, relatives, and others involved can be consulted more often, particularly for symptom alleviation with a possible life-shortening effect.

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Acknowledgment

We thank Johan Vanoverloop and Joachim Cohen for their statistical guidance, the Federal and Flemish Ministry of Public Health for their cooperation in the data collection, all participating physicians, and all members of the European End-of-Life Decisions (EURELD) consortium, with special thanks to Freddy Mortier.

Authors' Disclosures of Potential Conflicts of Interest

The authors indicated no potential conflicts of interest.

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