

# End-of-Life Decision Making in Europe and Australia

## A Physician Survey

Bregje D. Onwuteaka-Philipsen, PhD; Susanne Fisher, PhD; Colleen Cartwright, PhD; Luc Deliens, PhD; Guido Miccinesi, MD; Michael Norup, MD, PhD; Tore Nilstun, PhD; Agnes van der Heide, MD, PhD; Gerrit van der Wal, PhD; for the European End-of-Life (EURELD) Consortium

**Background:** The frequencies with which physicians make different medical end-of-life decisions (ELDs) may differ between countries, but comparison between countries has been difficult owing to the use of dissimilar research methods.

**Methods:** A written questionnaire was sent to a random sample of physicians from 9 specialties in 6 European countries and Australia to investigate possible differences in the frequencies of physicians' willingness to perform ELDs and to identify predicting factors. Response rates ranged from 39% to 68% (N=10 139). Using hypothetical cases, physicians were asked whether they would (probably) make each of 4 ELDs.

**Results:** In all the countries, 75% to 99% of physicians would withhold chemotherapy or intensify symptom treatment at the request of a patient with terminal cancer. In

most cases, more than half of all physicians would also be willing to deeply sedate such a patient until death. However, there was generally less willingness to administer drugs with the explicit intention of hastening death at the request of the patient. The most important predictor of ELDs was a request from a patient with decisional capacity (odds ratio, 2.1-140.0). Shorter patient life expectancy and uncontrollable pain were weaker predictors but were more stable across countries and across the various ELDs (odds ratios, 1.1-2.4 and 0.9-2.4, respectively).

**Conclusion:** Cultural and legal factors seem to influence the frequencies of different ELDs and the strength of their determinants across countries, but they do not change the essence of decision making.

*Arch Intern Med.* 2006;166:921-929

IT IS KNOWN THAT END-OF-LIFE DECISIONS (ELDs) are part of medical practice everywhere, albeit with different frequencies in different countries.<sup>1-8</sup> Several studies<sup>2,9-18</sup> have aimed to detect factors associated with attitudes toward ELDs and the decision of whether to make an ELD. Determinants of ELDs have been found to include particular clinical situations (such as terminal illness), unbearable pain and suffering, lack of decisional capacity, a patient's request,<sup>2,11,16-18</sup> and physician characteristics, including sex, age, religion, and specialty.<sup>10-14</sup> However, direct comparisons of results between countries are difficult because the methods used were not sufficiently similar, and most studies were restricted to particular specialties or a specific ELD.

In the European End-of-Life (EURELD) study, hypothetical cases were used to systematically investigate willingness to make ELDs in 6 European countries and Australia. The objectives were to investigate its frequency, the extent to which this differed among countries, and the extent to which situational characteristics (patient or fam-

ily request, lack of decisional capacity, uncontrollable pain, and life expectancy) and physician characteristics (age, sex, religion, and specialty) influence the decision making of physicians for different types of ELDs. Possible differences among countries in determinants and their relative strengths were also investigated.

## METHODS

### STUDY DESIGN AND DEFINITIONS

A written questionnaire with structured questions was sent to a sample of practicing physicians in Australia and 6 European countries: Belgium (Flanders), Denmark, Italy (Emilia-Romagna, Trento, Tuscany, and Veneto), the Netherlands, Sweden, and Switzerland.

An ELD is a medical decision that may shorten a life. Instead of using terms that could be interpreted differently by different physicians in different countries, precise descriptions of 4 ELDs were provided:

Withholding a third course of chemotherapy, taking into account the probability or certainty that this would hasten the end of the patient's life.

Author Affiliations are listed at the end of this article.

Group Information: The EURELD Consortium investigators are listed at the end of this article.

Intensifying the alleviation of pain/symptoms by using drugs such as opioids, taking into account the probability or certainty that this would hasten the end of the patient's life.

Administering drugs, such as benzodiazepines or barbiturates, to keep a patient in deep sedation until death, without giving (artificial) hydration or nutrition.

Administering drugs with the explicit intention of hastening the patient's end of life (with or without an explicit request from the patient).

## STUDY POPULATION

In each country, a random sample of 300 physicians was drawn from each professional register of 9 specialties in which physicians attend to dying patients relatively frequently: anesthesiology, general practice, geriatrics, gynecology, internal medicine, neurology, oncology (not a separate registered specialty in the Netherlands), pulmonology, and surgery. There were some differences by country in the extent to which physicians attended to dying patients; anesthesiologists, for example, were not attending physicians in all countries. In Italy, the sample was not drawn from professional registers but from hospital and general practice registers. When there were fewer than 300 physicians working in a specialty, all the specialists were included in the sample. In Italy, general practitioners were oversampled. The number of questionnaires sent out varied from 1870 in Denmark to 3873 in Italy. Response rates, adjusted for physicians who were no longer practicing or who were untraceable (ranging from 2 in Italy to 332 in the Netherlands), were as follows: Australia, 50% (n=1478); Belgium, 58% (n=1750); Denmark, 68% (n=1217); Italy, 39% (n=1508); the Netherlands, 61% (n=1275); Sweden, 60% (n=1514); and Switzerland, 64% (n=1397).

Anonymity was guaranteed by not numbering the questionnaires. The respondents were asked to return a card, separately from the questionnaire, to indicate that they had responded. In Denmark, the Netherlands, Sweden, and Switzerland it was feasible to perform a nonresponse study, which found that responders and nonresponders did not differ in sex, age, or religion. Nonresponders agreed less frequently and less strongly with the statement "The use of drugs in lethal doses on the explicit request of the patient is acceptable for patients with a terminal illness with extreme uncontrollable pain" (36% of nonresponders vs 57% of responders). The most frequently mentioned reason for not responding was "no time" (51%).

## MEASUREMENT INSTRUMENT

The 8-page questionnaire consisted of prestructured questions. Country-specific versions were made from a common English version, which was translated into the languages of the countries and then translated back into English to search for inconsistencies. Willingness to make ELDs was measured with the help of 4 hypothetical cases concerning a patient with terminal cancer. In all 4 cases, the patient is aged 71 years, has cancer with extensive brain and bone metastases, and has undergone burdensome chemotherapy twice. Undergoing chemotherapy once more would give a limited chance of long-standing remission (<10%).

Case 1: The patient is clearheaded and can still communicate well. You estimate the patient's life expectancy (without chemotherapy) to be no more than 2 weeks. The patient has pain that is difficult to control despite the use of analgesic drugs in high doses.

Case 2: The patient is clearheaded and can still communicate well. You estimate the patient's life expectancy (without chemotherapy) to be at least 3 months. Pain can be adequately

controlled, but the patient is extremely tired, short of breath, and bedridden.

Case 3: The patient is drowsy or subcomatose and communication is not possible. You estimate the patient's life expectancy (without chemotherapy) to be no more than 2 weeks. Pain can be adequately controlled, but the patient is extremely tired, short of breath, and bedridden.

Case 4: The patient is drowsy or subcomatose and communication is not possible. You estimate the patient's life expectancy (without chemotherapy) to be at least 3 months. The patient has pain that is difficult to control despite the use of analgesic drugs in high doses.

The cases varied systematically in 3 factors: (un)controllable pain, (lack of) decisional capacity, and life expectancy (<2 weeks vs  $\geq 3$  months). After each case description, the physician was asked whether he or she would perform any 1 of 4 specific ELDs (1) if the patient requested it (if the patient lacked decisional capacity this would be in the form of an advance directive), (2) if the family requested it, or (3) on the physician's own initiative because of medical futility (in the case of forgoing chemotherapy) or to reduce suffering (for the other 3 ELDs). Response options were scored on a 5-point Likert scale: yes, probably yes, undecided, probably no, and no (eFigure available at: <http://www.archinternmed.com>)

## STATISTICAL ANALYSIS

The data from all the countries were combined in a common database to ensure identical coding and analysis. When presenting frequencies, we used weighting factors to correct for the different sampling fractions and response rates in the different strata. Regression models were fitted for each country and each ELD. The dependent variable was dichotomized, combining "probably yes" and "yes" on one side and "probably no" and "no" on the other side and omitting "undecided." The multiple logistic regression analysis was corrected for the possible dependency within the answers of each respondent. This was accomplished by using generalized estimating equations. The independent variables used were the request of the patient or family, the 3 factors that varied in the cases (uncontrollable pain, decisional capacity, and life expectancy), and several background characteristics (sex, age, specialty, and religion being important in forming professional attitudes toward ELDs). Because of the stratification according to specialty, this variable was included in all the analyses. For 2 variables—request of the patient or family and decisional capacity of the patient—it was necessary to introduce interaction terms to the models. In this way, the effects of a patient's or family's request and the decisional capacity of the patient were estimated for the different subgroups. To achieve comparability among countries and different ELDs, all the described independent variables were entered into each model.

## RESULTS

### FREQUENCIES OF WILLINGNESS TO PERFORM ELDs

#### At the Patient's Request

Most physicians, in all the countries, would probably comply with a patient's request, regardless of whether it was made in an advance directive, to intensify the alleviation of pain or other symptoms or, especially, to withhold chemotherapy (**Table 1**). For deep sedation and,

**Table 1. Intentions of Physicians in 6 European Countries and Australia on Making End-of-Life Decisions in 4 Hypothetical Cases\***

Variable	Australia (n = 1478)				Belgium (n = 1750)				Denmark (n = 1217)				Italy (n = 1508)				The Netherlands (n = 1275)				Sweden (n = 1514)				Switzerland (n = 1397)			
	Case				Case				Case				Case				Case				Case							
	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4
Withholding chemotherapy																												
On patient's request†	99	99	99	98	98	96	99	98	91	92	98	97	95	90	96	92	95	95	99	98	97	94	98	95	96	96	99	98
On relatives' request without informing patient	9	7	90	83	34	25	85	78	20	12	82	72	45	38	84	75	9	6	82	72	16	10	83	71	20	12	88	78
On own initiative, because of medical futility	40	34	84	77	59	52	91	87	54	40	88	82	73	62	92	83	35	25	82	74	71	59	91	86	71	57	95	88
Intensifying pain/symptom medication																												
On patient's request†	96	91	95	96	98	91	96	98	98	87	90	93	85	76	79	84	98	88	91	97	93	82	87	91	90	75	85	90
On relatives' request without informing patient	20	10	81	82	50	29	76	80	34	13	67	70	49	33	60	66	11	3	61	69	25	11	66	70	21	10	60	65
On own initiative, to reduce suffering	64	46	82	84	80	56	84	87	79	47	80	83	79	61	74	80	45	21	63	71	73	52	78	85	68	40	74	81
Deep sedation until death																												
On patient's request†	63	40	73	69	83	54	86	85	52	22	58	49	72	44	66	68	70	34	78	71	55	29	56	48	76	45	72	75
On relatives' request, without informing patient	8	4	55	50	24	11	60	55	10	2	39	32	31	14	45	46	2	0	38	40	6	1	31	28	10	4	43	45
On own initiative, to reduce suffering	26	14	55	50	39	18	63	60	25	8	46	38	51	25	56	59	11	4	39	35	22	9	38	35	32	17	51	56
Ending of life																												
On patient's request†	24	15	27	26	54	41	59	60	23	11	26	23	14	9	13	13	59	43	50	55	6	5	8	9	24	18	28	29
On relatives' request, without informing patient	2	1	15	13	5	2	26	26	3	1	12	12	2	1	4	4	0	0	13	15	1	1	3	2	1	1	9	10
On own initiative, to reduce suffering	9	5	19	16	13	6	28	28	12	5	20	17	5	2	6	7	5	2	12	10	2	2	5	4	8	5	13	15

\*Data are given as the rounded and weighted percentage of "yes" and "probably yes" responses.

†For cases 1 and 2: a patient's request at the moment described in the hypothetical case. For cases 3 and 4: a request as previously formulated in an advance directive.

especially, the ending of life, the percentages were generally lower and varied more by case and country. Percentages were systematically and substantially lower for case 2, that is, the patient with decisional capacity with a relatively long life expectancy and controllable pain.

#### At the Request of the Family

Far fewer physicians said that they would (probably) adhere to the request of the family for an ELD if the patient had decisional capacity (case 1 and especially case 2) than if the patient was subcomatose. For a patient who lacks decisional capacity, they would (probably) have done so in most cases in all the countries if the request concerned withholding chemotherapy. Adherence to the request of the family of a patient lacking decisional capacity for terminal sedation until death would (probably) be done most frequently in Belgium and least frequently in Sweden. Ending the life of a patient who lacks decisional capacity at the family's request would (probably) be done by a small group of physicians in most countries.

Adherence to the request by the family of a patient with decisional capacity was highest among physicians from Belgium and Italy for all ELDs except ending of life. It was lowest among physicians in the Netherlands. For ending a life at the request of the family of a patient with decisional capacity, the percentages were very low for all countries.

#### On the Physician's Own Initiative

The percentages of physicians willing to make ELDs on their own initiative to reduce suffering were similar across cases and countries to those of physicians willing to make ELDs at the family's request, although the frequencies were generally higher than those for (probable) adherence to a request from the family, especially for patients lacking decisional capacity, and for withholding chemotherapy and intensifying alleviation of pain/symptoms (Table 1).

#### PREDICTORS OF WILLINGNESS TO PERFORM ELDs

##### Request

**Tables 2, 3, 4, and 5** present the regression models by country for each of the 4 ELDs. For all 4 ELDs in all 7 countries, a patient's request substantially increased the likelihood of the physician's willingness to perform the action compared with the physician doing it on his or her own initiative. The interaction between request and decisional capacity made the likelihood of compliance greater for a request by a patient with decisional capacity than for an advance directive of a subcomatose patient. The strength of the effect of the patient's request differed according to

**Table 2. Predictors of (Probably) Forgoing a Third Course of Chemotherapy\***

Variable	Odds Ratio (95% CI)						
	Australia (n = 1233)	Belgium (n = 1685)	Denmark (n = 1160)	Italy (n = 1477)	The Netherlands (n = 1040)	Sweden (n = 1431)	Switzerland (n = 1306)
Request							
Request of patient with decisional capacity	140 (85-228)	20 (16-25)	10 (8.2-13.1)	8.9 (6.8-11)	41 (28-59)	10 (8.1-13)	13 (9.6-17)
Advance directive of subcomatose patient	22 (6.9-61)	11 (5.2-22)	4.6 (2.5-9.1)	4.1 (2.2-7.6)	17 (5.3-52)	3.8 (1.9-7.4)	7.9 (3.1-20)
Request of family of subcomatose patient	NS	0.56 (0.41-0.75)	0.30 (0.22-0.44)	0.35 (0.30-0.41)	NS	0.27 (0.18-0.40)	0.34 (0.23-0.50)
Request of family of patient with decisional capacity	0.09 (0.07-0.11)	0.24 (0.21-0.27)	0.10 (0.09-0.2)	0.56 (0.39-0.81)	0.10 (0.08-0.12)	0.06 (0.05-0.07)	0.07 (0.06-0.08)
Own initiative of physician	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Decisional capacity							
Subcomatose patient, request of the family	137 (87-215)	12 (9.2-18)	25 (16-37)	6.7 (4.6-9.7)	82 (50-133)	26 (18-39)	37 (23-59)
Subcomatose patient, own initiative of physician	9.6 (8.0-11)	5.5 (4.7-6.5)	8.3 (6.8-10)	4.2 (3.6-4.9)	11 (9.2-14)	5.8 (4.8-6.9)	7.6 (6.1-9.5)
Subcomatose patient, advance directive	NS	2.9 (1.7-5.3)	3.8 (2.0-6.9)	1.9 (1.1-3.2)	4.6 (1.8-12)	2.1 (1.2-3.6)	4.6 (2.0-11)
Patient with decisional capacity	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Life expectancy <2 wk†	1.5 (1.4-1.6)	1.5 (1.4-1.6)	1.6 (1.5-1.8)	1.8 (1.6-1.9)	1.8 (1.6-2.1)	1.8 (1.6-1.9)	1.7 (1.6-1.9)
Uncontrollable pain†	0.89 (0.82-0.96)	NS	NS	0.86 (0.80-0.93)	NS	NS	NS
Physician's sex (female)†	NS	0.72 (0.59-0.87)	NS	NS	0.73 (0.56-0.94)	NS	NS
Physician's age (>50 y)†	NS	NS	NS	NS	1.3 (1.1-1.6)	2.0 (1.7-2.4)	1.3 (1.1-1.5)
Physician's life stance							
Religious; important for professional attitude	NS	1.3 (1.1-1.5)	NS	NI/NA	NS	NS	NS
Nonreligious; important for professional attitude	NS	NS	NS	NI/NA	NS	NS	NS
No specific life stance or not important for professional attitude	1.00	1.00	1.00	NI/NA	1.00	1.00	1.00

Abbreviations: CI, confidence interval; NI/NA, not included/not asked; NS, not significant.

\*Multiple logistic regression. The reference group is (probably) not forgoing a third course of chemotherapy; the category "undecided" is excluded from this analysis.  
†Dichotomous variables.

the ELD, diminishing in strength from withholding chemotherapy (odds ratio [OR], 8.9 [Italy] to 140.0 [Australia]), through intensifying the alleviation of pain/symptoms (OR, 4.4 [Sweden and Switzerland] to 37.0 [the Netherlands]) and deep sedation (OR, 2.4 [Italy] to 18.0 [the Netherlands]), to ending of life (OR, 2.2 [Denmark] to 3.2 [Switzerland]), except in Belgium and the Netherlands, where the ORs for ending of life were relatively high (ORs, 8.7 and 49.0, respectively). There were large differences in the strength of the effect among the countries.

Physicians in all 7 countries were less likely to make an ELD at the request of the family than on their own initiative. This was always the case for requests by the family of patients with decisional capacity; for patients who lack decisional capacity it was the case for all ELDs except ending of life.

### Decisional Capacity

In all the countries, physicians were more likely to perform all types of ELDs for patients who lack decisional capacity than for patients with decisional capacity (Tables 2, 3, 4, and 5). The interaction with request made this like-

lihood greatest when the family of a subcomatose patient requested an ELD, followed by situations in which the physician would decide on his or her own initiative, and least when there was an advance directive from the patient. In all the countries, the patient being subcomatose had the greatest influence on decisions to withhold chemotherapy and the least influence on ending of life. The influence of a patient lacking decisional capacity combined with a request from the family varied, with the effect being generally highest in Australia (OR, 10-137) and the Netherlands (OR, 43-82) and lowest in Belgium (OR, 6.8-12.0) and Italy (OR, 2.5-6.7), except for ending of life, in which the place of Belgium was taken by Sweden (OR, 3.2).

### Life Expectancy and Uncontrollable Pain

A life expectancy of less than 2 weeks and uncontrollable pain were positive predictors of physicians making an ELD except for the decision to withhold chemotherapy, in which case uncontrollable pain had no influence (Tables 2, 3, 4, and 5). The effects of these 2 determinants were similar in strength, with ORs of 0.9 to 2.4 across the different countries and ELDs.

**Table 3. Predictors of (Probably) Intensifying the Alleviation of Symptoms by Using Drugs, Taking Into Account the Probability or Certainty That This Could Hasten the Patient's End of Life\***

Variable	Odds Ratio (95% CI)						
	Australia (n = 1230)	Belgium (n = 1663)	Denmark (n = 1161)	Italy (n = 1473)	The Netherlands (n = 1040)	Sweden (n = 1429)	Switzerland (n = 1303)
Request							
Request of patient with decisional capacity	15 (11-19)	9.8 (8.0-11.9)	6.7 (5.7-7.8)	2.1 (1.8-2.4)	37 (28-49)	4.4 (3.8-5.0)	4.4 (3.8-5.0)
Advance directive of subcomatose patient	4.1 (2.4-6.8)	4.9 (3.1-7.7)	NS	1.6 (1.2-2.0)	6.7 (3.7-12.2)	1.9 (1.4-2.5)	2.1 (1.6-2.7)
Request of family of subcomatose patient	NS	0.57 (0.43-0.74)	0.30 (0.21-0.47)	0.31 (0.27-0.36)	NS	0.42 (0.32-0.55)	0.45 (0.31-0.63)
Request of family of patient with decisional capacity	0.09 (0.08-0.11)	0.25 (0.22-0.28)	0.07 (0.06-0.9)	0.58 (0.45-0.76)	0.18 (0.13-0.25)	0.09 (0.08-0.10)	0.11 (0.09-0.13)
Own initiative of physician	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Decisional capacity							
Subcomatose patient, request of the family	40 (27-58)	6.8 (5.1-9.2)	13 (9.4-19)	2.7 (2.2-3.3)	43 (29-64)	11 (9.0-16)	12 (8.9-16)
Subcomatose patient, own initiative of physician	4.5 (3.8-5.2)	3.0 (2.6-3.5)	3.1 (2.7-3.6)	1.4 (1.3-1.6)	6.2 (5.3-7.2)	2.5 (2.2-2.8)	2.9 (2.6-3.3)
Subcomatose patient, advance directive	NS	NS	0.68 (0.45-0.98)	NS	NS	NS	1.4 (1.1-1.8)
Patient with decisional capacity	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Life expectancy <2 wk†	1.4 (1.3-1.5)	1.4 (1.3-1.5)	1.7 (1.6-1.9)	1.2 (1.1-1.2)	1.6 (1.4-1.7)	1.4 (1.3-1.5)	1.5 (1.4-1.6)
Uncontrollable pain†	1.5 (1.4-1.7)	1.9 (1.8-2.1)	2.4 (2.2-2.6)	1.8 (1.6-1.9)	2.4 (2.1-2.6)	2.0 (1.8-2.1)	2.0 (1.9-2.2)
Physician's sex (female)†	NS	NS	NS	1.4 (1.1-1.7)	NS	NS	NS
Physician's age (>50 y)†	NS	NS	NS	NS	NS	NS	NS
Physician's life stance							
Religious; important for professional attitude	NS	NS	NS	NI/NA	NS	NS	0.76 (0.64-0.91)
Nonreligious; important for professional attitude	NS	NS	NS	NI/NA	NS	NS	NS
No specific life stance or not important for professional attitude	1.00	1.00	1.00	NI/NA	1.00	1.00	1.00

Abbreviations: CI, confidence interval; NI/NA, not included/not asked; NS, not significant.

\*Multiple logistic regression. The reference group is (probably) not intensifying alleviation of pain/symptoms; the category "undecided" is excluded from this analysis.

†Dichotomous variables.

### Background Characteristics

The background characteristics of the physicians were of less importance in their decision making than the characteristics of each case (Tables 2, 3, 4, and 5). In several countries, the physician's age had an influence on the decision to withhold chemotherapy or to deeply sedate a patient until death, with physicians older than 50 years being more inclined to do so. Religion played a role only in the decision to end life; physicians with a religious life stance that is important for their professional attitude were less inclined to decide to end the patient's life (OR, 0.32 [Belgium] to 0.70 [Denmark]). Medical specialists were generally less inclined than general practitioners to decide to deeply sedate a patient until death or to end a patient's life (data not shown).

### COMMENT

The EURELD study is the first international study on ELDs to systematically assess different possible predictors of decision making and in which the use of common study

methods and questionnaires make it possible to compare differences among countries. A limitation is the use of hypothetical cases: willingness to perform ELDs will not always be equal to decision making in practice. Real behavior is more influenced by cultural and situational factors than by intended behavior.<sup>19</sup> On the other hand, the hypothetical cases made it possible to confront physicians from different countries with identical situations, including those that might be rare in some countries. Finally, the fact that nonrespondents somewhat less frequently considered euthanasia acceptable might have caused nonresponder bias.

The same factors predict all ELDs in all the countries, albeit with varying strengths. This suggests that the basis for deciding to perform each action is similar everywhere and that physicians use similar principles in their decision making. Differences in the strength of the different predictors would occur then because these principles are valued differently in different countries. It is known, for example, that patient autonomy is valued highly in the Netherlands, Switzerland, and Australia and less especially in Italy and Sweden.<sup>20</sup> In accordance with

**Table 4. Predictors of (Probably) Giving Drugs, Such as Benzodiazepines or Barbiturates, to Keep the Patient in Deep Sedation Until Death\***

Variable	Odds Ratio (95% CI)						
	Australia (n = 1232)	Belgium (n = 1662)	Denmark (n = 1161)	Italy (n = 1468)	The Netherlands (n = 1038)	Sweden (n = 1429)	Switzerland (n = 1303)
Request							
Request of patient with decisional capacity	4.1 (3.5-4.7)	5.9 (5.2-6.6)	3.2 (2.8-3.7)	2.4 (2.2-2.7)	18 (15-23)	4.0 (3.5-4.5)	5.1 (4.5-5.7)
Advance directive of subcomatose patient	1.9 (1.5-2.5)	2.8 (2.2-3.6)	1.4 (1.1-1.9)	1.7 (1.4-2.1)	3.8 (2.8-6.9)	1.7 (1.3-2.2)	2.1 (1.6-2.7)
Request of family of subcomatose patient	NS	0.78 (0.63-0.98)	0.62 (0.39-0.98)	0.46 (0.41-0.52)	NS	0.67 (0.46-0.99)	0.58 (0.41-0.85)
Request of family of patient with decisional capacity	0.18 (0.15-0.23)	0.43 (0.39-0.48)	0.18 (0.14-0.23)	0.70 (0.55-0.89)	0.18 (0.13-0.27)	0.18 (0.15-0.22)	0.18 (0.15-0.22)
Own initiative of physician	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Decisional capacity							
Subcomatose patient, request of the family	26 (18-37)	8.8 (7.1-11)	16 (11-22)	3.4 (2.7-4.2)	72 (41-126)	14 (10-19)	14 (10-18)
Subcomatose patient, own initiative of physician	5.5 (4.4-6.8)	4.8 (4.4-5.3)	4.6 (4.0-5.2)	2.2 (2.0-2.5)	13 (10-15)	3.8 (3.4-4.3)	4.2 (3.8-4.8)
Subcomatose patient, with advance directive	2.2 (1.7-2.9)	2.3 (1.8-2.9)	2.1 (1.6-2.7)	1.6 (1.3-1.9)	2.6 (1.8-4.0)	1.6 (1.3-2.1)	1.7 (1.3-2.2)
Patient with decisional capacity	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Life expectancy <2 wk†	1.9 (1.8-2.1)	2.0 (1.9-2.1)	2.3 (2.1-2.6)	1.7 (1.6-1.8)	2.4 (2.2-2.6)	2.1 (2.0-2.3)	1.7 (1.5-1.8)
Uncontrollable pain†	1.5 (1.4-1.6)	1.9 (1.8-2.0)	1.8 (1.7-1.9)	1.9 (1.8-2.0)	1.8 (1.7-2.0)	1.8 (1.7-1.9)	2.0 (1.8-2.2)
Physician's sex (female)†	NS	NS	NS	NS	0.76 (0.59-0.98)	0.77 (0.63-0.94)	NS
Physician's age (>50 y)†	NS	1.5 (1.3-1.8)	1.3 (1.1-1.6)	1.5 (1.2-1.7)	NS	1.3 (1.1-1.6)	1.5 (1.2-1.7)
Physician's life stance							
Religious; important for professional attitude	0.76 (0.61-0.94)	NS	NS	NI/NA	NS	NS	NS
Nonreligious; important for professional attitude	1.6 (1.1-2.3)	NS	NS	NI/NA	NS	NS	NS
No specific life stance or not important for professional attitude	1.00	1.00	1.00	NI/NA	1.00	1.00	1.00

Abbreviations: CI, confidence interval; NI/NA, not included/not asked; NS, not significant.

\*Multiple logistic regression. The reference group is (probably) not deeply sedating until death; the category "undecided" is excluded from this analysis.

†Dichotomous variables.

this, ELDs are discussed more often with patients in the Netherlands and Switzerland.<sup>1</sup> In Italy, sanctity of life is more important than quality of life, whereas the opposite is true in the Netherlands and Sweden.<sup>21</sup>

The fact that physicians in the hypothetical cases almost always decided to withhold chemotherapy and, to a somewhat lesser extent, to use drugs to increase the alleviation of pain/symptoms taking into account the probability that this would hasten the end of the patient's life suggests that this is now generally accepted medical practice in the Western world. Possibly this is partly due to the growing notion that the effect of opioids on survival might be much smaller than frequently thought.<sup>22-24</sup> This acceptance was less the case for deep sedation until death and, especially, explicit hastening of the patient's end of life, although there are physicians in every country who would decide to perform these actions under certain circumstances (with the fewest in Sweden and Italy). The fact that the intention to end the life of a patient at his or her own request was expressed at a substantially higher frequency in the Netherlands and Belgium is probably due to the euthanasia legislation in these countries.<sup>25</sup>

The strongest predictor of all the ELDs in all the countries is a request from the patient. This is in accordance with findings from a previous study.<sup>16</sup> This request is especially important if the patient is competent but also if a patient who lacks decisional capacity has made the request in an advance directive. In both situations, physicians would generally be more inclined to make an ELD than they would be on their own initiative, whereas they would be less inclined to adhere to a request of the family, especially when the patient has decisional capacity. In contrast to the limited literature on the effectiveness of advance directives, this suggests that it would be useful for persons who want to influence the decisions about their treatment if they lose decisional capacity to make an advance directive.<sup>26-28</sup>

The request of the patient or family can be considered a culturally determined factor, and it is the one that most differs in strength among the countries. The other determinant that differs greatly is decisional capacity, probably because of its interaction with request. The influence of the medical predictors, for example, life expectancy and pain, is similar in the different countries. This supports the find-

**Table 5. Predictors of (Probably) Administering Drugs With the Explicit Intention of Hastening the Patient's End of Life\***

Variable	Odds Ratio (95% CI)						
	Australia (n = 1229)	Belgium (n = 1654)	Denmark (n = 1161)	Italy (n = 1449)	The Netherlands (n = 1040)	Sweden (n = 1429)	Switzerland (n = 1304)
Request							
Request of patient with decisional capacity	3.0 (2.5-3.6)	8.7 (7.4-10)	2.2 (1.9-2.6)	2.5 (2.1-2.9)	49 (37-66)	2.4 (1.9-3.1)	3.2 (2.8-3.8)
Advance directive of subcomatose patient	1.6 (1.1-2.2)	3.5 (2.6-4.7)	NS	1.8 (1.3-2.4)	8.9 (4.8-16)	NS	2.0 (1.5-2.8)
Request of family of subcomatose patient	NS	NS	0.51 (0.27-0.97)	NS	NS	NS	NS
Request of family of patient with decisional capacity	0.22 (0.17-0.30)	0.31 (0.26-0.38)	0.18 (0.13-0.25)	0.44 (0.36-0.55)	0.16 (0.09-0.29)	0.39 (0.28-0.56)	0.18 (0.13-0.24)
Own initiative of physician	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Decisional capacity							
Subcomatose patient, request of the family	10 (6.5-16)	11 (7.9-15)	7.7 (4.9-12)	2.5 (1.8-3.6)	44 (19-105)	3.2 (1.7-6.1)	7.9 (5.0-12)
Subcomatose patient, own initiative of physician	2.7 (2.3-3.1)	4.3 (3.7-4.9)	2.7 (2.4-3.1)	1.6 (1.4-1.8)	5.8 (4.4-7.7)	2.5 (1.9-3.2)	2.3 (2.0-2.7)
Subcomatose patient, advance directive	NS	1.7 (1.3-2.2)	1.5 (1.1-2.0)	NS	NS	NS	1.5 (1.1-2.0)
Patient with decisional capacity	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Life expectancy <2 wk†	1.4 (1.3-1.5)	1.4 (1.4-1.5)	1.6 (1.5-1.7)	1.2 (1.1-1.3)	1.4 (1.3-1.5)	NS	1.1 (1.1-1.2)
Uncontrollable pain†	1.3 (1.2-1.4)	1.5 (1.4-1.5)	1.4 (1.3-1.6)	1.3 (1.2-1.4)	1.4 (1.3-1.6)	NS	1.3 (1.2-1.3)
Physician's sex (female)†	NS	NS	NS	NS	NS	0.57 (0.36-0.89)	NS
Physician's age (>50 y)†	NS	NS	NS	NS	NS	1.9 (1.3-2.9)	NS
Physician's life stance							
Religious; important for professional attitude	0.38 (0.27-0.53)	0.32 (0.25-0.40)	0.70 (0.20-0.99)	NI/NA	0.57 (0.42-0.76)	0.56 (0.35-0.90)	0.47 (0.36-0.62)
Nonreligious; important for professional attitude	NS	2.0 (1.5-2.7)	2.1 (1.3-3.6)	NI/NA	NS	NS	NS
No specific life stance or not important for professional attitude	1.00	1.00	1.00	NI/NA	1.00	1.00	1.00

Abbreviations: CI, confidence interval; NI/NA, not included/not asked; NS, not significant.

\*Multiple logistic regression. The reference group is (probably) not ending life; the category "undecided" is excluded from this analysis.

†Dichotomous variables.

ings from an earlier part of the EURELD study in which the ELD that differed least in frequency between countries was alleviation of pain and symptoms. It is probable that this ELD, more than the others, is a direct response to the patient's medical situation.<sup>1</sup>

In all 7 countries, a patient's request positively influenced the physician's decisions much more than did requests from the patient's family, with this influence generally being strongest in the Netherlands and Australia. This is contrary to previous results on actual ELD practices.<sup>1</sup> The present study concerns only differences and similarities among physicians in different countries and does not take into account possible sociocultural differences and similarities among patients or families. It is possible that in some countries (eg, Italy) patients may be reluctant to request an ELD either because they do not want to do so or because they sense that this is not something that patients should ask their physician or that a physician would grant. However, this study suggests that if they did ask, there is certainly a possibility that the physician would comply with their request.

With respect to surrogate decision making for patients who lack decisional capacity, the request of the family was found to be important in all countries but especially in the Netherlands and Australia. Possibly this has to do with the high level of communication that takes place with respect to ELD in these countries.<sup>1,7,9</sup>

There is an ongoing debate about whether deep sedation until death is solely a palliative treatment for refractory symptoms that itself has no possible life-shortening effect or whether it should be considered an ELD.<sup>29-32</sup> The fact that similar factors influence the decision to perform it or not suggests a similarity with other ELDs. This might imply either that it is more an ELD than a palliative treatment or that all ELDs have common ground with palliative treatments. This common ground could be the target of reducing serious suffering in the last phase of life.

We conclude that cultural and legal factors influence the frequencies of different ELDs and the strength of the different determinants of these decisions but that they do not change the essence of the decision making. Therefore, it might be as fruitful for the international

debate on ELDs to focus on the similarities between countries, cultures, and types of regulation, thereby making it possible to learn from each other's experiences, as it is to merely point out the differences. Most important, this study reveals that for all 4 ELDs, and in all 7 countries, the presence or absence of a patient's request is very important for physicians in their decision making. This is an important consideration for medical practice, research, and the public health debate on end-of-life care.

**Accepted for Publication:** October 3, 2005.

**Author Affiliations:** Department of Social Medicine (Drs Onwuteaka-Philipsen and van der Wal) and Institute for Research in Extramural Medicine (Dr van der Wal), VU University Medical Centre, Amsterdam, the Netherlands; Institute of Social and Preventive Medicine, University of Zurich, Zurich, Switzerland (Dr Fisher); Aged Services Learning & Research Collaboration, Southern Cross University, Coffs Harbour, Australia (Dr Cartwright); End-of-Life Care Research Group, Vrije Universiteit Brussel, Brussels, Belgium (Dr Deliens); Epidemiology Unit, Center for Study and Prevention of Cancer, Florence, Italy (Dr Miccinesi); Department of Medical Philosophy and Clinical Theory, University of Copenhagen, Copenhagen, Denmark (Dr Norup); Department of Medical Ethics, University of Lund, Lund, Sweden (Dr Nilstun); and Department of Public Health, Erasmus MC, University Medical Center Rotterdam, Rotterdam, the Netherlands (Dr van der Heide).

**Correspondence:** Bregje D. Onwuteaka-Philipsen, PhD, Department of Social Medicine, VU University Medical Centre, van der Boecherstraat 7, 1081 BT Amsterdam, the Netherlands (b.philipsen@vumc.nl).

**Author Contributions:** Dr Onwuteaka-Philipsen had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

**EURELD Consortium Institutions and Investigators:** *Australia:* Gail Williams and Malcolm Parker (University of Queensland, Brisbane) and Margaret Steinberg (Queensland University of Technology, Brisbane); *Belgium:* Johan Bilsen (Vrije Universiteit Brussel, Brussels) and Freddy Mortier and Julie van Geluwe (Ghent University, Ghent); *Denmark:* Annemarie Dencker and Anna Paldam Folker (University of Copenhagen, Copenhagen); *Italy:* Eugenio Paci (Center for Study and Prevention of Cancer, Epidemiology Unit, Florence), Riccardo Cecioni (Center for Study and Prevention of Cancer), Lorenzo Simo nato (University of Padua, Padua), Silvia Franchini (Local Health Authority, Trento), and Alba Carola Finarelli (Regional Department of Health, Bologna); *the Netherlands:* Johannes J. M. van Delden (Julius Center, University Medical Center Utrecht, Utrecht) and Paul J. van der Maas (Erasmus MC, University Medical Center Rotterdam, Rotterdam); *Sweden:* Rurik Lofmark (Lansjukhuset, Gavle); *Switzerland:* Georg Bosshard, Karin Faisst, and Ueli Zellweger (University of Zurich, Zurich).

**Financial Disclosure:** None.

**Funding/Support:** This study was supported by grant QLRT-1999-30859 from the 5th framework program of

the European Commission and by contract BBW 99.0889 from the Swiss Federal Office for Education and Research for the Swiss part of the project.

**Role of the Sponsors:** The sponsors had no role in the design and conduct of the study; in the collection, management, analysis, and interpretation of the data; or in the preparation, review, and approval of the manuscript.

**Additional Resources:** The online-only eFigure is available at <http://www.archinternmed.com>.

**Acknowledgment:** We are indebted to the thousands of physicians in the participating countries who provided the data; to all the assistants working on the project; to the national and regional medical associations and other authoritative bodies that supported the study; to the national advisory boards for their support; to Jos Twisk for his advice on the statistical analysis to be used; and to Paul Kretchmer, MBA, PhD, at San Francisco Edit, San Francisco, Calif, for his assistance in editing this manuscript.

## REFERENCES

1. van der Heide A, Deliens L, Faisst K, et al. End-of-life decision-making in six European countries: descriptive study. *Lancet*. 2003;362:345-350.
2. Emanuel EJ. Euthanasia and physician-assisted suicide: a review of the empirical data from the United States. *Arch Intern Med*. 2002;162:142-152.
3. Ganzini L, Nelson HD, Schmidt TA, Kraemer DF, Delorit MA, Lee MA. Physicians' experiences with the Oregon Death with Dignity Act. *N Engl J Med*. 2000;342:557-563.
4. Ward BJ, Tate PA. Attitudes among NHS doctors to requests for euthanasia. *BMJ*. 1994;308:1332-1334.
5. Førde R, Asland OG, Falkum E. The ethics of euthanasia: attitudes and practice among Norwegian physicians. *Soc Sci Med*. 1997;45:887-892.
6. Kirschner R, Elkeles T. Patterns of performance by German physicians and their opinions regarding euthanasia [in German]. *Gesundheitswesen*. 1998;60:247-253.
7. Kuhse H, Singer P, Baume P, Clark M, Rickard M. End-of-life decisions in Australian medical practice. *Med J Aust*. 1997;166:191-196.
8. Mitchell K, Owens RG. National survey of medical decisions at the end of life made by New Zealand general practitioners. *BMJ*. 2003;327:202-203.
9. Cuttini M, Nadai M, Kaminski M, et al. End-of-life decisions in neonatal intensive care: physicians' self-reported practises in seven European countries. *Lancet*. 2000;355:2112-2118.
10. Vincent JL. Forgoing life support in western European intensive care units: the results of an ethical questionnaire. *Crit Care Med*. 1999;27:1626-1633.
11. Emanuel EJ, Fairclough DL, Daniels ER, Clarridge BR. Euthanasia and physician-assisted suicide: attitudes and experiences of oncology patients, oncologists, and the public. *Lancet*. 1996;347:1805-1810.
12. Cohen JS, Fihn SD, Boyko EJ, Jonsen AR, Wood RW. Attitudes toward assisted suicide and euthanasia among physicians in Washington State. *N Engl J Med*. 1994;331:89-94.
13. Hinkka H, Kosunen E, Lammi EK, et al. Decision making in terminal care: a survey of Finnish doctors' treatment decisions in end-of-life scenarios involving a terminal cancer and a terminal dementia patient. *Palliat Med*. 2002;16:195-204.
14. Mortier F, Bilsen J, Vander Stichele H, Bernheim J, Deliens L. Attitudes, socio-demographic characteristics, and actual end-of-life decisions of physicians in Flanders, Belgium. *Med Decis Making*. 2003;23:502-510.
15. Di Mola G, Borsellino P, Brunelli C, et al. Attitudes toward euthanasia of physician members of the Italian Society for Palliative Care. *Ann Oncol*. 1996;7:907-911.
16. Ho R. Assessing attitudes toward euthanasia: an analysis of the subcategorical approach to right to die issues. *Pers Individ Dif*. 1998;25:719-734.
17. Rogers JR. Assessing right to die attitudes: a conceptually guided measurement model. *J Soc Issues*. 1996;52:63-84.
18. Hanson LC, Danis M, Mutran E, Kenan NL. Impact of patient incompetence on decisions to use or withhold life-sustaining treatment. *Am J Med*. 1994;97:235-241.
19. Willems DL, Daniels ER, van der Wal G, van der Maas PJ, Emanuel EJ. Atti-

- tudes and practices concerning the end of life: a comparison between physicians from the United States and from the Netherlands. *Arch Intern Med.* 2000;160:63-68.
20. Miccinesi G, Fischer S, Paci E, et al. Physicians' attitudes towards end-of-life decisions: a comparison between seven countries. *Soc Sci Med.* 2005;60:1961-1974.
  21. Rebagliato M, Cuttini M, Broggin L, et al. Neonatal end-of-life decision making: physicians' attitudes and relationship with self-reported practices in 10 European countries. *JAMA.* 2000;284:2451-2459.
  22. Morita T, Tsunoda J, Inoue S, Chihara S. Effects of high dose opioids and sedatives on survival in terminally ill cancer patients. *J Pain Symptom Manage.* 2001; 21:282-289.
  23. Sykes N, Thorns A. The use of opioids and sedatives at the end of life. *Lancet Oncol.* 2003;4:312-318.
  24. Thorns A, Sykes N. Opioid use in last week of life and implications for end-of-life decision-making. *Lancet.* 2000;356:398-399.
  25. Deliens L, van der Wal G. The euthanasia law in Belgium and the Netherlands. *Lancet.* 2003;362:1239-1240.
  26. Teno J, Lynn J, Wenger N, et al. Advance directives for seriously ill hospitalized patients: effectiveness with the patient self-determination act and the SUPPORT intervention. *J Am Geriatr Soc.* 1997;45:500-507.
  27. Teno JM, Licks S, Lynn J, et al; SUPPORT Investigators. Do advance directives provide instructions that direct care? Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *J Am Geriatr Soc.* 1997;45: 508-512.
  28. The AM, Pasman R, Onwuteaka-Philipsen B, Ribbe M, van der Wal G. Withholding the artificial administration of fluids and food from elderly patients with dementia: ethnographic study. *BMJ.* 2002;325:1326-1330.
  29. Billings JA, Block SD. Slow euthanasia. *J Palliat Care.* 1996;12:21-30.
  30. Quill TE, Lo B, Brock DW. Palliative options of last resort: a comparison of voluntarily stopping eating and drinking, terminal sedation, physician-assisted suicide, and voluntary active euthanasia. *JAMA.* 1997;278:2099-2104.
  31. Sulmasy DP, Ury WA, Ahronheim JC, et al. Responding to intractable terminal suffering. *Ann Intern Med.* 2000;133:560-562.
  32. Sulmasy DP, Ury WA, Ahronheim JC, et al. Palliative treatment of last resort and assisted suicide. *Ann Intern Med.* 2000;133:562-563.

	Yes	Probably	Undecided	Probably Not	No
Would you withhold the third course of chemotherapy . . .					
if that is what the patient requests?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
without informing the patient if that is what the relatives request?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
on your own initiative because a third chemotherapy would be medically futile?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Would you intensify the alleviation of symptoms by using drugs, taking into account the probability or certainty that this could hasten the end of the patient's life . . .					
if that is what the patient requests?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
without informing the patient if that is what the relatives request?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
on your own initiative to reduce suffering?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Would you give drugs, such as benzodiazepines or barbiturates, to keep the patient in deep sedation until death . . .					
if that is what the patient requests?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
without informing the patient if that is what the relatives request?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
on your own initiative to reduce suffering?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Would you administer drugs with the explicit intention of hastening the patient's end of life . . .					
if that is what the patient requests?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
without informing the patient if that is what the relatives request?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
on your own initiative to reduce suffering?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**eFigure.** Using a 5-point Likert scale, the physician was asked whether he or she would perform any 1 of 4 specific end-of-life decisions after each of the following 4 hypothetical case descriptions. Case 1: the patient is clearheaded and can still communicate well. You estimate the patient's life expectancy (without chemotherapy) to be no more than 2 weeks. The patient has pain that is difficult to control despite the use of analgesics in high doses. Case 2: the patient is clearheaded and can still communicate well. You estimate the patient's life expectancy (without chemotherapy) to be at least 3 months. Pain can be adequately controlled, but the patient is extremely tired, short of breath, and bedridden. Case 3: the patient is drowsy or subcomatose and communication is not possible. You estimate the patient's life expectancy (without chemotherapy) to be no more than 2 weeks. Pain can be adequately controlled, but the patient is extremely tired, short of breath, and bedridden. Case 4: the patient is drowsy or subcomatose and communication is not possible. You estimate the patient's life expectancy (without chemotherapy) to be at least 3 months. The patient has pain that is difficult to control, despite the use of analgesics in high doses. All 4 cases have the following characteristics in common: the patient is aged 71 years and has cancer with extensive brain and bone metastases. The patient has undergone burdensome chemotherapy twice. Undergoing chemotherapy once more would give a limited chance of long-standing remission (<10%).