Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated cross-sectional survey

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Summary

Background In 2002, the euthanasia act came into effect in the Netherlands, which was followed by a slight decrease in the euthanasia frequency. We assessed frequency and characteristics of euthanasia, physician-assisted suicide, and other end-of-life practices in 2010, and assessed trends since 1990.

Methods In 1990, 1995, 2001, 2005, and 2010 we did nationwide studies of a stratified sample from the death registry of Statistics Netherlands, to which all deaths and causes were reported. We mailed questionnaires to physicians attending these deaths (2010: n=8496 deaths). All cases were weighted to adjust for the stratification procedure and for differences in response rates in relation to the age, sex, marital status, region of residence, and cause and place of death.

Findings In 2010, of all deaths in the Netherlands, 2·8% (95% CI 2·5–3·2; 475 of 6861) were the result of euthanasia. This rate is higher than the 1·7% (1·5–1·8; 294 of 9965) in 2005, but comparable with those in 2001 and 1995. Distribution of sex, age, and diagnosis was stable between 1990 and 2010. In 2010, 77% (3136 of 4050) of all cases of euthanasia or physician-assisted suicide were reported to a review committee (80% [1933 of 2425] in 2005). Ending of life without an explicit patient request in 2010 occurred less often (0·2%; 95% CI 0·1–0·3; 13 of 6861) than in 2005, 2001, 1995, and 1990 (0·8%; 0·6–1·1; 45 of 5197). Continuous deep sedation until death occurred more frequently in 2010 (12·3% [11·6–13·1; 789 of 6861]) than in 2005 (8·2% [7·8–8·6; 521 of 9965]). Of all deaths in 2010, 0·4% (0·3–0·6; 18 of 6861) were the result of the patient's decision to stop eating and drinking to end life; in half of these cases the patient had made a euthanasia request that was not granted.

Interpretation Our study provides insight in consequences of regulating euthanasia and physician-assisted suicide within the broader context of end-of-life practices. In the Netherlands the euthanasia law resulted in a relatively transparent practice. Although translating these results to other countries is not straightforward, they can inform the debate on legalisation of assisted dying in other countries.

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Introduction

At the end of life, many patients need comfort-oriented care. Such care might include end-of-life decision making (eg, on forgoing burdensome treatment or intensifying alleviation of pain or other symptoms). During this period, people can even develop a death wish, when suffering becomes overwhelming.[1,2] Patients might then ask their physician to end their life. In most countries physicians are not allowed to grant such a request, but there is much debate on this issue.[3–6] Concerns expressed include the fear of an expanding practice of euthanasia (eg, among vulnerable groups such as older people or incompetent patients). It is not known to what extent refused requests for euthanasia result in patients ending their own life.

Since 2002, the Netherlands has been one of the few countries where euthanasia and physician-assisted suicide are, under strict conditions, regulated by law. Comparable laws exist in Belgium and Luxembourg; Oregon, Montana, Washington (USA), and Switzerland have legally regulated assistance in suicide.[7,8] In the Netherlands, euthanasia is defined as the administering of lethal drugs by a physician with the explicit intention to end a patient's life on the patient's explicit request. In physician-assisted suicide the patient self-administers medication that was prescribed intentionally by a physician. In the Netherlands, the enactment of the euthanasia law was preceded by several decades of debate among medical practitioners, lawyers, ethicists, politicians, and the general public in which a reporting procedure was developed.[7] This debate has been informed by nationwide studies on end-of-life decision making that were done in 1990, before the first reporting procedure, 1995, 2001, and 2005.[9–13] These studies have allowed monitoring of the practice of end-of-life decision making in relation to development of the regulatory system. In 2005, 3 years after enactment of the euthanasia law, the euthanasia rate had decreased significantly, from 2·6% of all deaths in 2001, to 1·7% in 2005, which was a reversal of the trend from 1990 to 2001. Ending of life without an explicit request of the patient had decreased, albeit not significantly (0·7% in 2001 and

	1990	1995	2001	2005	2010
Number of deaths in the Netherlands	128 824	135 675	140 377	136 402	136 056
Number of studied cases	5197	5146	5617	9965	6861
Most important end-of-life decision					
Euthanasia	141 (1·7% [1·4–2·1])	257 (2·4% [2·1–2·6])	310 (2·6% [2·3–2·8])	294 (1·7% [1·5–1·8])	475 (2·8% [2·5–3·2])
Assisted suicide	18 (0·2% [0·1–0·3])	25 (0·2% [0·1–0·3])	25 (0·2% [0·1–0·3])	17 (0·1% [<0·1–0·1])	21 (0·1% [0·1–0·2])
Ending of life without explicit patient request	45 (0·8% [0·6–1·1])	64 (0·7% [0·5–0·9])	42 (0·7% [0·5–0·9])	24 (0·4% [0·2–0·6])	13 (0·2% [0·1–0·3])
Intensified alleviation of symptoms	1166 (18·8% [17·9–19·9])	1161 (19·1% [18·1–20·1])	1312 (20·1% [19·1–21·1])	1478 (24·7% [23·5–26·0])	2202 (36·4% [35·2–37·6])
Forgoing of life-prolonging treatment	991 (17·9% [17·0–18·9])	1097 (20·2% [19·1-21·3])	1210 (20·2% [19·1–21·3])	767 (15·6% [15·0–16·2])	974 (18·2% [17·3–19·1])
Total	2361 (39·4% [38·1–40·7])	2604 (42·6% [41·3–43·9])	2899 (43·8% [42·6–45·0])	2570 (42·5% [41·1-43·9])	3685 (57·8% [56·7–59·0])
Continuous deep sedation*†	NA	NA	..	521 (8·2% [7·8–8·6])	789 (12·3% [11·6–13·1])
Patient deciding to end life by stopping eating and drinking	NA	NA	NA	NA	18 (0·4% [0·3–0·6])

Data are absolute number or number of patients (weighted % [95% CI]). All percentages are weighted for sampling fractions, non-response, and random sampling deviations, to make them representative for all deaths in the year studied. Therefore, the percentages presented cannot be derived from the unweighted absolute numbers presented. NA=not available. *Continuous deep sedation might have been provided in conjunction with practices that possibly hastened death. †In 2001, continuous deep sedation was only studied when it occurred in conjunction with an end-of-life decision; the frequency was 5·6%; corresponding numbers are 7·1% in 2005 and 11% in 2010.

Table 1: **Frequency of euthanasia, assisted suicide, and other end-of-life practices in the Netherlands in 1990, 1995, 2001, 2005, and 2010**

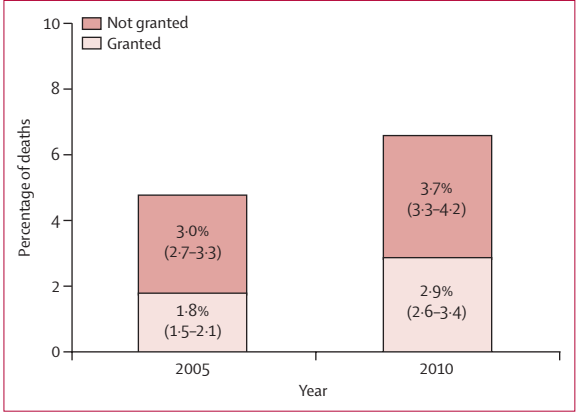

Figure: **Weighted percentage (95% CI) of all deaths preceded by a granted or ungranted request for euthanasia or physician-assisted suicide**
A request can be ungranted for different reasons, among which a refusal of the physician, or the patient dying before the physician could decide on granting the request. There were 9965 deaths in 2005 and 6861 deaths in 2010. Absolute unweighted numbers: 252 granted requests and 251 ungranted for euthanasia in 2005; and 496 granted requests and 270 ungranted requests in 2010.

0·4% in 2005).[9] In 2010, 8 years after enactment of the euthanasia law, we investigated how end-of-life decision making practices have further developed.

Methods

Study design

In 2010, we undertook a nationwide death-certificate study that was largely similar to earlier studies done in 1990, 1995, 2001, and 2005.[9–13] We drew a random sample from the central death registry of Statistics Netherlands, to which all deaths and causes were reported. The period studied was Aug 1, through Nov 1, in all studied years. All deaths that occurred in that period were assigned to one of five strata. When the cause of death clearly precluded end-of-life decision making (eg, instant death in a traffic accident), cases were assigned to stratum one. These cases were retained in the sample, but no questionnaires were sent out to the physician. On the basis of cause of death, cases were assigned to one of the other strata looking at the likelihood that an end-of-life decision had preceded death: when this decision was unlikely (eg, acute myocardial infarction or aneurysm) cause of death was allocated to stratum two, when this decision was possible (eg, heart failure or Parkinson's disease) to stratum three, and when this decision was more probable (eg, cancer) to stratum four. Cases were assigned to stratum five when the physician had noted on the death certificate that they had actively ended the life of the patient. The final sampling contained 50% of the cases of stratum five, 25% of the cases in stratum four, 13% of those in stratum three, 8% of those in stratum one and two. To ensure that children younger than 17 years of age and nonwestern immigrants, two small groups in death statistics, were represented well in the sample all deaths in which an end-of-life decision could not be precluded in these groups were sampled.

All attending physicians of the sampled cases in strata two to five received a questionnaire. The data collection procedure precluded identification of physician and patient. The Ministry of Justice gave a guarantee that no physician could be prosecuted on the basis of information given to the researchers. According to Dutch policy, the study did not require review by an ethics committee.

Questionnaire

The questionnaire focused on end-of-life decision making that might have preceded the death of the patient involved. The four key questions addressed the following factors: (1) whether the respondent had withheld or withdrawn

medical treatment while taking into account the possible hastening of death; (2) whether the respondent had intensified measures to alleviate pain or other symptoms while taking into account or partly intending the possible hastening of death; (3) whether the respondent had withheld or withdrawn medical treatment with the explicit intention of hastening death; or (4) whether the respondent had administered, supplied, or prescribed drugs with the explicit intention of hastening death, resulting in the patient's death (appendix). These questions were validated in the 1990 and 1995 study, and were kept identical in all years studied. If more than one of the key questions was answered affirmatively, the act that involved the most explicit intention was used to classify the case. If the intention was similar, the administration of drugs prevailed over the withholding or withdrawing of treatment. If question four was answered affirmatively and if the act was done in response to an explicit request by the patient, the act was classified as euthanasia or assisted suicide (depending on whether or not the patients had taken the drugs themselves). If question four was answered affirmatively and the act was not done in response to an explicit request by the patient, the act was classified as ending of life without explicit request.

Details about the decision-making process, the type of drugs that had been used, and the degree to which death had been hastened as estimated by the physician, were asked for the most important end-of-life decision, if any. Physicians were further asked to choose the term that they thought best described their end-of-life decision: "forgoing treatment", "alleviation of symptoms", "palliative or terminal sedation", "ending of life", "assisted suicide", or "euthanasia". Finally, we asked whether the patient had been "deeply and continuously sedated until death", whether the patient had made a request for euthanasia or physician-assisted suicide that was not granted, and whether patients had purposely ended their life by stopping eating and drinking.

See Online for appendix

	All deaths in 2010 (%)	Euthanasia and physician-assisted suicide			Ending of life without explicit request			Intensified alleviation of symptoms		
		2001	2005	2010	2001	2005	2010	2001	2005	2010
Age (years)										
0–64 (n=2079)	19%	139 (5·0% [4·1–6·0])	131 (3·5% [2·7–4·4])	191 (5·6% [4·6–6·7])	11 (1·0% [0·7–1·5])	13 (1·0% [0·7–1·5])	4 (0·2% [0·1–0·5])	303 (18·9% [17·3–20·7])	384 (21·4% [19·7–23·2])	533 (30·5% [28·5–32·5])
65–79 (n=2156)	31%	134 (3·3% [2·6–4·1])	126 (2·1% [1·5–2·8])	191 (4·0% [3·2–4·9])	11 (0·4% [0·2–0·8])	5 (0·3 % [0·1–0·6])	4 (0·3% [0·1–0·6])	456 (20·8% [19·1–23·5])	536 (25·4% [23·4–26·7])	721 (35·3% [33·3–37·3])
≥80 (n=2626)	51%	58 (1·4 % [1·0–1·9])	54 (0·8% [0·5–1·2])	114 (1·4% [1·0–1·9])	20 (0·7% [0·4–1·1])	6 (0·2% [0·1–0·4])	5 (0·2% [0·1–0·4])	553 (20·2% [18·6–21·7])	558 (25·6% [24·2–27·6])	948 (39·2% [37·1–40·8])
Sex										
Male (n=3538)	49%	175 (3·1% [2·6–3·7])	181 (2·0% [1·6–2·5])	281 (3·5% [2·9–4·2])	19 (0·7% [0·5–1·0])	11 (0·4 % [0·2–0·7])	7 (0·2% [0·1–0·4])	591 (19·1% [17·7–20·3])	731 (23·7% [22·4–25·2])	1101 (34·5% [33·4–36·5])
Female (n=3278)	52%	156 (2·5% [2·0–3·1])	130 (1·5% [1·1–2·0])	215 (2·5% [1·9–3·0])	23 (0·7% [0·4–1·0])	13 (0·4% [0·2–0·7])	6 (0·2% [0·1–0·4])	721 (21·1% [19·6–22·4])	747 (25·7% [24·5–27·5])	1101 (38·2% [36·4–39·6])
Cause of death										
Cancer (n=3055)	31%	280 (7·4% [6·5–8·4])	269 (5·1% [4·4–6·0])	415 (7·6% [6·7–8·6])	24 (1· 0% [0·7–1·4])	9 (0·3% [0·1–0·6])	6 (0·2% [0·1–0·4])	709 (33·4% [31·2–34·6])	989 (37·1% [35·1–38·7])	1369 (47·7% [46·2–49·8])
Cardiovascular disease (n=931)	22%	6 (0·4% [0·1–1·0])	7 (0·3% [0·1–0·9])	15 (0·5% [0·2–1·3])	4 (0·6% [0·2–1·4])	2 (0·2% [0·1–0·8])	0	128 (11·1% [9·0–13·0])	175 (14·3% [11·8–16·3])	193 (21·5% [18·7–24·5])
Other or unknown (n=2875)	47%	45 (1·2% [0·8–1·7])	35 (0·4% [0·2–0·7])	66 (1·1% [0·8–1·6])	14 (0·5% [0·3–0·8])	13 (0·6% [0·3–0·9])	7 (0·3% [0·1–0·6])	475 (17·1% [15·6–18·4])	314 (24·1% [22·4–25·6])	640 (36·0% [34·2–37·8])
Type of physician*										
General practitioner (n=3424)	45%	274 (5·8% [5·1–6·7])	272 (3·7% [3·1–4·4])	456 (5·8% [5·1–6·7])	20 (0·6% [0·4–0·9])	6 (0·2% [0·1–0·4])	5 (0·2% [0·1–0·4])	609 (20·9% [19·6–22·4])	686 (23·9% [22·5–25·3])	1152 (34·3% [32·4–35·6])
Clinical specialist (n=1248)	26%	48 (1·8% [1·1–2·7])	22 (0·5% [0·2–1·0])	16 (0·9% [0·4–1·6])	18 (1·2% [0·7–2·0])	7 (0·7% [0·3–1·4])	2 (0·4% [0·1–0·9])	300 (18·2% [15·9–20·2])	352 (22·7% [20·5–25·1])	546 (32·1% [29·4–34·6])
Elderly care physician (n=1588)	29%	9 (0·4% [0·1–0·8])	12 (0·2% [0·1–0·6])	29 (0·4% [0·1–0·8])	4 (0·4% [0·1–0·8])	4 (0·3% [0·1–0·7])	6 (0·2% [0·1–0·6])	403 (31·7% [29·7–34·3])	410 (35·7% [33·6–38·3])	504 (45·8% [43·5–48·4])
Total (n=6861)	100%	331 (2·8% [2·4–3·2])	311 (1·8% [1·5–2·1])	496 (3·0% [2·5–3·3])	42 (0·7% [0·5–0·9])	24 (0·4% [0·2–0·6])	13 (0·2% [0·1–0·3])	1312 (20·1% [19·1–21·1])	1478(24·7% [23·5–26·0)	2202 (36·4% [35·2–37·6])

Data are percentage or absolute number of patients (weighted % [95% CI]). Percentages are weighted for sampling fractions, non-response, and random sampling deviations, to make them representative of all deaths in the year studied. Therefore, the percentages presented cannot be derived from the unweighted absolute numbers presented.
*Missing observations for 2005: five for euthanasia and physician-assisted suicide, six for ending of life without explicit request, and 30 for intensified alleviation of symptoms.

Table 2: **Frequencies of euthanasia or physician-assisted suicide, ending of life without explicit request, and intensified alleviation of symptoms in 2001, 2005 and 2010, according to patient characteristics**

Statistical analyses

All cases were weighted to adjust for the stratification procedure and for differences in response rates in relation to age, sex, marital status, region of residence, and cause and place of death. The results were then extrapolated to 2010, to reflect all deaths in 2010 in the Netherlands (n=136 058). This weighting procedure was done in all years studied (1990, 1995, 2001, 2005, and 2010). As a result of this weighting procedure the percentages presented cannot be derived from the absolute unweighted numbers presented. 95% CIs were calculated. This procedure took into account the weighting by standardising the weighting factors to the actual number of cases.

Role of funding source

The sponsor of the study had no role in study design, data collection, data analysis, data interpretation, or writing of the report. The corresponding author had full access to all the data in the study and had final responsibility for the decision to submit for publication.

Results

Of the 8496 questionnaires that were mailed, 6263 were returned and eligible for analysis (response rate 74%). Response rates in the different strata ranged between 64% and 84%, with response being higher in strata in which the likelihood of an end-of-life decision was higher. Response rates in 1990, 1995, 2001, and 2005 were comparable (range 74% to 78%). The frequency of euthanasia increased between 2005 and 2010 (table 1). The frequency of physician-assisted suicide remained low over the years. The figure shows that the increase in the number of instances of euthanasia is related to both an increase in the number of explicit requests for

	Euthanasia and physician-assisted suicide		Ending of life without explicit request		Intensified alleviation of symptoms	
	2005 (n=262)	2010 (n=496)	2005 (n=24)	2010 (n=13)	2005 (n=1478)	2010 (n=2202)
Discussion						
Discussion with or previous wish of patient	262 (100·0%)	496 (100·0%)	10 (60·0% [36·6–77·9])	6 (59·1% [31·6–86·1])	554 (35·3% [32·5–37·4])	760 (32·9% [31·1–35·0])
Discussion with relative(s)	200 (75·5% [70·0–80·4])	346 (70·5% [67·0–75·0])	13 (80·9% [57·8–92·9])	7 (72·2% [38·6–90·9])	724 (54·0% [51·5–56·5])	962 (48·6% [46·9–51·1])
Discussion with other physician(s)	230 (87·7% [84·3–92·1])	459 (93·8% [91·5–95·9])	15 65·3% [44·7–84·4])	5 (53·4% [25·1–80·8])	411 (29·5% [27·6–32·3])	596 (27·9% [26·1–29·9])
No discussion with any of the above	0	0	4 (19·1% [7·1–42·2])	5 (24·9% [5·0–53·8])	613 (38·2% [35·5–40·5])	994 (41·2% [39·0–43·1])
Drugs*						
Neuromuscular relaxants†	197 (67·0% [61·5–72·9])	392 (72·2% [68·0–75·9])	5 (23·4% [9·7–46·7])	1 (1·6% [0·1–36·0])	..	..
Barbiturates†	10 (8·5% [6·0–13·3])	37 (7·9% [5·8–10·8])	2 (6·0% [0·2–21·5])	0	..	..
Benzodiazepines and opioids	9 (6·7% [4·1–10·6])	28 (13·3% [10·0–15·9])	5 (22·4% [7·1–42·2])	4 (26·1% [5·2–54·1])	384 (23·7% [21·8–26·6])	853 (37·1% [35·0–39·0])
Benzodiazepines	7 (7·0% [4·1–10·6])	7 (3·0% [10·0–15·9])	1 (3·3% [0·1–21·1])	1 (9·0% [0·1–36·3])	71 (3·5% [3·1–5·1])	119 (4·8% [4·1–6·0])
Opioids	13 (10·5% [7·3–14·9])	5 (3·1% [1·7–4·9])	7 (40·2% [22·1–63·4])	7 (63·3% [32·2–86·4])	947 (69·4% [66·7–71·4])	1134 (56·4% [53·9–58·1])
Other	1 (0·3%)	2 (0·5% [0·3–2·3])	3 (4·7% [0·2–21·3])	0	58 (3·4% [2·2–4·0])	37 (1·7% [1·2–2·3])
Shortening of life						
Probably no life shortening	2 (0·7% [0·2–3·3])	1 (0·4%)	3 (17·2% [4·7–37·4])	1 (9·4% [0·1–36·3])	778 (54·2% [51·5–56·5])	1275 (58·6% [56·9–61·0])
Less than a week	101 (44·1% [37·9–49·9])	166 (40·3% [35·6–44·2])	14 (68·3% [44·7–84·4])	10 (76·1% [46·2–95·0])	397 (26·8% [24·7–29·3])	587 (26·9% [25·2–28·9])
A week or more	153 (53·9% [47·8–59·9])	322 (58·0% [53·7–62·4])	6 (11·6% [2·7–32·3])	1 (9·1% [0·1–36·3])	47 (3·4% [2·2–4·0])	61 (3·1% [2·3–3·8])
Unknown	6 (1·3% [0·2–0·3])	7 (1·3% [0·3–2·3])	1 (2·9% [0·1–21])	1 (5·4% [0·1–36·3])	256 (15·6% [14·1–17·8])	279 (11·4% [9·7–12·3])
Most appropriate term for decision according to physician						
Euthanasia or assisted suicide	225 (82·8% [78·3–87·4])	412 (76·7% [73·3–80·7])	0	0	0	1 (<0·1%)
Ending of life	5 (0·5% [0·2–3·3])	9 (2·0% [1·0–3·7])	4 (17·2% [4·7–37·4])	0	0	1 (<0·1%)
Alleviation of symptoms	7 (3·6% [1·9–6·9])	2 (1·5% [1·0–3·7])	8 (33·3% [15·6–55·3])	4 (40·6% [13·9–68·4])	849 (57·5% [54·4–59·5])	1201 (57·5% [55·9–60·1])
Non-treatment decision	1 (0·2%)	0	1 (3·9% [0·1–21])	1 (1·7% [0·0–36])	79 (5·5% [4·0–6·2])	625 (8·3% [6·9–9·2])
Palliative or terminal sedation	22 (12·2% [7·9–15·7])	44 (18·1% [14·6–21·3])	10 (41·8% [22·1–63·4])	7 (52·2% [25·1–80·8])	281 (19·2% [17·0–21·0])	486 (20·3% [18·3–21·7])
Unknown	2 (0·7% [0·1–2·7])	8 (1·7% [1·0–3·7])	1 (3·8% [0·1–21·1])	1 (5·5% [0·1–36·3])	269 (17·8% [16·0–20·0])	355 (13·9% [12·5–15·4])

Data are absolute number of patients (weighted % [95% CI]). Percentages are weighted for sampling fractions, non-response and random sampling deviations, to make them representative for all deaths in the year studied. Therefore the percentages presented cannot be derived from the unweighted absolute numbers presented. *Drugs could have been neuromuscular relaxants, in any combination; barbiturates, alone or in combination with other drugs except neuromuscular relaxants; the combination of benzodiazepines and opioids possibly in combination with other drugs except neuromuscular relaxants or barbiturates; benzodiazepines alone or in combination with other drugs except neuromuscular relaxants, barbiturates, and opioids; or other drugs than the ones mentioned above. †Not asked separately for insensitifed alleviation of symptoms.

Table 3: **Characteristics of euthanasia or physician-assisted suicide, ending of life without explicit request, and intensified alleviation of symptoms, in 2005 and 2010**

euthanasia (from 4·8% [95% CI 4·4–5·2; 503 of 9965] of all deaths surveyed in 2005 to 6·7% [6·1–7·3; 766 of 6861] in 2010) and the proportion of requests that were granted (from 37% [252 of 503] to 45% [496 of 766] of requests). The frequency of ending of life without an explicit patient request decreased over the years (from 0·8% [95% CI 0·6–1·1; 45 of 5197] of all deaths in 1990 to 0·2% [0·1–0·3%; 13 of 6861] in 2010). While the frequency of forgoing of life-prolonging treatment was relatively stable over the years, the frequency of intensified alleviation of symptoms increased, especially between 2005 and 2010. The percentage of all cases in which physicians intensified alleviation of symptoms, rather than only cases in which that action was most important, was 30% (29–31; 1832 of 5617) in 2005 and 45% (44–46; 2777 of 6861) in 2010. For forgoing treatment, the percentage of all cases in which treatment was forgone, thus also when this factor was not the most important, was 28% (95% CI 27–29; 1434 of 5617) in 2005 and 37% (36–39; 2103 of 6861) in 2010 (data not shown).

We also saw an increase of continuous deep sedation until death. A small proportion of patients in 2010 had intentionally hastened death by stopping eating and drinking (table 1). Further analysis showed that in 0·2% (seven of 6861) of all deaths patients had intentionally stopped eating and drinking after an ungranted euthanasia request. Another 0·04% (13 of 6861) had committed suicide with drugs or another method after an ungranted euthanasia request. Thus, in 7% (20 of 270) of deaths in which the patient had made a ungranted euthanasia request the patient hastened death him or herself (data not shown).

Euthanasia and physician-assisted suicide most often concern younger people, cancer patients, and patients attended by general practitioners (table 2). The decreased frequency of ending of life without explicit patient request is most pronounced in people younger than 65 years of age, where it decreased between 2001 and 2010, and among clinical specialists (table 2). For intensified alleviation of symptoms the increase was consistently seen in all patient groups.

The most important reasons for the physician to grant the euthanasia requests that were mentioned most often in 2010 were the wish of the patient (85% [420 of 496]; 82% [219 of 262] in 2005), no prospect of improvement (82% [405 of 496]; 85% [223 of 262] in 2005), no more options for treatment (73% [370 of 496]; not asked in 2005), and loss of dignity (61% [311 of 496]; 60% [164 of 262] in 2005). Between 2005 and 2010, no clear differences were seen in the percentage of cases in which physician discussed end-of-life decisions with the patient, relatives, and other physicians. Both in 2005 and 2010, most cases of euthanasia and physician-assisted suicide were undertaken with neuromuscular relaxants and barbiturates. A non-significant decrease occurred in use of these drugs for ending of life without explicit request (from 29·4% [95% CI 14·9–49·4; seven of 24] to 1·6% [0·1–31·0; one of 13]). Intensified alleviation of symptoms was more commonly done with a combination of benzodiazepines and opioids in 2010 than in 2005 (table 3). No clear differences were seen between the years in the estimated degree to which end-of-life decisions had shortened life. In 2010, euthanasia and physician-assisted suicide were estimated to have shortened the patient's life by a week or more in 58% (322 of 496) of cases, compared with 9% (one of 13) for ending of life without explicit request and 3% (61 of 2202) for intensified alleviation of symptoms. In over half of all cases of intensified alleviation of symptoms, the physician estimated that life had not been shortened;

	Not reported (n=45)	Reported (n=443)	Total (n=496)*
Age (years)			
0–64	14 (20·5% [9·5–34·6])	174 (38·1% [33·4–42·4])	191 (34·8% [30·9–39·3])
65–79	18 (47·3% [31·7–62·1])	170 (39·4% [34·5–43·6])	191 (40·7% [36·6–45·3])
≥80	13 (32·2% [18·2–46·6])	99 (22·5% [18·0–25·7])	114 (24·5% [21·2–28·8])
Sex			
Male	24 (53·7% [37·9–68·3])	254 (58·1% [53·4–62·6])	281 (57·2% [52·7–61·4])
Female	21 (46·3% [31·7–62·1])	189 (41·9% [37·4–46·6])	215 (42·8% [38·6–47·3])
Cause of death			
Cancer	36 (63·4% [46·5–76·2])	371 (83·1% [79·6–86·6])	415 (79·1% [75·4–82·6)
Cardiovascular disease	2 (9·8% [3·7–24·1])	13 (2·5% [1·6–5·0])	15 (4·0% [2·5–6·2])
Other/unknown	7 (26·8% [14·6–41·9])	59 (14·4% [10·8–17·2])	66 (16·9% [13·6–20·2])
Type of physician			
General practitioner	36 (71·4% [55·7–83·6])	408 (92·5% [90·2–95·2])	269 (88·1% [85·0–90·8])
Clinical specialist	2 (23·8% [12·9–39·5])	14 (4·4% [2·4–6·3])	7 (8·4% [5·8–10·8])
Elderly care physicians	7 (4·8% [0·5–15·2])	21 (3·1% [1·6–5·0])	35 (3·5% [2·5–6·2])
Drugs			
Neuromuscular relaxants	1 (<0·1%)	386 (90·2% [86·9–92·7])	392 (72·2% [68·0–75·9])
Barbiturates	1 (<0·1%)	36 (9·8% [7·3–13·1])	37 (7·9% [5·8–10·8])
Benzodiazapines and opioids	28 (66·7% [51·0–80·0])	0	28 (13·3% [10·0–15·9])
Benzodiazepines	7 (15·4% [6·5–29·4])	0	7 (3·0% [1·7–4·9])
Opioids	5 (15·4% [6·5–29·4])	0	5 (3·1% [1·7–4·9])
Other	1 (2·5% [0·1–11·8])	1 (<0·1%)	2 (0·5% [0·3–2·3])
Shortening of life			
Probably no life shortening	1 (2·6% [0·1–11·8])	0	1 (0·4%)
Less than a week	39 (87·0% [73·2–94·9])	126 (28·2% [23·8–32·2])	166 (40·3% [35·6–44·2])
A week or more	5 (10·4% [3·7–24·1])	315 (71·3% [66·9–75·3])	322 (58·0% [53·7–62·4])
Unknown	0	2 (0·6% [0·3–2·3])	7 (1·3% [0·3–2·3])
Most appropriate term for the act according to physician			
Euthanasia or assisted suicide	0	432 (97·4% [95·0–98·4])	412 (76·7% [73·3–80·7])
Ending of life	1 (2·5% [0·1–11·8])	8 (1·6% [0·9–3·8])	9 (2·0% [1·0–3·7])
Alleviation of symptoms	2 (7·5% [2·5–21])	0	2 (1·5% [1·0–3·7])
Palliative or terminal sedation	4 (90·0% [2·5–21·2])	2 (0·7% [0·3–2·3])	44 (18·1% [14·6–21·3])

Data are absolute number of patients (weighted % [95% CI]). All percentages are weighted for sampling fractions, non-response, and random sampling deviations, to make them representative of all deaths in the Netherlands in 2010. Therefore the percentages presented cannot be derived from the unweighted absolute numbers presented. *For eight cases, it was not known whether the physician had reported the case to a euthanasia review committee.

Table 4: **Characteristics of reported and unreported cases of euthanasia and physician-assisted suicide**

this is a small increase compared with 2005 (table 3). Finally, in 2010, of all physicians who had indicated in the questionnaire to have made an end-of-life decision that was classified as euthanasia or physician-assisted suicide, most classed "euthanasia", "assisted suicide", or "ending of life" the most appropriate term for their act, followed by "palliative or terminal sedation"; these classifications are comparable with 2005. In 2010, ending of life without explicit patient request was never labelled as "ending of life" (in 2005 about a fifth of cases were classed as "ending of life"); it was mostly labelled as "palliative or terminal sedation" or "alleviation of symptoms" (table 3).

The absolute number of cases of euthanasia or physician-assisted suicide in 2010 was about 4050. In 2010, 3136 (77%) cases of euthanasia or physician-assisted suicide were reported to euthanasia review committees in the Netherlands.[14] In our questionnaire we also asked whether physicians had reported their act to a euthanasia review committee. With these data a similar reporting rate was calculated (table 4). The reporting rate in 2010 is comparable with the reporting rate of 2005 (80%; 1933 of 2425), and higher than the reporting rate before enactment of the law (18% [486 of 2700] in 1990; 41% [1466 of 3600] in 1995, and 54% [2054 of 3800] in 2001). In the unreported cases the drugs used were hardly ever neuromuscular relaxants or barbiturates and the most appropriate term according to the physician was never "euthanasia" or "assisted suicide" (table 4). Furthermore, in cases in which the physician had reported to a euthanasia review committee the estimated shortening of life was more often a week or more than in unreported cases (table 4). Finally general practitioners were more inclined to report whereas clinical specialists were less inclined to report.

Discussion

After the modest decrease in euthanasia frequency 3 years after enactment of the euthanasia law, we saw an increase 8 years after the enactment. A rise in the number of patients requesting euthanasia explains this increase partly. While more than half of these requests were not granted, physicians granted requests more often in 2010 than in 2005. As no differences occurred in patient characteristics of cases of euthanasia and physician-assisted suicide, the increase seems not to be due to expansion to other patient groups.

Euthanasia is still mostly undertaken in younger people, cancer patients, and in general practice rather than in hospitals or nursing homes. As the rate of euthanasia and physician-assisted suicide in 2010 was comparable with the rate before enactment of the law in 2001, some physicians might have been unsure about how the law would work in practice, in 2005, shortly after the enactment of the law, making them more reluctant to undertake euthanasia. In Belgium, the euthanasia rate decreased from 1·1% in 1998 to 0·3% in 2001, shortly before enactment of a euthanasia law in 2002, increasing again to 1·9% in 2007.[15] Although, in Belgium the increase occurred just before the enactment of the law, this trend might represent a similar phenomenon as in the Netherlands because in Belgium the euthanasia law was heavily debated before its enactment.[16]

After publication of the Dutch 1990 study,[13] the subject that raised the most international debate was the number of cases of ending of life without an explicit patient request (panel).[18,19] The frequency of this practice has been decreasing since. One reason for this decrease might be the increased attention for palliative care over the last decade,[20,21] Additionally, this decrease might be related to the regulation of euthanasia and physician-assisted suicide, through enabling patients and physicians to openly discuss end-of-life preferences. In Belgium, where a euthanasia law was enacted in 2002, the rate of ending of life without request was higher in 1998 (3·2%) than in 2001 (1·5%) and 2007 (1·8%).[15] In the UK the rate ending life without request was stable between 2004 and 2008 (0·3%).[22] While there is debate in the UK about regulation of assisted dying, no law exists on euthanasia or physician-assisted suicide in the UK. Not withstanding the decrease of ending of life without explicit request, information on characteristics of these cases is important to assess this practice. Although the absolute numbers are small, in half of these cases the decision has been discussed with the patient and in a quarter of cases the physician did not discuss the decision with either patient, relative, or other physicians.

The frequency of intensified alleviation of symptoms has risen, especially between 2005 and 2010. This finding is unexpected because evidence shows that the life-shortening effects of opioids are often overestimated.[23–25] Yet, in over half of the cases in which symptoms were alleviated while taking into account a possible life-shortening effect, the physician thought that life had actually not been shortened. Knowledge about the limited life-shortening potential of opioids thus might have taken away reluctance in physicians and patients to use opioids. This effect is probably related to increased attention for palliative care in the Netherlands, which could also explain the rising use of continuous deep sedation until death.[20,21] This finding is in line with results of a study in Dutch nursing homes showing an increase in the use of pain relief and no change in treatment with antibiotics of dementia patients with pneumonia over a decade.[26] In Belgium, an increase in intensified alleviation of pain and symptoms and in continuous deep sedation also coincided with increased attention for palliative care.[15] In the UK, a decrease in the use of intensified alleviation of symptoms was noted, from 30% in 2004 to 22% in 2008. However, whether these rates are comparable is debatable because in 2004 wording in the questionnaires was similar to the wording in our studies (taking into account possible life-shortening effect), whereas in 2008 the wording was different (knowledge of probable or certain hastening of life).[20]

We noted that in 2010, according to their physician, in 0·4% (18 of 6861) of all deaths the patient intentionally had stopped eating and drinking. This is substantially lower than the rate recorded in a proxy-report in a Dutch population-based survey in 2009.[27] Physicians are not always aware of patients intentionally stopping eating and drinking. The survey showed that in 72% of cases the person stopping eating and drinking had a disease diagnosis. However, a sample of deceased people might yield more accurate estimates of end-of-life practices than a population-based sample of proxies. We noted that in almost half of patients who intentionally stopped eating and drinking, they had made a euthanasia request that was not granted, which is a similar percentage as reported in the proxy survey. While this proportion is substantial, it is a minority of all deceased patients whose request did not result in euthanasia. An even smaller group committed suicide after their euthanasia request was not granted. We are not aware of studies of patients intentionally ending their life in the course of a serious illness in other countries. Whether the legal option of euthanasia or physician-assisted suicide influences these rates would be interesting to know.

8 years after enactment of the euthanasia law the percentage of cases that were reported to the review committees, which is a legal obligation, stabilised. In unreported cases virtually all physicians labelled their decision themselves as "palliative or terminal sedation" or as "alleviation of symptoms", and none of them used neuromuscular relaxants or barbiturates. By contrast, in reported cases virtually all physicians labelled their act as "euthanasia" or "assisted suicide", and all used neuromuscular relaxants or barbiturates, the drugs advised for undertaking euthanasia or physician-assisted suicide by the Royal Dutch Association for Pharmacy and by the Euthanasia Review Committees. These characteristics of unreported cases have led some to argue that cases of euthanasia in which opioids were used should not be included in the euthanasia rate.[28] Excluding unreported cases would make for a reporting rate of about 100%, both in 2005 and 2010. However, use of opioids was only classified as euthanasia when physicians affirmed that death was caused by administering this drug with the intention to end life. Hastening of death by administration of opioids in these cases cannot be ruled out. Obviously, the classification scheme used in our studies is more likely to result in an overestimation than in an underestimation of the euthanasia frequency. In any case, our finding that about 100% of the cases in which the advised drugs were used were reported suggests that non-reporting by physicians is not related to unwillingness to report cases of euthanasia. This finding seems more related to lack of clarity about or discrepancy between effects of drugs and intention with regard to hastening death. Further education seems the most appropriate way to further increase the reporting rate.

***Panel:* Research in context**

Systematic review

The Netherlands, Belgium, and Luxembourg are the only countries in the world where the ending of a patient´s life by a physician on the patient´s explicit request is legally allowed, if strict criteria are met. Physician assistance in a patient's suicide is, also under strict conditions, legally allowed in Switzerland, and some states in the USA. We searched PubMed and Medline databases for reports on the frequency of the use of euthanasia and physician-assisted suicide and the main background characteristics of these practices. We used the search terms "euthanasia", "assisted suicide", "epidemiology", "incidence", and "frequency". Our search was limited to articles that were published in English during the past 10 years, which presented studies about physician-assistance in dying in adults.

Interpretation

Studies from countries where euthanasia and physician-assisted suicide are not legal mainly focus on health-care professionals' attitudes towards end-of-life decision making and physician assistance in dying. In these studies, the term euthanasia is not always referring to the practice of a physician ending a patient's life on his or her explicit request. The frequencies and main background characteristics of physicians' involvement in ending their patients' lives on their explicit request during the past 10 years have been studied in the Netherlands, USA, UK, Belgium, Germany, and in one international study that included Sweden, Denmark, the Netherlands, Belgium, Switzerland, Italy, and Australia (the Eureld study).[17] The frequency of this practice varies between countries, with the highest rates in countries where it is legal. In all countries, this practice mainly involves patients with incurable cancer who are in the end stage of their disease. Whereas in the Netherlands euthanasia and physician-assisted suicide are mainly done by general practitioners in patients who are dying at home, physician assistance in dying is a more hospital-based practice in other countries. The frequency of physicians ending a patient's life in the absence of an explicit request does not seem to be increased in countries where euthanasia is legalised.

Together with the high response rates and the availability of data for over two decades, an important strength of the study is the substantial sample of deaths that is representative for all deaths in all settings nationwide. A limitation is that information is derived from physicians, making us rely on the physicians' assessment of the situation. While this approach is the best source for information on the physicians' experiences, such as the physicians intention or the most appropriate term for the decision according to the physician, it can be more difficult for physicians to assess the life-shortening effect of drugs. Additionally, physicians might give socially desirable answers. However, we noted a similar reporting rate when comparing reporting based on information given by our respondents with the actual number of cases of euthanasia and physician-assisted suicide reported to Euthanasia Review Committees in 2010.[14] Finally, our study does not enable the assessment of quality of care or decision making on the patient level. For instance, to assess whether symptom control was sufficient is not possible. Our study's strength lies in providing population-level information relevant to health policy.

In conclusion, 8 years after the enactment of the Dutch euthanasia law, the incidence of euthanasia and physician-assisted suicide is comparable with that in the period before the law. The reporting rate seems to have

stabilised at about eight out of ten cases. Euthanasia and physician-assisted suicide did not shift to different patient groups and the frequency of ending of life without explict request continued to fall. Although translating these results to other countries is not straightforward, they can inform the debate on legalisation of euthanasia or physician-assisted suicide in other countries.

Contributors

BDO-P, JJMvD, and AvdH designed the study. BDO-P wrote the report. CP and GJFdJ-K collected the data. BDO-P, AB-S, CP, and GJFdJ-K analysed the data. All authors interpreted the data. CP, GJFdJ-K, JJMvD, and AvdH critically reviewed the report.

Conflicts of interest

We declare that we have no conflicts of interest.

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Euthanasia in the Netherlands: what lessons for elsewhere?

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The Netherlands is one of the few places in the world where euthanasia and physician-assisted suicide are legal under specific circumstances. In *The Lancet*, Bregje Onwuteaka-Philipsen and colleagues present the findings from their analysis of trends in euthanasia and physician-assisted suicide before and after the 2002 enactment of the euthanasia law in the Netherlands[1]—the most recent rigorously designed, empirical study done in the country to date. By sampling all deaths in the Netherlands, the investigators were able to analyse trends and report some reassuring findings, but they also identified cases that raise ethical concerns.

After a decrease shortly after the legislation was passed in 2002, the frequency of euthanasia in the Netherlands has increased to 2·8% of all deaths in 2010 (95% CI 2·5–3·2), slightly above the 2001 level. The frequency of physician-assisted suicide has been stable (at 0·1% [0·1–0·2] of all deaths in 2010). Abuse has not been widespread, and there is no apparent disproportionate use in vulnerable populations. Physicians do not substitute hastening death for the provision of palliative care. Instead, they intensify the alleviation of symptoms (in 36·4% [35·2–37·6] of patients in 2010) much more often than they undertake euthanasia or physician-assisted suicide, and the increase in the alleviation of symptoms is also much steeper than the increase in euthanasia. Physicians grant fewer than half of euthanasia requests from patients. These findings, together with other reports,[2] provide reassurance to individuals who do not oppose euthanasia and physician-assisted suicide as violations of their religious beliefs or professional ethics. However, the effect of these data on euthanasia debates elsewhere might be limited, because countries differ greatly in demography, culture, and organisation of medical care.

The cases that raise ethical concerns merit attention from all physicians, irrespective of their views on euthanasia and physician-assisted suicide. Physicians have a professional responsibility for quality improvement,[3] which should include end-of-life care. Improvement in the overall quality of end-of-life care would benefit a much larger number of patients than those who request euthanasia. First, the line between euthanasia and the less controversial, much more common practice of palliative sedation can be blurred in clinical practice. Even when euthanasia and physician-assisted suicide are illegal, patients might request them, and on occasion physicians oblige.[4–6] In about 20% of cases the investigators classified as euthanasia or physician-assisted suicide, the physicians viewed the case as alleviation of symptoms (1·5% [1·0–3·7]) or palliative or terminal sedation (18·1% [14·6–21·3]). In other studies, physicians also misclassify some cases of euthanasia.[7,8] The goal of palliative sedation is to relieve a patient's refractory symptoms, to the point of unconsciousness if necessary. All physicians, even opponents of euthanasia, should support proportionate palliative sedation, which uses the least sedation needed to control refractory symptoms.[9] But physicians who say they are undertaking palliative sedation sometimes cross the line to euthanasia. One reason for this happening might be confusion regarding intention. The physician's intention to hasten the patient's death is crucial in the Dutch definition of euthanasia and assisted suicide. Intention should be judged not only by physicians' statements but also by actions.[10,11] If a physician increases the dose of opioids or sedatives in an unresponsive patient in the absence of clinical signs or symptoms that could reasonably be interpreted as distress—such as restlessness, grimacing, withdrawal from stimuli, hypertension, or tachycardia[12,13]—these actions could be inferred as intention to hasten death.

Second, decisions about palliative sedation, especially continuous deep sedation until death, should be

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discussed with patients or families. Ethically, these practices might involve a trade-off between awareness and comfort. Patients vary in how they want to set this balance, and physicians are unlikely to know a patient's preferences without explicitly asking them. However, in 41·2% of cases (39·0–43·1) classified by the investigators as intensified alleviation of symptoms, the physician did not discuss the decision with the patient, relatives, or another physician. Knowing why such discussions do not occur, especially in cases of palliative or terminal sedation, would be a first step towards facilitating and improving these important conversations.

Third, physicians' failure to report cases of euthanasia and physician-assisted suicide, as required by Dutch law, in about 20% of cases raises concerns. More detailed information about non-reported cases would be useful. How did physicians explain how they characterised their actions and their intentions with regard to hastening death? Did they discuss these decisions with patients and families? Was there an association between failure to report and failure to discuss these decisions with patients and families? Such additional information might identify unresolved ethical or clinical issues and suggest how to improve the reporting of euthanasia in the Netherlands.

Finally, cases of euthanasia without the explicit request of the patient are contrary to Dutch law and ethically problematic, especially when the physician did not discuss euthanasia with the patient, family, or another physician. Some readers will be reassured that the frequency of this rare practice has decreased over time. However, an in-depth analysis of these cases might reveal more widespread conceptual confusions or flaws in practice.

We commend Onwuteaka-Philipsen and colleagues for their careful, rigorous study, but additional information from in-depth interviews in ethically problematic cases is needed. How do physicians think through these difficult situations? What key concepts are uncertain, misunderstood, or might need modification? How do doctors talk with patients and families about these practices, and are there missed opportunities to improve such discussions? By answering these questions, physicians can improve the quality of care for dying patients and their families, irrespective of their views on euthanasia and physician-assisted suicide.

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