

SPECIAL ARTICLE

End-of-Life Practices in the Netherlands under the Euthanasia Act

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ABSTRACT

BACKGROUND

In 2002, an act regulating the ending of life by a physician at the request of a patient with unbearable suffering came into effect in the Netherlands. In 2005, we performed a follow-up study of euthanasia, physician-assisted suicide, and other end-of-life practices.

METHODS

We mailed questionnaires to physicians attending 6860 deaths that were identified from death certificates. The response rate was 77.8%.

RESULTS

In 2005, of all deaths in the Netherlands, 1.7% were the result of euthanasia and 0.1% were the result of physician-assisted suicide. These percentages were significantly lower than those in 2001, when 2.6% of all deaths resulted from euthanasia and 0.2% from assisted suicide. Of all deaths, 0.4% were the result of the ending of life without an explicit request by the patient. Continuous deep sedation was used in conjunction with possible hastening of death in 7.1% of all deaths in 2005, significantly increased from 5.6% in 2001. In 73.9% of all cases of euthanasia or assisted suicide in 2005, life was ended with the use of neuromuscular relaxants or barbiturates; opioids were used in 16.2% of cases. In 2005, 80.2% of all cases of euthanasia or assisted suicide were reported. Physicians were most likely to report their end-of-life practices if they considered them to be an act of euthanasia or assisted suicide, which was rarely true when opioids were used.

CONCLUSIONS

The Dutch Euthanasia Act was followed by a modest decrease in the rates of euthanasia and physician-assisted suicide. The decrease may have resulted from the increased application of other end-of-life care interventions, such as palliative sedation.

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THE INCREASING IMPORTANCE OF CHRONIC diseases as a cause of death and the attention currently being paid to patient-centered care at the end of life have created interest in the role of medicine in the timing and mode of death and dying.¹ In many instances, death is not merely the result of the natural course of a lethal disease: medical decision making often contributes.²⁻⁵ Such decision making concerns the use of medical treatment to prolong the life of seriously ill patients. Furthermore, the alleviation of severe symptoms sometimes involves the use of drugs that have as a potential side effect the shortening of life. Difficult situations can occur when patients feel that their suffering is unbearable, feel hopeless, and ask their physician to help them to terminate their life. In most countries, physicians are not allowed to grant such a request, although physician assistance in dying is now a topic of debate in many countries.⁶⁻⁸

In the Netherlands, euthanasia is defined as death resulting from medication that is administered by a physician with the explicit intention of hastening death at the explicit request of the patient.⁹ In assisted suicide, the patient self-administers medication that was prescribed by a physician. In the early 1990s, the practices of euthanasia and physician assistance in suicide were liable to legal prosecution in the Netherlands. The public prosecutor mostly dismissed physicians from prosecution if they were found to have adhered to a number of requirements. Research in 1990 indicated that the reporting rate for euthanasia and physician assistance in suicide was only 18.0%.¹⁰ After the official establishment of a reporting procedure in 1993, the reporting rate increased to 40.7% in 1995.¹¹

The reporting procedure was updated in 1998 to involve the initial review of the deaths by multidisciplinary review committees that advised the public prosecutor about whether or not the requirements for careful practice had been fulfilled. As a result, the reporting rate further increased to 54.1% in 2001.¹² The reporting procedure was widely endorsed by physicians, and the review committees only rarely found serious violations of the requirements for careful practice. Furthermore, the frequencies of euthanasia and assisted suicide seemed to have stabilized in 2001.¹³ Nonreporting was most common in cases in which physicians had administered opioids rather than neuromuscular relaxants or barbiturates.¹⁴

In April 2002, after three decades of debate and research, the Euthanasia Act was passed to regulate the ending of life by a physician at the request of a patient who was suffering unbearably without hope of relief. The act officially legalized euthanasia and physician-assisted suicide for the first time, but in effect it simply legalized an existing practice, since physicians had not been prosecuted for actions to end the lives of patients as long as the actions were consistent with the standards of care that had been established in the early 1990s. The most important change was that, under the act, the review committees forward to the legal prosecutor only cases in which the requirements for careful practice are not met.

Physician assistance in dying is also legally regulated in other countries. The Oregon Death with Dignity Act legalizing physician-assisted suicide was enacted into law in 1997, and in 2002 Belgium adopted a law on euthanasia that is largely similar to the Dutch law.¹⁵⁻¹⁹ However, the Netherlands is the first country where large-scale research has provided insight into the practices of euthanasia and assisted suicide and their use in end-of-life decision making. Large nationwide studies of practices in 1990, 1995, and 2001 have provided data on the frequency and characteristics of euthanasia, physician-assisted suicide, and other medical acts that may hasten death.^{10,13,20} These studies have proved the importance of end-of-life decision making in current medical practice, and they have had a major influence on national policymaking and the further development of end-of-life care. In 2005, we performed a follow-up study to assess the effects of the 2002 Dutch law and changes in end-of-life care. We also assessed the reporting rates for euthanasia and assisted suicide and physicians' reasons for nonreporting.

METHODS

STUDY DESIGN

We performed a death-certificate study that was largely similar to the large-scale studies of practices in 1990, 1995, and 2001.^{10,13,20} A stratified sample of death cases was drawn from the central death registry of Statistics Netherlands, which receives death certificates for all deaths that occur in the Netherlands. All 43,959 deaths that occurred between August and November 2005 were assigned to one of five strata, which were denoted

1 through 5. When the cause of death was one in which it was clear that no physician's assistance in dying could have been provided (e.g., sudden death from a car accident), the death was assigned to stratum 1. These cases were retained in the sample, but no questionnaires were sent to the physicians, because no further information was needed to determine that no physician's assistance in dying had been provided. When the likelihood that a physician's assistance in dying had been provided was deemed to be high, the death was assigned to stratum 5. The final sample contained half the cases in stratum 5, 25% of the cases in stratum 4, 12.5% of those in stratum 3, 8.3% of those in stratum 2, and all cases in stratum 1.

For all sampled cases for which the cause of death did not preclude physician assistance in dying, attending physicians were mailed a four-page questionnaire (see the Supplementary Appendix, available with the full text of this article at www.nejm.org). The anonymity of both physicians and patients was guaranteed, because returned questionnaires were opened only after all information about the identities of the patient and physician had been removed.

QUESTIONNAIRE

The questionnaire was mailed with a letter signed by the Chief Inspector for Health Care and the president of the Royal Dutch Medical Association. Of the 6860 questionnaires that were mailed to physicians, 5342 were returned (response rate, 77.8%). According to Dutch policy, the study did not require review by an ethics committee or written informed consent from the patients' families, because the data collection was anonymous with regard to the deceased patient and the attending physician.

The questionnaire focused on the characteristics of the end-of-life decision making that may have preceded the death of the patient involved. There were four key questions, addressing whether the respondent had withheld or withdrawn medical treatment while taking into account the possible hastening of death; had intensified measures to alleviate pain or other symptoms while taking into account the possible hastening of death or appreciating that possibility; had withheld or withdrawn medical treatment with the explicit intention of hastening death; or had administered, supplied, or prescribed drugs with the

explicit intention of hastening death, resulting in the patient's death.

The wording of these questions was identical to that in the previous studies. If the last of the four key questions was answered affirmatively and if the act was performed in response to an explicit request by the patient, the act was classified as euthanasia if the physician had administered (or had assisted in administering) the drug and was classified as physician-assisted suicide if the patient had taken the drug himself or herself. For cases in which physicians responded affirmatively to more than one of the four key questions, the act that involved the most explicit intention with regard to the hastening of death was used to classify the act. For cases in which there was no single most explicit intention, the administration of drugs prevailed over the withholding or withdrawing of treatment.

The key questions were followed by questions 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. We also asked whether the patient had been deeply and continuously sedated before death. Our questionnaire also contained new questions about whether or not cases were reported as required by the Euthanasia Act, as well as about the reasons for nonreporting. Physicians were further asked to choose the term that they thought best described their act: refraining from treatment, alleviation of symptoms, palliative or terminal sedation, ending of life, assisted suicide, or euthanasia.

STATISTICAL ANALYSIS

The percentages reported were weighted to adjust for differences in the percentages of deaths sampled from each of the five strata and differences in response rates in relation to the age, sex, marital status, region of residence, and cause and place of death of the patients. After adjustment, the percentages were extrapolated to cover a 12-month period, to reflect the 136,402 deaths in the Netherlands in 2005. Weighting factors were calculated in three steps. First, the inverse of the percentage of deaths sampled from each stratum was taken. The resulting factor was multiplied by a second factor that was calculated by dividing the sampled number of deaths by the number of deaths for which we received a questionnaire from the physician for each combination of characteristics

of patients. The weighting factor that resulted from steps 1 and 2 was multiplied by a factor that was calculated in the third step, by dividing the actual number of cases in the population of deceased persons in 2005 for each combination of characteristics of patients by the number of cases from the first two weighting steps.

Confidence intervals were calculated for the estimates of the rates of euthanasia, assisted suicide, and other end-of-life practices. Rates across years were compared with the use of chi-square tests. Logistic-regression analysis was performed to assess the factors that helped to determine the physicians' labeling of their acts. All statistical procedures took into account the weighting procedure by standardizing the weighting factors to the actual total number of cases. P values of less than 0.05 were considered to indicate statistical significance.

RESULTS

In 2005, 1.7% of all deaths in the Netherlands were the result of euthanasia, as compared with 2.6% in 2001, 2.4% in 1995, and 1.7% in 1990 (Table 1). Assisted suicide was less common than euthanasia in each year and, like the euthanasia rate, declined in frequency in 2005. Furthermore, 0.4% of all deaths were the result of the use of lethal drugs not at the explicit request of the patient; this percentage was not significantly different from those in previous years. Intensified alleviation of symptoms as the most important end-of-life decision increased in frequency from 20.1% in 2001 to 24.7% in 2005. However, the percentage of cases in which physicians intensified the alleviation of symptoms, rather than only cases in which that action was most important, were similar: 30.1% in 2001 and 30.2% in 2005. The withholding or withdrawing of potentially life-prolonging treatment as the most important decision decreased in frequency from 20.2% in 2001 to 15.6% in 2005. These percentages were 30.4% and 27.5%, respectively, when all cases involving the withholding or withdrawing of life-prolonging treatment were included, rather than only cases in which that action was most important. Of all deceased patients in 2005, 8.2% were continuously and deeply sedated before death. Such sedation was provided in conjunction with decisions that possibly hastened death, such as decisions to withhold hydration and nutrition, in 7.1% of

deaths in 2005, as compared with 5.6% in 2001. In the remaining 1.1% of patients who were sedated, the sedation was not provided in conjunction with decisions that possibly hastened death. (No figure is available for 2001.)

We had data from 2005 and 2001 about the rates of euthanasia, assisted suicide, ending of life without an explicit request by the patient, and continuous deep sedation in conjunction with possible hastening of death in various subgroups of patients (Table 2). The rates in 1995 and 1990 (data not shown) were similar to those in 2001. In both 2005 and 2001, the highest rates of euthanasia or assisted suicide were found for patients aged 64 years or younger, for men, and for patients with cancer. Furthermore, most acts of euthanasia or assisted suicide were carried out by general practitioners. The rate of euthanasia or assisted suicide was lower in 2005 than in 2001 for both sexes, all age groups, patients with all diagnoses, and all physician specialties. The rate of the ending of life without an explicit request by a patient was similar in each subgroup. Like euthanasia and assisted suicide, continuous deep sedation in conjunction with the possible hastening of death in 2005 was used most often in patients aged 64 years or younger, in men, and in patients with cancer; the rates of this practice in these subgroups were higher than those in 2001.

Before end-of-life decisions were made, physicians discussed euthanasia and assisted suicide with all patients whose death was caused by either act (Table 3). The physician also discussed the decision to perform euthanasia or assisted suicide with relatives of the patient in 75.5% of deaths in 2005 and with one or more colleagues in 87.7% of deaths. When life was ended without the explicit request of the patient, there had been discussion about the act or a previous wish of the patient for the act in 60.0% of patients, as compared with 26.5% in 2001. In 2005, the ending of life was not discussed with patients because they were unconscious (10.4%) or incompetent owing to young age (14.4%) or because of other factors (15.3%). Of all cases of the ending of life in 2005 without an explicit request by the patient, 80.9% had been discussed with relatives. In 65.3% of cases, the physician had discussed the decision with one or more colleagues.

In 73.9% of all cases of euthanasia or assisted suicide in 2005, life was ended with the use of neuromuscular relaxants or barbiturates; opioids

Table 1. Frequencies of Euthanasia, Assisted Suicide, and Other End-of-Life Practices in the Netherlands, According to Year.*

Variable	1990	1995	2001	2005
No. of studied deaths†	5197	5146	5617	9965
No. of questionnaires	4900	4604	5189	5342
Most important practice that possibly hastened death — % (95% CI)				
Euthanasia	1.7 (1.5–2.0)	2.4 (2.1–2.6)‡	2.6 (2.3–2.8)‡	1.7 (1.5–1.8)
Assisted suicide	0.2 (0.1–0.3)	0.2 (0.1–0.3)	0.2 (0.1–0.3)‡	0.1 (0.1–0.1)
Ending of life without explicit request by the patient	0.8 (0.6–1.0)‡	0.7 (0.5–0.9)‡	0.7 (0.5–0.9)	0.4 (0.2–0.6)
Intensified alleviation of symptoms	18.8 (17.9–19.9)‡	19.1 (18.1–20.1)‡	20.1 (19.1–21.1)‡	24.7 (23.5–26.0)
Withholding or withdrawing of life-prolonging treatment	17.9 (17.0–18.9)‡	20.2 (19.1–21.3)‡	20.2 (19.1–21.3)‡	15.6 (15.0–16.2)
Total	39.4 (38.1–40.7)‡	42.6 (41.3–43.9)	43.8 (42.6–45.0)	42.5 (41.1–43.9)
Continuous deep sedation§	NA	NA	NA	8.2 (7.8–8.6)

* All percentages were weighted for the sampling fractions, for nonresponse, and for random-sampling deviations. CI denotes confidence interval, and NA not available.

† The number of deaths is largest in 2005 because all deaths in which the cause of death precluded physician assistance during dying were included, whereas only 1 in 12 of these deaths was included in the other study years.

‡ $P < 0.05$ for comparison with the frequency for 2005.

§ Continuous deep sedation may have been provided in conjunction with practices that possibly hastened death.

were used in 16.2% of all cases. In the same year, the ending of life without an explicit request by the patient more frequently involved the use of opioids (58.5%). Physicians were asked to estimate the amount of time by which life was shortened owing to the use of lethal drugs. In 2005, life was estimated to have been shortened by at least 1 week in 53.9% of all cases of euthanasia or assisted suicide and in 11.6% of all cases of the ending of life without an explicit request by the patient. The type of drugs used and the extent to which life was shortened were similar in 2005 and 2001.

In absolute terms, the numbers of cases of euthanasia or assisted suicide in 2005 were 2297 and 113, respectively. The review committees evaluated 1933 of the 2410 cases in 2005, with a reporting rate of 80.2%. For 28 cases, the physicians were asked about the reasons for nonreporting; for 76.1% of these cases, physicians answered that they had not perceived their act as the ending of life. Other reasons given were that the physician had doubts about whether the criteria for careful practice had been met (9.7%) or that the physician regarded the ending of life as a private agreement between physician and patient (6.6%). When asked to choose the most appro-

priate term for cases that were classified as euthanasia or assisted suicide in our study (an affirmative answer to the last of the four key questions) (260 cases), 76.2% of physicians chose “euthanasia,” “assisted suicide,” or the “ending of life.” End-of-life practices in the remaining cases were labeled by physicians as “alleviation of symptoms” or “palliative or terminal sedation.” Results of a logistic-regression analysis revealed that physicians were more likely to label the prescribing of drugs with the explicit intention of hastening death as “euthanasia” or “assisted suicide” when the drugs were neuromuscular relaxants or barbiturates than when the drugs were opioids or other types ($P < 0.001$).

DISCUSSION

The enactment of the Dutch euthanasia law was followed by a modest decrease in the rates of euthanasia, assisted suicide, and ending of life without an explicit request by the patient and an increase in the rate of continuous deep sedation near the end of life. These findings represent a significant reversal of the trends in end-of-life decision making that were found between 1990 and 2001.¹³ The high response rate, the fact that

Table 2. Rates of Euthanasia or Assisted Suicide, Ending of Life without an Explicit Request by the Patient, and Continuous Deep Sedation in 2001 and 2005, According to Characteristics of Patients.*

Characteristic	Deaths in 2005 Studied†	Percentage of All Deaths	Euthanasia or Assisted Suicide		Ending of Life without Explicit Request by Patient		Continuous Deep Sedation‡	
			2001	2005	2001	2005	2001	2005
	<i>no.</i>		<i>percent</i>					
Age								
0–64 yr	2583	19.2	5.0	3.5	1.0	1.0	5.9	9.0
65–79 yr	3462	32.4	3.3	2.1	0.4	0.3	6.9	7.4
≥80 yr	3920	48.4	1.4	0.8	0.7	0.2	3.3	5.4
Sex								
Male	5371	49.7	3.1	2.0	0.7	0.4	5.2	7.2
Female	4594	51.3	2.5	1.5	0.7	0.4	4.9	6.4
Cause of death								
Cancer	2760	28.8	7.4	5.1	1.0	0.3	5.7	10.8
Cardiovascular disease	4882	31.9	0.4	0.3	0.6	0.2	2.4	3.5
Other or unknown	2323	39.3	1.2	0.4	0.5	0.6	6.2	6.5
Type of physician§								
General practitioner	5135	41.3	5.8	3.7	0.6	0.2	2.9	9.1
Clinical specialist	2891	32.3	1.8	0.5	1.2	0.7	7.9	5.5
Nursing home physician	1458	24.5	0.4	0.2	0.4	0.3	7.4	6.2
Total	9965	100.0	2.8	1.8	0.7	0.4	5.1	6.8

* All percentages were weighted for the sampling fractions, for nonresponse, and for random-sampling deviations. Percentages may not total 100 because of rounding.

† The number of deaths studied and the percentages of deaths in all subgroups of patients were similar in 2001, as reported by Onwuteaka-Philipsen et al.¹³

‡ All cases of continuous deep sedation that were provided in conjunction with a practice that possibly hastened death (i.e., in conjunction with euthanasia, assisted suicide, or ending of life without an explicit request by the patient) were classified as that practice rather than as deep sedation in this table.

§ The 2005 sample included 481 physicians with an unknown specialty.

both the study design and the key questions were kept constant over the years, the endorsement of the study by authoritative medical bodies, and the guarantee of anonymity of patients and physicians all strengthen the validity and reliability of our results.

We focus on three possible explanations for these trends. First, some epidemiologic factors should be considered. As a result of the aging of society, the percentages of deaths of people 80 years of age or older, which is the age group for which euthanasia and assisted suicide are least common, increased from 45.3% in 2001 to 48.4% in 2005. However, decreased rates of these practices were found in all age groups, and the age shift can explain only about 0.1% of the total decrease. The percentage of deaths from cancer,

which is the most common diagnosis in patients receiving physician assistance in dying, remained stable between 2001 and 2005, as did the percentages of deaths attended by general practitioners, clinical specialists, and nursing home physicians.

Second, Dutch physicians have been found to consider high-quality end-of-life care as an alternative to euthanasia or assisted suicide, at least in some cases.¹³ In our study, we found that euthanasia and assisted suicide were to some extent replaced by continuous deep sedation. Sedation was most common in the subgroups in which euthanasia or assisted suicide were also most common: patients under 80 years of age, men, patients with cancer, and patients attended by general practitioners. One study showed that the use of deep sedation near the end of life is often pre-

Table 3. Discussion of Ending-of-Life Practices, Use of Drugs in the Ending of Life, and Time by Which Life Was Shortened in 2001 and 2005.*

Variable	Euthanasia or Assisted Suicide		Ending of Life without Explicit Request by Patient	
	2001	2005	2001	2005
No. of deaths studied	335	258	58	24
Discussion of practice (%) †				
With patient (or previous wish of patient)	100.0	100.0	26.5	60.0
With relative of patient	96.0	75.5	100.0	80.9
With ≥1 other physician	90.7	87.7	65.2	65.3
Drugs administered (%) ‡				
Neuromuscular relaxants	63.2	65.4	1.7	22.9
Barbiturates	10.8	8.5	2.3	5.3
Opioids	21.6	16.2	74.7	58.5
Benzodiazepines	0	6.6	2.3	2.7
Other drugs	0.9	0.3	0	4.5
Unknown	3.5	2.9	19.0	6.0
Shortening of life (%)				
By <1 wk	45.9	44.8	77.3	85.5
By ≥1 wk	54.1	53.9	18.1	11.6
Unknown	0	1.3	4.7	2.9

* All percentages were weighted for the sampling fractions, for nonresponse, and for random-sampling deviations.

† Ending-of-life practices could have been discussed with any combination of patients, relatives, and physicians.

‡ Drugs administered could have been neuromuscular relaxants, in any combination; barbiturates, alone or in combination with other drugs except neuromuscular relaxants; opioids, alone or in combination with other drugs except neuromuscular relaxants and barbiturates; benzodiazepines, alone or in combination with other drugs except neuromuscular relaxants, barbiturates, and opioids; or other drugs, in any combination.

ceded by a discussion of the option of euthanasia.²¹ The types of suffering that prompt requests for euthanasia overlap with those that prompt requests for sedation, although the emphasis is more on existential suffering and physical deterioration in euthanasia and more on physical suffering in sedation.²² Physicians also sometimes administer sedatives when they have the explicit intention of hastening death, such that sedation and euthanasia are not mutually exclusive in all cases.

Third, the attitudes of physicians toward opioids and their understanding of the effects of the drugs may have contributed to a decrease in the frequency of euthanasia. During the last decade, there has been increasing evidence that the potentially life-shortening effects of opioids are often overestimated.²³⁻²⁶ In the Netherlands, the results of the study of the 2001 practices¹³ sparked a debate about whether or not opioids can be used for euthanasia, because of their doubtful lethal

potential and the likelihood of side effects.^{14,27} The review committees have disapproved the use of opioids for euthanasia. As a result, physicians may have become less inclined to attribute life-shortening effects to opioids. Thus, the decrease in the percentage of cases of euthanasia in which opioids were used in 2005 as compared with 2001 may be at least partly the result of variation in the attribution by physicians of their acts, not only from an actual change in practices. It is difficult to assess whether or not such variation in attribution is justified in all cases. The tendency among physicians to attribute less life-shortening effects to their acts may extend to end-of-life decision making in a broader sense, relating to the decreased frequency in 2005 of decisions to withhold or withdraw potentially life-prolonging treatment. The shifting of attitudes toward the use of opioids may also have contributed to the trend of decreased rates of the ending of life without an explicit request by the patient. Apparently, the

Dutch system of regulating euthanasia has not resulted in increased rates of this practice, which is sometimes referred to as nonvoluntary euthanasia.

The reporting rates for euthanasia and physician-assisted suicide increased from 18.0% in 1990, when these practices were illegal and the first procedure for review had yet to be developed, to 80.2% in 2005, a time when euthanasia and assisted suicide were no longer of questionable legality if performed according to established requirements for careful practice. Our study reports, for the first time, quantitative data about the causes of nonreporting. Few physicians indicated that they did not report their case because of doubts about whether they had met the criteria and feared legal prosecution. A large majority of nonreported cases appeared to have involved acts to end life as defined in our study (an affirmative answer to the last of the four key questions on the questionnaire) but were not labeled by the physician as euthanasia or physician-assisted suicide. These cases mostly involved drugs with uncertain lethal effects, such as opioids and seda-

tives. As a result, the review committees mainly evaluate cases in which death was hastened with neuromuscular relaxants or barbiturates. In such cases, physicians virtually always adhere to the requirements for careful practice. However, the transparency that is envisaged by the Dutch law apparently does not extend to all cases of euthanasia.

In conclusion, the enactment of the Dutch euthanasia law was followed by a moderate decrease in the rates of physician assistance in dying. This trend may have resulted from changes in epidemiologic patterns, an increased use of deep sedation and other means of alleviating symptoms near the end of life, and a decreased inclination among physicians to believe that opioids hasten death.

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