Public health

@ Euthanasia and other end-of-life decisions in the Netherlands in 1990, 1995, and 2001

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Empirical data on the rate of euthanasia, physician-assisted suicide, and other end-of-life decisions have greatly contributed to the debate about the role of such practices in modern health care. In the Netherlands, the continuing debate about whether and when physician-assisted dying is acceptable seems to be resulting in a gradual stabilisation of end-of-life practices. We replicated interview and death-certificate studies done in 1990 and 1995 to investigate whether end-of-life practices had altered between 1995 and 2001. Since 1995, the demand for physician-assisted death has not risen among patients and physicians, who seem to have become somewhat more reluctant in their attitude towards this practice.

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In the Netherlands, euthanasia, physician-assisted suicide, and other medical end-of-life decisions have been discussed for several decades in the medical profession, by legal and ethics specialists, in public debates, and in the national parliament. The first quantitative studies of the rate and major characteristics of these practices were done in 1990.[1,2] Those studies provided a reliable overview of end-of-life decision-making practices in the Netherlands and had an important impact on the national and international debate. End-of-life decision making became recognised as a part of modern health care for many patients who are approaching death; about 39% of all deaths seemed to be preceded by a medical decision that probably or certainly hastened death. The deliberate hastening of death by administration of lethal drugs was rare, but was most frequently used at the explicit request of the patient. However, this decision was also made in about 1000 cases per year without an explicit request. Alleviation of severe pain and symptoms by use of opioids or similar drugs in high doses, while taking into account hastening of death as a possible but not intended side-effect, seemed to be a frequent practice, as were decisions to withhold or withdraw potentially life-prolonging treatments.

The hastening of death by administration of lethal drugs is an act at the border of accepted medical practice, and, therefore, some form of control was deemed necessary by the Dutch parliament. Since 1991, Dutch physicians have had to report all cases in which they administered or supplied drugs with the explicit intention of hastening a patient's death, to enable legal assessment by the Public Prosecutor. This notification procedure was assessed in 1995, and developments in end-of-life decision-making practices were simultaneously monitored by replicating the 1990 incidence studies.[3,4] The rate of euthanasia had significantly increased during this 5-year period, but the rate of physician-assisted suicide and ending of life without a patient's explicit request had remained virtually unchanged. After the 1995 study, the notification procedure was revised, and came into force in 1998. Cases were assessed by the Public Prosecutor only after being advised by a multidisciplinary committee of medical, ethics, and legal specialists. The renewed notification procedure was assessed in 2001–02, in combination with another rate study.

We present new data on the rate in 2001 of euthanasia, physician-assisted suicide, and other end-of-life decisions in the Netherlands, and a longitudinal analysis of decision-making practices since 1990. We investigated also physicians' attitudes towards end-of-life decision making during the period 1990–2001.

Physician interviews and death-certificate studies

We studied end-of-life decision-making practices and attitudes in 1990, 1995, and 2001. All studies consisted of physician interviews and death-certificate studies. Details of the 1990 and 1995 studies have been described elsewhere.[1–5] The questions and study designs that were used to collect the data were identical in all years.

For the interview studies, we interviewed random samples of physicians stratified by specialty. We included family physicians, nursing-home physicians, and clinical specialists (cardiologists, surgeons, and specialists in internal medicine, pulmonology, and neurology). These physicians covered an average of 95% of all deaths in the Netherlands in the studied periods. Respondents had to be actively practising medicine at the time of interview and had to have done so for the previous 2 years in the same specialty and place. We selected addresses from the professional registries of the specialties involved. In 1990, 405 (152 family physicians, 203 clinical specialists, and 50 nursing-home physicians; 91%) of 447 eligible physicians agreed to be interviewed, as did 405 (124, 207, and 74, respectively; 89%) of 455 in 1995, and 410 (125, 208, and 77, respectively; 85%) of 482 in 2001. We drew the 1995 and 2001 samples independently from the previous years.

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	1990 (128 824)	1995 (135 675)	2001 (140 377)
Interview studies (n [95% CI])			
Number of requests for euthanasia or assisted suicide later in disease	25 100 (23 400–27 000)	34 500 (31 800–37 100)	34 700 (32 200–37 100)
Number of explicit requests for euthanasia or assisted suicide at a particular time	8900 (8200–9700)	9700 (8800–10 600)	9700 (8800–10 500)
End-of-life practices (% [95% CI])			
Euthanasia	1·9% (1·6–2·2)	2·3% (1·9–2·7)	2·2% (1·8–2·5)
Physician-assisted suicide	0·3% (0·2–0·4)	0·4% (0·2–0·5)	0·1% (0·0–0·2)
Ending of life without patient's explicit request	..*	0·7% (0·5–0·8)	0·6% (0·4–0·9)
Death-certificate studies (% [95% CI])			
Euthanasia	1·7% (1·4–2·1)	2·4% (2·1–2·6)	2·6% (2·3–2·8)
Physician-assisted suicide	0·2% (0·1–0·3)	0·2% (0·1–0·3)	0·2% (0·1–0·3)
Ending of life without patient's explicit request	0·8% (0·6–1·1)	0·7% (0·5–0·9)	0·7% (0·5–0·9)
Alleviation of symptoms with possible life-shortening effect	18·8% (17·9–19·9)	19·1% (18·1–20·1)	20·1% (19·1–21·1)
Non-treatment decision	17·9% (17·0–18·9)	20·2% (19·1–21·3)	20·2% (19·1–21·3)
Total	39·4% (38·1–40·7)	42·6% (41·3–43·9)	43·8% (42·6–45·0)

*Frequency not assessed in this study.

Table 1: **End-of-life practices in the Netherlands in 1990, 1995, and 2001**

All interviews were done in person by experienced physicians, who were extensively trained to use the structured questionnaires. The interview schedule addressed experiences of and attitudes about end-of-life decision making. We defined end-of-life decisions as: euthanasia, the administration of drugs with the explicit intention of ending the patient's life on his or her explicit request; physician-assisted suicide, the prescription or supply of drugs with the explicit intention to enable the patient to end his or her own life; and ending of life without explicit request, the administration of drugs with the explicit intention of ending the patient's life without an explicit request from the patient. All data from the interview studies were weighted for differences in the sampling fractions in the different strata. Furthermore, estimates of absolute numbers were extrapolated to all deaths in the Netherlands by correcting for the, on average, 5% of deaths covered by other physicians than the seven types sampled.

In the death-certificate studies, we drew random samples from the central death registry of Statistics Netherlands, to which all deaths are reported. The period studied was Aug 1, to Dec 1, in all studied years. Every death during the study periods was examined by one of two physicians and assigned to one of five strata: stratum one, the cause of death precluded any kind of end-of-life decision (eg, a car accident resulting in instant death); stratum 2, sudden death in the presence of pre-existent disease; stratum 3, non-sudden death due to chronic disease; stratum 4, cancer deaths and deaths that were probably preceded by long-term terminal illness; and stratum five, the information on the death certificate made an end-of-life decision very likely. The sample fraction for strata one and two was a twelfth, for stratum three an eighth, for stratum four a quarter, and for stratum five a half. No questionnaire was sent out for stratum one. For all other sampled cases, the reporting physicians were asked to complete a four-page self-administered questionnaire on medical decision making that had preceded the death concerned. 76% of questionnaires were returned in 1990, 77% in 1995, and 74% in 2001; the numbers of cases studied after questionnaires were returned were 5197, 5146, and 5617, respectively.

The key questions in the death-certificate questionnaire were whether respondents had: withheld or withdrawn medical treatment while taking into account or explicitly intending (possible) hastening of death; intensified the lessening of pain or symptoms while taking into account or appreciating (possible) hastening of death; and administered, supplied, or prescribed drugs with the explicit intention of hastening the patient's death. If the third question was answered with yes, we classified the case as euthanasia if the drug had been given by someone other than the patient at his or her explicit request (written or otherwise), or as physician-assisted suicide if the patient had taken the drug himself or herself. We classified all other cases in which this question was answered with yes as ending of life without the patient's explicit request. For cases in which more than one question had been answered with yes, the decision with the most explicit intention prevailed over other decisions. If intentions were similar, the answer to question three prevailed over question two, and that for question two prevailed over the answer to question one. If the answer to question one was the most predominant decision, cases were classified as non-treatment decisions; if question two was the most predominant decision, cases were classified as alleviation of symptoms with possible life-shortening effects.

The study design of the interview and the death-certificate studies ensured anonymity for all patients who died. Furthermore, the data-collection procedure for the death-certificate studies precluded identification of any physician. In each of the 3 years studied, all Dutch physicians received a letter explaining the purpose of the studies and how anonymity would be guaranteed, signed by the chief of the Inspectorate for Health Care and the chairman of the Royal Dutch Medical Association.

Frequency of assisted deaths and end-of-life decisions

The total annual number of deaths in the Netherlands increased by 5·3% between 1990 and 1995, and by 3·5% between 1995 and 2001. The number of explicit requests for euthanasia or assisted suicide rose from 8900 in 1990 to 9700 in 1995, which is an increase of 9·0%. Between 1995 and 2001, the number remained stable at 9700 (table 1).

The death-certificate studies showed the rate of euthanasia increased from 1·7% of all deaths in 1990 to 2·4% in 1995, and further to 2·6% in 2001. In the interview studies, no further increase was found in 2001. The frequency of physician-assisted suicide and the ending of life without the patient's explicit request remained virtually unchanged during all years. The lessening of pain or other symptoms while taking into account or appreciating a possible life-shortening effect occurred in 18·8% of all deaths in 1990, 19·1% in 1995, and in 20·1% in 2001. The incidence of non-treatment decisions rose between 1990 and 1995, but remained stable in 2001 (table 1).

In 2001, the proportion of physicians who ever in their

	1990 (n=405)	1995 (n=405)	2001 (n=410)	p*
Euthanasia or assisted suicide				
Performed it ever	54%	53%	57%	0·33
Performed it in previous 24 months	24%	29%	30%	0·08
Never performed it but would be willing to do so under certain conditions	34%	35%	32%	0·51
Would never perform it but would refer patient to another physician	8%	9%	10%	0·22
Would never perform it nor refer patient	4%	3%	1%	0·002
Ending of life without a patient's explicit request				
Performed it ever	27%	23%	13%	<0·0001
Performed it in previous 24 months	10%	11%	5%	0·009
Never performed it but would be willing to do so under certain conditions	32%	32%	16%	<0·0001
Would never perform it	41%	45%	71%	<0·0001

*Based on logistic regression analysis with study year as predictor.

Table 2: **Interview study findings on euthanasia, physician-assisted suicide, and ending of life without a patient's explicit request in 1990, 1995, and 2001**

working career had performed euthanasia or assisted in suicide was 57%. Family physicians were more frequently involved in this practice than clinical specialists and nursing-home physicians. The increase in number of physicians who had ever performed euthanasia or assisted in suicide between 1995 and 2001 was among family physicians (1995 63%, 2001 71%) and nursing-home physicians (1995 21%, 2001 36%), but not clinical specialists (1995 37%, 2001 37%). For physicians who would never perform euthanasia, the proportion fell consistently: 4% in 1990, 3% in 1995, and 1% in 2001 (table 2).

The proportion of physicians who were ever engaged in the ending of life without a patient's explicit request decreased from 27% in 1990 to 23% in 1995, and further to 13% in 2001. Furthermore, physicians' unwillingness to ever do so increased, especially after 1995, from 45% in 1995 to 71% in 2001. We saw the decrease in willingness mainly among family physicians and clinical specialists; nursing-home physicians were already quite reluctant in 1995 (table 2).

Table 3 shows the developments in the rate of end-of-life decisions according to several characteristics of patients and type of physician. The data are based on the death-certificate studies. During the whole study period, euthanasia and physician-assisted suicide were relatively uncommon among patients dying at the age of 80 years or older. In 1995, the rate of euthanasia had increased especially among people aged 80 years or younger. Euthanasia was more frequent among male than female patients in 1990, but not in 1995 and 2001. Euthanasia and physician-assisted suicide were mainly performed among patients dying of cancer. The rise in the rate of euthanasia was also largest among cancer patients, and remained invariably low among patients with circulatory diseases. Euthanasia and physician-assisted suicide were mainly performed by family physicians, who frequently care for patients dying at home. The proportion of euthanasia cases among patients dying while being cared for by a nursing-home physician had stabilised, but the absolute number of cases among nursing-home patients had grown because of the increased involvement of nursing-home physicians in death.

Ending of life without a patient's explicit request occurred most frequently among people dying at age younger than 65 years. Among these patients the

	1990 (n=5197)					1995 (n=5146)					2001 (n=5617)				
	Number of death cases studied (%)	Proprtion of deaths after an end-of-life decision (%)				Number of death cases studied (%)	Proportion of deaths after an end-of-life decision (%)				Number of death cases studied (%)	Proportion of deaths after an end-of-life decision (%)			
		Euthanasia and assisted suicide	Ending of life without explicit request	Alleviation of symptoms	Non-treatment decision		Euthanasia and assisted suicide	Ending of life without explicit request	Alleviation of symptoms	Non-treatment decision		Euthanasia and assisted suicide	Ending of life without explicit request	Alleviation of symptoms	Non-treatment decision
Characteristic															
Age (years)															
0–64	1170 (22%)	3·0	1·6	20	13	1313 (21%)	4·6	1·1	21	14	1435 (20%)	5·0	1·0	19	16
65–79	1999 (37%)	2·3	0·5	20	15	1792 (36%)	2·9	0·6	20	17	1773 (34%)	3·3	0·4	21	19
>80	2038 (41%)	1·0	0·7	17	23	2041 (43%)	1·2	0·6	18	26	2409 (45%)	1·4	0·7	20	23
Sex															
Male	2664 (52%)	2·1	1·1	17	16	2611 (50%)	2·2	0·7	19	17	2602 (49%)	3·1	0·7	19	18
Female	2533 (48%)	1·7	0·5	20	20	2535 (50%)	2·8	0·7	20	24	3015 (51%)	2·5	0·7	21	22
Cause of death															
Cancer	2174 (30%)	4·4	1·7	35	17	2119 (29%)	7·0	1·0	36	17	2306 (29%)	7·4	1·0	33	17
Circulatory disease	1103 (29%)	0·5	0·3	9	15	910 (29%)	0·3	0·1	8	11	958 (25%)	0·4	0·6	11	12
Other or unknown	1920 (40%)	1·1	0·5	13	21	2117 (43%)	1·0	0·9	15	29	2353 (46%)	1·2	0·5	17	27
Type of physician															
Family physician	1766 (42%)	3·1	0·6	19	13	2493 (45%)	4·3	0·5	18	11	2421 (42%)	5·8	0·6	21	13
Clinical specialist	2356 (41%)	1·4	1·1	15	19	1560 (36%)	1·8	1·1	17	25	1493 (35%)	1·8	1·2	18	28
Nursing-home physician	986 (17%)	0·1	0·6	28	31	929 (19%)	0·3	0·5	27	36	1213 (24%)	0·4	0·4	32	31

Table 3: **Death-certificate study findings on end-of-life practices according to patients' characteristics in 1990, 1995, and 2001**

	1990 (n=405)	1995 (n=405)	2001 (n=410)	p*
Physicians' attitudes				
People have the right to decide about their own life and death	64%	64%	56%	0·02
When patients know that their physician is willing to perform euthanasia if needed, they will less frequently ask for it	46%	53%	47%	0·20
Adequate pain control and terminal care make euthanasia redundant	37%	31%	33%	0·04
Substantial economic measures in health care will increase the pressure on physicians to provide assistance in dying	9%	12%	15%	0·005
During the preceding 5 years				
Became more permissive	25%(	18%	12%	<0·0001
Became more restrictive	14%	12%	20%	0·02
Remained unchanged	61%	70%	69%	0·01

*Based on logistic regression analysis with study year as predictor.

Table 4: **Interview study findings on physicians' attitudes towards end-of-life decision making in 1990, 1995, and 2001**

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incidence decreased between 1990 and 1995 from 1·6% to 1·1%, but in 2001, it had remained virtually unchanged at 1·0%. Ending of life without a patient's explicit request occurred somewhat more frequently among male than among female patients in 1990, but the proportions were equal for both sexes in 1995 and 2001. This practice frequently involved patients with cancer, and was performed most commonly by clinical specialists.

Alleviation of pain or symptoms while taking into account or appreciating a life-shortening effect occurred in about one in five cases in all age-groups. This practice occurred more frequently among female than male patients, frequently involved cancer patients, and was practised most commonly by nursing-home physicians. This practice increased most among people aged 80 years and older, and among patients with diseases other than cancer. Decisions to withhold or withdraw potentially life-prolonging treatment were most frequently made for elderly patients. The increase in non-treatment decisions for elderly patients we noted in 1995, did not continue to 2001. The high frequency of such decisions among female patients is explained partly by the fact that women generally die at older ages than do men. Whereas other end-of-life decisions were especially evoked by having cancer, non-treatment decisions commonly involved other diagnoses as well.

Physicians' attitudes to rights at end of life

Physicians' attitudes towards people's rights in end-of-life decision making have altered only slightly during the period 1990–2001. In 1990 and 1995, 64% of all physicians thought that people have the right to decide about their own life and death; in 2001 this proportion was slightly lower. Fewer than half thought that patients would be less inclined to ask for euthanasia if they knew that their physician is willing to perform it if needed. About a third thought that euthanasia could be avoided by providing adequate palliative care to terminal patients, but in 1995 and 2001, this proportion seems to be lower than in 1990. There seems to be a slightly increasing anxiety among physicians that economic measures are going to affect end-of-life decision making. In 2001, physicians more frequently reported having become more restrictive about euthanasia and less frequently permissive (table 4).

Changes over time

The rate of euthanasia and explicit requests by patients for physicians' assistance in dying in the Netherlands seems to have stabilised, and physicians seem to have become somewhat more restrictive in their use. Euthanasia remains mainly restricted to groups other than patients with cancer, people younger than 80 years, and patients cared for by family physicians, who were already frequently involved in 1990. The continuing debate on whether and when physician-assistance in dying may be acceptable and on procedures to ensure transparency and quality assurance seems to have contributed to this stabilisation.

The rate of physician-assisted suicide remains remarkably low compared with that for euthanasia, despite recommendations of leading authorities such as the Royal Dutch Medical Association to choose physician-assisted suicide if possible.[6] There is an argument that patients' autonomy and responsibility in end-of-life decision making are more articulated in assisting with suicide than in providing euthanasia. Such features might, however, be overruled by the physicians', and probably the patients', need to control the act and to have medical assistance available in case of unforeseen difficulties.[7] Euthanasia is also frequently preferred over assisted suicide because of physical weakness or incapacity of patients.[8]

The combination of a decreasing proportion of physicians who have ever engaged in ending of life without a patient's explicit request and a stable number of such cases could be partly explained by the rise in the number of physicians in the Netherlands. Furthermore, physicians who are still willing to end life without a patient's explicit request may be engaging in these practices frequently. In previous studies, we have noted that the explicit intention of hastening death is similar to that with which euthanasia is performed. Other characteristics of these cases, however, such as the frequent use of morphine or other opioids, are frequently more similar to the alleviation of symptoms in which hastening of death was not an explicit intention.[9] Such alleviation of symptoms precedes death in about 20% of all cases, and was the only end-of-life decision that had clearly increased in 2001, especially for nursing-home patients. In addition to a growing interest in palliative care at the end of life, reports in which the life-shortening potential of opioids is limited and evidence that the quality of terminal care is commonly less than optimum may have contributed to a diminished reluctance to use opioids in palliative care for terminal patients.[10–15]

We find the absence of a rise in the proportion of non-treatment decisions after 1995 surprising. Advances in medical technology increase the number of possible interventions to treat seriously ill patients and the health-care costs for such interventions also increase, especially in the elderly age-groups. A growing number of interventions might also involve a growing number of decisions not to apply them, but this hypothesis is not reflected in our findings. Non-treatment decisions concern many different interventions in various situations.[16,17] To refrain from potentially life-prolonging treatment might not always be perceived as an end-of-life decision, especially when such abstinence is inspired

mainly by medical motives or involves low-grade technology.

Our study has some obvious limitations. First, it is limited to the experiences and attitudes of physicians. Views of patients, their family, and other caregivers were not studied. Furthermore, no inferences can be made from our data on the quality of end-of-life care. We asked physicians what they did (or did not) do and why they did it (or not), but avoided any reference to a moral assessment of their practices. The high participation rates in all studies and the coherence of the data between different studies and different years supports the idea that our findings are a reliable overview of end-of-life decision-making practices in the Netherlands.

Death and dying have become increasingly part of medical decision making, and health care is currently attributed much responsibility for the quality of the dying process. There is a growing awareness that end-of-life care should aim at improving the quality of life of patients and their families through the prevention and relief of pain and symptoms.[18] The current frequency of end-of-life decisions may represent a stable number of cases that can be expected in a modern Western society in which end-of-life decision making is frequently and openly discussed and, under specified circumstances, accepted. Advances in medicine may further improve the importance and impact of end-of-life decision making.

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