Nationwide study of decisions concerning the end of life in general practice in the Netherlands

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Abstract

***Objective*—To gain insight into decisions made in general practice about the end of life.**

***Design*—Study I: interviews with 405 physicians. Study II: analysis of death certificates with data obtained on 5197 cases in which decisions about the end of life may have been made. Study III: prospective study with doctors from study I: questionnaires used to collect information about 2257 deaths. The information was representative for all deaths in the Netherlands.**

***Results*—Over two fifths of all patients in the Netherlands die at home. General practitioners took fewer decisions about the end of life than hospital doctors and doctors in nursing homes (34%, 40%, and 56% of all dying patients, respectively). Specifically, decisions to withhold or withdraw treatment to prolong life were taken less often. Euthanasia or assisted suicide, however, was performed in 3·2% of all deaths in general practice compared with 1·4% in hospital practice. In over half of the cases concerning pain relief or non-treatment general practitioners did not discuss the decision with the patient, mostly because of incapacity of the patient, but in 20% of cases for "paternalistic" reasons. Older general practitioners discussed such decisions less often with their patients. Colleagues were consulted more often if the general practitioner worked in group practice.**

***Conclusion*—Differences in work situation between general practitioners and hospital doctors and differences between the group of general practitioners contribute to differences in the number and type of decisions about the end of life as well as in the decision making process.**

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Introduction

General practitioners as well as hospital doctors and doctors in nursing homes are increasingly confronted with medical decisions about the end of life. This is partly because of the growing number of technologies to prolong life and an increase in the prevalence of chronic diseases in an aging population. A weakening of the taboo of discussing death and dying may also have contributed to the number of cases in which such decisions have to be taken.

In 1990-1 we performed the first nationwide study on decisions about the end of life in medical practice.[1-3] The purpose of this article is to give insight into such decisions made by the general practitioners. We compared the occurrence of these decisions in general practice—that is, in patients' homes—with that in hospital and in nursing homes. We also studied differences between general practitioners in the decision making process.

In the Netherlands there are several important differences between general practitioners and hospital doctors. Most general practitioners practise single handedly so they are less audit oriented. General practitioners have a long standing relationship with most of their patients. They visit patients at home if required. They function as gatekeepers of clinical medicine. Together with the fact that most patients prefer to die at home, these could all be reasons for differences in the number and type of decisions about the end of life and in the decision making process.

Methods

In 1990 the Dutch government set up a committee chaired by Professor Remmelink, attorney general of the Dutch Supreme Court, to provide information on euthanasia and other decisions about the end of life. We were asked by the committee to do this study. The term "end of life decision" covers all decisions by physicians concerning actions aimed at hastening death or actions for which the physician takes into account the probability that the patient will die sooner. The end of life decisions considered were euthanasia or assisted suicide (both active and at the patient's explicit request); life terminating acts without explicit request[4]; decisions to withhold or withdraw treatment that would probably prolong life, including decisions to refrain from further diagnosis; and decisions to alleviate pain or symptoms with the probable result of shortening life.

We undertook three studies. We give only a brief summary of the methods because they are described in more detail elsewhere.[1-3] The end of life decisions were classified on the basis of three questions: what did the physician do? what was the physician's intention? and did the patient request this end of life decision? If, for example, the physician had administered a drug with the explicit purpose of ending the patient's life at the patient's explicit request this decision was classified as euthanasia (studies II and III). In the interview study we could use the term euthanasia because in that setting apparent misconceptions about the definition generally used in the Netherlands could be corrected.[5]

INTERVIEW STUDY (STUDY I)

We interviewed a stratified random sample of physicians who had practised in their current job for at least two years. Stratification was according to type of specialty. In all we invited 447 physicians, but 41 (9%) refused to participate, mainly because of lack of time (an interview lasted 2½ hours on average). One interview, however, yielded useless information. Hence only 405 respondents remained. Of the 405 physicians interviewed, 152 were general practitioners, 50 were doctors in nursing homes, and 203 were hospital

doctors (cardiologists, surgeons, internists, pulmonologists, and neurologists). For each type of decision the physician was asked if he or she had ever made such a decision. If so, we asked detailed questions about characteristics of the patient and the decision.

DEATH CERTIFICATE STUDY (STUDY II)

In the Netherlands all deaths are reported to Statistics Netherlands. A stratified sample of death certificates was studied for the period August to November 1990. Stratification was based on the probability that an end of life decision had been made. So the forms detailing cause of death for all 41 587 deaths that occurred during this period were examined by two physicians and assigned to one of five groups. When the cause of death precluded the possibility of any kind of end of life decision—for example, a road traffic accident resulting in instant death—the case was assigned to group 0 and no questionnaire was sent. When the chance of an end of life decision was thought to be high—for example, in most deaths from cancer—the case was classified into group 4. There were six times as many cases in group 4 as there were in group 1 (0·5% and 0·083%, respectively).

Of all deaths in the study period, 6942 cases were drawn. Of these, 299 belonged to group O. Anonymous questionnaires were sent to the attending physicians in the 6643 cases in groups 1 to 4. Of these 5038 (76%) were returned. Our results are based on 5197 cases. The physician was asked if an end of life decision had been made. If so further questions were asked. If more than one end of life decision had been made the questions concerned only the most important decision. If, for example, a decision not to treat had been made and (later on) euthanasia was performed the most important end of life decision was euthanasia, and further questions concerned euthanasia rather than the decision not to treat.

A weighting procedure was applied to derive valid estimates for the whole population of dead people. The weights were derived after subdivision of the sample according to place of death, cause of death, age, and sex.[3]

PROSPECTIVE STUDY (STUDY III)

All interviewees of study I were asked to participate in a prospective study and 324 (80%) agreed. For all patients who died in the six months after study I and for whom the interviewees had been the attending physician they filled in the same questionnaire as used in study II. A total of 2257 deaths were described.

The best basis for quantitative estimates is study II because of the greater number of deaths and the sampling method, which was based on individual deaths. Results of the other studies are mentioned if they differed notably from those in study II or if they contained relevant extra information not available from study II.

TABLE I—*Age, sex, and diagnosis of dead patients, according to type of physician (study II). Values are percentages (numbers)* **

Variables of patients	General practitioners (n=2356)	Hospital doctors (n=1766)	Doctor in nursing homes (n=986)	Total (n=5108)
Age (years):				
0-49	7 (145)	10 (164)	1 (16)	7 (325)
50-64	16 (430)	16 (314)	3 (40)	14 (784)
65-79	35 (860)	44 (807)	30 (311)	38 (1978)
⩾80	43 (921)	30 (481)	65 (619)	41 (2021)
Male sex	54 (1280)	55 (963)	37 (363)	51 (2606)
Diagnosis:				
Cancer	36 (1196)	29 (755)	17 (215)	30 (2166)
Cardiovascular diseases	34 (544)	33 (383)	19 (165)	31 (1092)
Diseases of nervous system	8 (177)	11 (171)	23 (216)	12 (564)
Diseases of pulmonary system	6 (132)	7 (117)	14 (127)	8 (376)
Other diseases	16 (307)	20 (340)	27 (263)	19 (910)

*Percentages are based on weighted data, so cannot be calculated directly from absolute numbers.

TABLE II—*Decisions about the end of life in cases of patients who did not die suddenly according to type of physician (study II). Values are percentages (numbers)* **

Decision	General practitioners	Hospital doctors	Doctors in nursing homes	Total
Pain relief	28 (528)	25 (392)	29 (244)	27 (1164)
Non-treatment	20 (324)	25 (339)	38 (324)	26 (987)
Euthanasia or assisted suicide	5·1 (114)	1·8 (40)	0·2 (3)	2·7 (157)
Life terminating acts without explicit request	0·8 (16)	1·9 (28)	0·3 (2)	1·2 (46)
No decision	46 (755)	46 (615)	33 (270)	44 (1640)
Total	100 (1737)	100 (1414)	100 (843)	100 (3994)

*Percentages are based on weighted data, so cannot be calculated directly from absolute numbers.

TABLE III—*Reasons for not discussing decisions about pain relief or non-treatment with patient,* * *according to type of physician (study II). Values are percentages (numbers)* †

Reason	General practitioners (n=361)	Hospital doctors (n=360)	Doctors in nursing homes (n=398)	Total (n=1119)
1 Diminished consciousness	65 (227)	80 (285)	53 (204)	67 (716)
2 Dementia	20 (62)	8 (27)	60 (237)	29 (326)
3 Clearly best for patient	34 (129)	18 (72)	13 (53)	21 (254)
4 Would have done more harm than good	11 (42)	6 (22)	4 (15)	6 (79)
3 or 4 only	20 (85)	10 (38)	4 (16)	11 (139)

*More than one answer possible.
†Percentages are based on weighted data, so cannot be calculated directly from absolute numbers.

Results

In 1990 about 129 000 deaths occurred in the Netherlands: 42% at home, 41% in hospital, and 16% in nursing homes. Given the total number of physicians per specialty, the yearly average of deaths was nine for general practitioners, 16 for hospital doctors, and 33 for doctors in nursing homes. Table I shows some characteristics of patients according to the type of attending doctor. The mean age of patients who died in general practice was 74 years, in hospital 71 years, and in nursing homes 81 years. Cancer was the most common diagnosis in patients dying at home. Cardiovascular diseases and diseases of the nervous system, including stroke, were the most common causes in hospital and nursing homes, respectively.

General practitioners took fewer end of life decisions than hospital doctors and doctors in nursing homes (34%, 40%, and 56% of all dying patients, respectively). This difference was mostly because of a larger proportion of sudden deaths in general practice. If sudden deaths were excluded from the denominator, the numbers were 54%, 54%, and 67%, respectively. Table II presents the distribution of end of life decisions made for each type of physician (excluding sudden deaths). Decisions about pain relief and non-treatment were commonly made by all physicians. The withholding of antibiotics and no (further) diagnosis were the non-treatment decisions most often made in general practice (study I). In 1990, three end of life decisions were made for each general practitioner, six for each hospital doctor, and 18 for each doctor in a nursing home. However, general practitioners performed euthanasia or assisted suicide three times more often than the other physicians. This would imply one case of euthanasia or assisted suicide every three years for general practitioners, once in four years for clinicians, and once in 14 years for doctors in nursing homes.

Pain relief or decisions not to treat, or both, were not discussed with the patient in over half (54%) of the cases in general practice. In such cases the family was involved in over half of them.

Table III shows the reasons for not discussing these decisions with the patient. In most cases this was related to the incapacity of the patient because of diminished consciousness or dementia. In a fifth of

TABLE IV—*Relation between general practitioner's discussion with patient about end of life decision and selected characteristics of patients and physicians (study III)*

Characteristic	% Of general practitioners who discussed decision with patient
Age of patient (years)***:	
<80 (n=112)	66
≥80 (n=70)	40
Competence of patient***:	
Competent or competence uncertain (n=122)†	80
Not competent (n=58)‡	9
Consultation with colleague***:	
Yes (n=76)	84
No (n=104)	36
How long life was shortened (weeks)	
<1 (n=127)	47
≥1 (n=53)	79
Age of general practitioner (years)**:	
<50 (n=129)	64
≥50 (n=53)	38
General practitioner religious:	
Yes (n=75)	45
No (n=105)	64
Size of practice*:	
<2500 (n=115)	63
≥2500 (n=67)	45

***P<0·001; **0·001<P<0·01; *0·01<P<0·05 on χ^2 test.
†In cases in which competence was uncertain researchers were not able to establish competence of patient from answers because answer on question "Why was the decision not discussed with the patient" was in most instances "this end of life decision was clearly the best for the patient" or "discussion would have done more harm than good."
‡Discussion with patient must have taken place before patient became incompetent.

TABLE V—*Relation between general practitioners' consultation with colleagues about decision about end of life and selected characteristics of patients and physicians (study III)*

Characteristic	% Of general practitioners who discussed decision with colleague
Age patient (years)***:	
<80 (n=111)	57
≥80 (n=69)	19
Competence of patient***:	
Competent or competence uncertain (n=120)†	54
Not competent (n=58)‡	19
Discussion with patient***:	
Yes (n=101)	63
No (n=79)	15
How long life was shortened (weeks)***:	
<1 (n=125)	33
≥1 (n=53)	64
Size of practice*:	
<2500 (n=115)	49
≥2500 (n=65)	31
Type of practice*:	
Singlehanded (n=102)	34
Other (n=78)	53

***P<0·001; **0·001<P<0·01; *0·01<P<0·05 on χ^2 test.
†In cases in which competence was uncertain researchers were not able to establish competence of patient from answers because answer on question "Why was the decision not dicussed with the patient" was in most instances "this end of life decision was clearly the best for the patient" or "discussion would have done more harm than good."
‡Discussion with patient must have taken place before patient became incompetent.

cases the general practitioners answered that they had not discussed the deccision because they considered it as the best for the patient or because a discussion would have done more harm than good. From here on these reasons are called "paternalistic," which is meant here to be a neutral term rather than a pejorative term.

Tables IV and V present the characteristics of patients and physicians that were significantly related to the proportion of patients or colleagues with whom the general practitioner had discussed an end of life decision. (Tables IV and V are based on results from study III because it contained background information on the physicians, which was not available in study II). No significant relations were found with sex of patient or of general practitioner, type of practice (singlehanded or other), region, and degree of urbanisation. Logistic regression analysis showed that the competence of the patient, consultation with a colleague, shortening life by more than one week, and the general practitioner being under 50 were all significantly and independently associated with the proportion of patients with whom the decision had been discussed.

The consultation of a colleague was significantly ($P<0·05$) related to the characteristics mentioned in table V (data from study III). Logistic regression analysis showed that discussion with the patient, younger age of the patient, shortening life by more than one week, and working in group practice were all significantly and independently associated with the proportion of decisions in which a colleague had been consulted.

Discussion

In the Netherlands other investigators have found similar estimates for the incidence of euthanasia or assisted suicide in general practice and in nursing homes.[6] They have not, however, studied other end of life decisions. The strength of our research lies in the high response rate in the three studies. The fact that the research data used for analysis were completely anonymous and immunity against legal prosecution based on the data was guaranteed, strengthens our conviction that the physicians answered honestly and that no serious biases exist in the material.

DECISIONS BASED ON TRUST

The number and kind of end of life decisions in general practice differed from those in hospital practice. A higher proportion of sudden deaths in general practice reduces the possibilty or necessity of making end of life decisions such as the relief of pain or symptoms with opioids and the withholding or withdrawal of treatment. Euthanasia or assisted suicide, however, is performed three times more often in general practice than in other practices. We attribute this difference to the generally long standing relationship between patient and physician in general practice. This forms the basis for sufficient mutual trust, which is needed in order to ask for and perform euthanasia.[7] In the Netherlands there is a strongly developed system of primary care.[8] Virtually everyone has his or her own general practitioner. Patients change their general practitioner only when they move to another area in most cases. Another explanation may be that terminally ill patients who are able to request euthanasia also strongly prefer to die at home. In the inteview study (study I) we found that of the patients who obtained euthanasia at home, 79% had chosen to die there and of those who obtained euthanasia in hospital, 45% had chosen to die there.

The longstanding relationship between patient and general practitioner could also be one of the reasons for the relatively large proportion of "paternalistic" reasons for not discussing the decisions about pain relief or non-treatment with patients. General practitioners are in general more familiar with the backgrounds of their patients, with the patients' relatives, and with the patients' past and present illnesses. This is perhaps why they more easily assume that they know what is best for the patient or that they will harm the patient by discussing these subjects. This paternalistic approach conflicts with the principle of autonomy.[9,10]

In different countries general practitioners have different opinions about the optimum balance between beneficence and autonomy; more general practitioners than in the United States or Britain choose to share information with patients about difficult medical decisions.[11] As we have said, paternalistic in this context does not necessarily have a negative connotation. In some cases of terminally ill patients dying at home

Practice implications

- In the Netherlands general practitioners make decisions about the end of life with the probable effect of shortening life in over half of their terminally ill patients (excluding those who die suddenly)
- The patient is involved in the decision making process in about half of these cases. In about 40% this is not possible because of diminished consciousness or dementia, while in about 10% the patient is not involved for "paternalistic reasons"
- General practitioners working in single practice consult a colleague less often about decisions about the end of life than do those working in group practice
- Decisions about the end of life will become even more important in general practice. More formal training is required

there is probably a tacit understanding between doctor and patient not to go on with treatment until death. Thus the decision not to give antibiotics to a patient in the final stages of lung cancer might have to be taken more explicitly in hospital than at home. One should, however, be cautious with this type of reasoning.

Younger general practitioners discuss end of life decisions more often with the patient, which could imply that in the future open discussion with the patient will be seen as more a matter of course.[12 13]

The strong positive association between the consultation of a colleague and whether the decision was discussed with the patient might reflect differences in the attitudes of physicians and also differences in how difficult the decision was to make.

Conclusions

We conclude that differences in work situation between general practitioners and hospital doctors and differences between individual general practitioners contribute to differences in the number and type of end of life decisions as well as in the decision making process.

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A DOCTOR WHO CHANGED MY PRACTICE

Roundshot in the meadow

Five years in urban practice had been difficult. There had been an unprovoked assault by an aggressive patient in a dark Bradford alley. The incident was never forgotten and I became proficient at judo. I was determined that I would never be caught so unprepared again. I gradually realised that my outlook had changed and after reading a book by Lewis Mumford on rural life I took a locum in a remote village. Perhaps this would be what I needed.

The doctor greeted us in his farmhouse. There would, he said, be no rush to start work. Next day, weather permitting, he planned to hold a shoot. Noticing my surprise, he took me to a large shed where inside, sleek and black on its carriage, was a ship's cannon of Nelson's day. Adjacent were cannon balls, ramrod, sponge, and a keg of powder. I was astonished and gaped at his arsenal.

"What do you shoot at?" I asked, trying not to sound surprised.

"The odd tree will do, but telegraph poles are much more fun." He pointed to a row that flanked a nearby meadow. "Not that they're easy to hit at this range," he confided seriously. "But if you do it's very satisfying. They split and come down snapping their wires." He smiled broadly.

"What about people using the lane? Doesn't the post office object? Surely people hear the gunfire."

"Folks round here mind their own business; anyway, we check the lane's empty first," he said nonchalantly. "The post office always puts up a new pole, they haven't figured it out yet. Perhaps they think that wet weather rots the poles." He laughed, looking westward in anticipation.

I was excited and amazed. I was certainly no innocent myself having made a variety of explosives at school, once even using tear gas which resulted in a partial evacuation. I had also made a breech loading cannon with quite a range. The doctor's gun, however, was superior to mine. Built to dismast a ship it would bring down any telegraph pole. I could visualise the scene, black billowing smoke, thunderous bangs, splinters flying as plunging shot wracked the post office's timbers. Such an opportunity would not come again.

The euphoria soon began to pass. This was going to be no rural retreat. No restoration of serenity could be expected here. I recognised some of my own darker side in the doctor and I became increasingly uneasy. My wife and I talked far into the night and decided to leave early next morning, a belated note of apology on the kitchen table. We passed the same row of telegraph poles, half expecting the whack of an incoming round.

This experience left us more unsettled and we took an immediate unplanned holiday in Austria. Within three months of returning we had left for Canada and a new life.

A few years later I read of the doctor's death in the *BMJ*. He had died following an explosion. I could see it all so clearly. Perhaps he had mixed black powder in a rush; perhaps his gun barrel had burst. I realised for the first time that I had met the doctor at a personal crossroad and he had nudged us towards a different path.

I still think of him, hand on cannon, looking for a target.—COLIN CHANDLER *is a general practitioner in Calgary, Canada*