End-of-life decisions in Dutch medical practice

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End-of-life decisions in Dutch medical practice

Beslissingen rond het levenseinde in de Nederlandse medische praktijk

Proefschrift

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Publications

Chapters 3-12 are based on the following (published, accepted, or submitted) articles:

3 Euthanasia and other medical decisions concerning the end of life. Van der Maas PJ, Van Delden JJM, Pijnenborg L, Looman CWN. Lancet 1991;338:669-74.

4 Dances with data. Reports from the Netherlands. Van Delden JJM, Pijnenborg L, Van der Maas PJ. Bioethics 1993;7:323-9.

5 Withdrawal or withholding of treatment at the end of life. Pijnenborg L, Van der Maas PJ, Kardaun JWPF, Glerum JJ, Van Delden JJM, Looman CWN. Arch Intern Med 1995;155:286-92.

6 Medical decisions at the end of life in cancer patients. Pijnenborg L, Glerum JJ, Kardaun JWPF, Van Delden JJM, Van der Maas PJ. (submitted).

7 Euthanasie en andere medische beslissingen rond het levenseinde in Nederland. II. Zorgvuldigheid en melding. Van der Maas PJ, Van Delden JJM, Pijnenborg L. Ned Tijdschr Geneeskd 1991;135:2082-8.

8 Life-terminating acts without explicit request of patient. Pijnenborg L, Van der Maas PJ, Van Delden JJM, Looman CWN. Lancet 1993;341:1196-9.

9 Nationwide study of decisions concerning the end of life in general practice in the Netherlands. Pijnenborg L, Van Delden JJM, Kardaun JWPF, Glerum JJ, Van der Maas PJ. BMJ 1994;309:1209-12.

10 Euthanasia: physicians' attitudes and practices. Pijnenborg L, Looman CWN, Van der Maas PJ. (submitted).

11 Changes in Dutch opinions on active euthanasia, 1966 through 1991. Van der Maas PJ, Pijnenborg L, Van Delden JJM. JAMA 1995 (in press).

12 The Dutch euthanasia debate in international perspective. Pijnenborg L, Van der Maas PJ. (submitted).

Part I
Objective and design

1 Introduction

1.1 Background

In the end, death comes to us all. This reality has not changed during centuries of attempting to unravel the mysteries of life and death. Even today, death is the most unescapable event in each human life. Life and time before death, however, have altered considerably. At least two changes are responsible for this.

The first is that, over the past hundred and fifty years, man has succeeded in changing his condition in such a way that, in the well developed countries, average life expectancy has doubled.[1] The strongly reduced perinatal and infant mortality have caused death to disappear almost completely from daily life in the Netherlands.[2]

A second important development is of much more recent date, basically dating only from after World War II: the development of modern medicine. Medical practice today is increasingly able to assist in curing the sick, in making life bearable for the sick and extending life for a shorter or longer period of time. In other words: death still comes to everyone, but the time at which this happens is often partly determined by decisions whether to stop or to continue treatment.

Obviously, this does not hold for all deaths. People still die from accidents or from acute fatal diseases such as acute myocardial infarction. In all non-sudden deaths, however, patient and physician are involved in a shorter or longer disease process. A considerable difference compared with the situation existing over one hundred years ago, when in some municipalities more than half of all deceased had no physician's assistance during their preceding disease.[3] Now that medicine can offer so much in terms of prolonging life and relieving suffering, the physician's task at the end of life is expanding. In the past, this task primarily involved the provision of terminal care. Increasingly, decision-making by the physician is among the medical responsibilities at the end of life.

1.2 Definition and type of end-of-life decisions

The term 'end-of-life decision' as used in this thesis covers all decisions by physicians concerning actions aimed at hastening death or actions for which the physician takes into account the probability that the end of the patient's life will be hastened. The actions concerned are: withdrawing or withholding of (possibly) life-prolonging treatment and administering, supplying or prescribing of (possibly) lethal drugs.

This thesis does not deal with:

- complications of medical interventions or 'errors' that carry no intent to hasten the end of the patient's life at all;
- other end-of-life decisions, e.g. concerning the care of the patient, the possibility of allowing the patient to die at home, and all usual medical interventions where (possible) hastening of the end of life is not under consideration.

The scope of this thesis encompasses the following end-of-life decisions: (The reasons for selecting this approach are discussed in detail in chapter 2.)

1 *Non-treatment decisions*, the withholding or withdrawal of treatment in situations where the treatment would probably have prolonged life.

2 *Alleviation of pain and symptoms* with opioids in such dosages that the patient's life might have been shortened.

3 *Euthanasia and physician-assisted suicide*, the prescription, supply or administration of drugs with the explicit intention to shortening life at the patient's explicit request.

4 *Life-terminating acts without the patient's explicit request.*

The term 'euthanasia' is used according to its accepted definition in the Netherlands, defined as the purposeful acting to terminate life by a person other than the person concerned upon request of the latter.[4] In this thesis, the physician is the acting person. Physician-assisted suicide is defined as the purposeful assisting of the person concerned to terminate life upon request of the latter.

The anticipatory decision not to resuscitate has already been discussed in the thesis of Van Delden.[5]

For those readers who are not familiar with cases of end-of-life decisions, examples are given below. Obviously, the four cases discussed do not represent the whole spectrum of end-of-life decisions.

Non-treatment decision

A 85 year-old woman was suffering from dementia in a terminal stage, and from foot gangrene. She was a resident of a nursing-home. Because of problems with swallowing, she had tube feeding. This regularly gave rise to complications, such as pneumonia. When another bout of pneumonia developed, the nursing-home physician decided, after consulting with the two daughters, not to administer any further antibiotics. The main reason for the decision was the poor quality of life. The physician regarded any further prolongation of life as being against the expected wish of the patient.

Alleviation of pain and symptoms with opioids
A 67 year-old terminally ill man with lung cancer and bone metastases, resulting in fractures of the vertebrae. Pain could be alleviated to a reasonable extent. The fact that increasing the dosage of opioids could shorten the patient's life was taken into account by the lung specialist. She had never specifically discussed matters such as hastening the end of life with the patient. However, she had told the patient that she would put an end to the suffering.

Afterwards, the physician estimated that intensifying the morphine had shortened life by a few hours or days. In her opinion, the patient had died of his illness.

Euthanasia
A 61 year-old woman was suffering from multiple sclerosis. She had had many discussions with her general practitioner, whom she had known for more than ten years, about her last stage of life and the expected difficulties. The physician had promised her that if her situation became unbearable, she would help her. Later on, when her breathing got worse, she explicitly asked her doctor for euthanasia. Her husband totally agreed with her decision. Another physician was consulted to reconfirm that all guidelines for euthanasia were fulfilled. The general practitioner then gave her some sedative and, when she felt quietly asleep, an injection of a muscle relaxant. She died one hour after administration of the sedative. The physician estimated that her life had been shortened by one or two weeks. Both her husband and the general practitioner were satisfied that she had died so peacefully.

Life-terminating act without the patient's explicit request
A 73 year-old man in a terminal stage of prostate cancer, with widespread bone metastases, decubitus and cachexia. The clinician had known the patient for three years. At first the pain could be alleviated with opioids, but this became more and more difficult. During the doctor's visits the patient had repeatedly stated that he wanted 'everything to be finished' if his situation became degrading or the suffering unbearable. The patient's consciousness deteriorated rapidly, before this was able to develop into an explicit request for life termination. His physical condition also worsened: the decubitus became very extensive and pain could not be alleviated sufficiently. After discussing the decision with a colleague, a nurse, and the son, the physician decided to administer a very high dosage of opioids, in order to shorten life.

An hour after this was administered, the patient died. In the doctor's estimation, life had been shortened by one week at the most. The main reasons for his decision were the degrading situation and the patient's suffering, the futility of further treatment, the absence of any chance of improvement and the earlier expressed wish. According to the physician, the patient's wish certainly referred to such a situation. The physician felt that his action had contributed to the quality of the end of life for this patient.

1.3 Objective of this thesis

As stated in the beginning, decision-making at the end of a patient's life is increasingly becoming one of the medical responsibilities of the physician. This is partly due to the fact that the medical technologies have developed considerably, and to the increase of chronic diseases in an ageing population. The purpose of this thesis is to explore the whole field of end-of-life decisions in medical practice, primarily seen from the physician's point of view. Empirical information on this subject is scarce. Until recently, more attention has been paid to the ethical debate around end-of-life decisions than to quantification.

The objective can be divided into four parts:

1 Quantification of end-of-life decisions

First, the incidence of end-of-life decisions in the Netherlands will be given. The characteristics of the decision-making process will be described with a focus on euthanasia (chapter 3). The discussion on the true incidence of euthanasia will be evaluated (chapter 4).

2 Description of the background of end-of-life decisions

In the next four chapters the end-of-life decisions will be discussed in more detail (chapter 5 to 8). Special attention will be paid to terminal cancer patients, and to the carefulness of the decision-making process.

3 Analysis of the role of the physician in end-of-life decisions

The two following chapters will further explore the physician's role in the end-of-life decision-making process (chapters 9 and 10). Do physicians of different specialties differ in their decision-making? Are there (also) differences within one specialty, with the general practitioners as example? And in what aspect do physicians who have ever performed euthanasia differ from those who have never performed it?

4 Exploration of the socio-historical perspective on euthanasia

The view will then be broadened to society (chapter 11 and 12): How has public opinion on euthanasia developed during the last decades? Why does the discussion in the Netherlands and/or the practice concerning euthanasia differ from other well developed countries? Although the focus of this study is on euthanasia, other end-of-life decisions inevitably also come under review.

In the last chapter, attention will be paid to the implication of the study for the attending physicians, and for the international debate (chapter 13). Ideally, a protocol for all end-of-life decisions would have been made. However, a general protocol to be applied in medical practice to e.g. all 'non-treatment decisions' is nearly impossible, since 'stopping antibiotics' and 'stopping artificial respiration' deserve quite different attention. Nevertheless, several general recommendations for a careful decision-making process in end-of-life decisions can and will be given.

1.4 Relation between this thesis and the Remmelink study

Although many readers will be more or less familiar with the 'Remmelink study', some background information should be provided before explaining the relationship between this thesis and the Remmelink study.

From the mid 1980s on, one of the central questions in Dutch political debate was whether euthanasia should be legalized, as proposed by some members of the Dutch parliament and by the State Commission or should remain a criminal act in principle, but with clear rules about when not to prosecute. This was possible, because under Dutch criminal law an illegal act need not always be prosecuted (see chapter 12).

The coalition government of the Christian Democratics and the Social Democrats that took office in 1989 decided to postpone the decision. In their coalition agreement they stated that a Commission was to be formed that would report on the 'extent and nature of medical euthanasia practice, based on the thought that there is no insight into the extent and nature of this practice'. This was done by the appointment on January, 1990 of the 'Commission of Inquiry into the Medical Practice concerning Euthanasia' by the Minister of Justice and the State Secretary of Welfare, Health and Culture. The Commission, chaired by Mr. Remmelink, at that time attorney general of the Dutch Supreme Court, was charged with reporting on the state of affairs with respect to the practice of performing an act or omission by a physician to terminate life of a patient, with or without an explicit and serious request of the patient. To perform its task, the Commission assigned the Department of Public Health of the Erasmus University Rotterdam to do an investigation. It contained three studies, together generally referred to as the 'Remmelink study'.

The first results were published fourteen months after the beginning of the investigation in a Dutch report as well as in an English version.[6,7] Only a fraction of the enormous amount of the information gained was used at that time. Most of the information in this thesis stems from the Remmelink study.

What does this thesis add to the Remmelink study report? Three answers can be given: more time, different perspective, and more material. The Remmelink study had to be carried out in an extremely short time. The present thesis allowed more time for a thorough analysis of the information on end-of-life decisions, for reading more literature, and for reflecting on the reactions to the Remmelink study after this was published. These items formed the basis for the next point: different perspective. In the Remmelink study, a description of end-of-life decisions was given per study. Integration of the results took place only in the concluding chapters. Furthermore, it only contained simple frequency tables, without showing interrelations.

This thesis is focused mainly on the different types of end-of-life decisions. For a final description and interpretation, material from all three studies has been integrated. The aim is to get closer to medical practice. Thus, all useful information available for an end-of-life decision such as 'non-treatment' will be brought together; detailed analysis will be done; the information will be described and explained; and finally, an attempt will be made to provide recommendations for improving the decision-making process.

Aside from the material from the Remmelink study, additional material has also been used, especially in chapters 11 and 12. However, the most important difference between this thesis and the Remmelink study is that not only could more or less objective conclusions be drawn, interpretations and recommendations could also be included, which was not the purpose of the researchers at the time the Remmelink study was compiled.

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2 Concepts and methods

In chapter 1, we mentioned the four types of end-of-life decisions. In this chapter, the concepts used to derive this classification will be discussed. Subsequently, the design of the study will be described.

2.1 Classification of end-of-life decisions

The decisions we intended to study were classified on the basis of three important questions:

1. What did the physician do?
2. What was the physician's intention in doing this?
3. Did the patient request this end-of-life decision?

2.1.1 What did the physician do?

This classification provides for a choice of three interventions on the part of the physician: either to withhold or to withdraw a (possibly) life-prolonging treatment, or to administer drugs that (possibly) hasten the end of life. Combinations of these interventions will frequently occur. If the aim is to shorten life by administering drugs, it is obvious that life-prolonging treatments will be withdrawn or withheld. Terminating a life-prolonging treatment can sometimes lead to the administration of possibly life-shortening drugs.

Persons other than the physician can be of importance. Self-administration by the patient of a drug prescribed or provided by the physician is a case of physician-assisted suicide. Persons other than the patient or physician can also administer such a substance, e.g. nurses or close relatives. Euthanasia in which exclusively persons other than the physician perform the actual intervention is only considered in this investigation if the substance used was prescribed or provided by the physician for this explicit purpose.

2.1.2 The physician's intention

This concept is one which is both complex and difficult to come to grips with in this investigation. It will be discussed here in general terms only.

It may be assumed that termination of life can never be the most important aim in the interaction between physician and patient. If a physician deliberately performs actions that shorten the patient's life it can be argued that, in the final analysis, termination of the patient's suffering is intended and that under certain circumstances, also according to the physician's judgement, this suffering is unable to be terminated in any way other than the termination of life.

In this investigation, the material bearing upon the intention of the physician was broken down into three categories:
- (acting with) the explicit purpose of hastening the end of life;
- (acting) partly with the purpose of hastening the end of life;
- (acting while) taking into account the probability that the end of life will be hastened.

The first and third categories can be distinguished clearly. If a physician administers a drug, withdraws a treatment or withholds one with the explicit purpose of hastening the end of life, then the intended outcome of that action is the end of the patient's life. This is not the case if the action is performed while taking into account the probability that this action will hasten the end of the patient's life. The possible subsequent death was not intended.

This distinction of two major categories still does not solve the difficulty that many physicians cannot always indicate what their intention actually had been in a specific case. Sometimes an intervention is performed to achieve one particular effect (e.g., pain relief) but the side-effect (e.g., death) is not unwelcome. Strictly speaking, this situation should be categorised as intentional intervention. In order to be considered unintentional, this side-effect should in fact not have been desired. This strict interpretation could not be adhered to when the questionnaire was constructed due to the fact that occasions arose in which, in the physician's opinion, neither description was able to do justice to his intention. We therefore allowed for the third category '(acting) partly with the purpose of hastening the end of life'. This description refers to a situation in which the patient's death was not foremost in the physician's mind, yet neither was it unwelcome. This type of intention was included specifically in the questionnaire for the alleviation of pain or symptoms.

2.1.3 The patient's wish

The patient's request is crucial for the discussion of end-of-life decisions. The (explicit) request of the patient even forms part of the definition of euthanasia[1-3] as used in current language of Dutch public health law. The term euthanasia is appropriate only once the patient requests an intervention to terminate life, perhaps making this request by means of a written advance directive. The patient's wish is also important if a medical intervention is not carried out. As permission is needed for all medical interventions, refusal by the patient implies that these may not be carried out.

However, the patient's request must meet certain requirements, all the more if it concerns a request for euthanasia. The 1987 draft law on euthanasia mentions 'a request made and adhered to voluntarily and after careful consideration'. The board of the Royal Dutch Medical Association included in their position on euthanasia the term 'explicit' in the definition of euthanasia. Moreover, the board gave a long-standing desire to die as one of the rules of due care.[1] In agreement with the foregoing the concept 'explicit request' is used as the dividing line.

2.1.4 The patient's judgement

In addition to the definition of the manner of acting and of the request, the concept of a patient who is unable to make a decision plays an important role in our classification. This is a difficult concept because there is as yet little agreement on the criteria applying in respect of the inability to take a decision.[4] A well-known legal definition is that someone is unable to make a decision if he is not able to reasonably appreciate his interests (preliminary draft law on surrogate decision-making), but we consider this definition less suitable for our purposes. Based on the available (mainly Anglo-Saxon) literature the concept of 'being able to make a decision' has been defined as 'able to appreciate the nature of (assess) the situation so as to reach a decision adequately'. It should be emphasised that this description gives no criterion as to the outcome of the decision but does so only for the process of arriving at the decision. Neither does it pass judgement on the patient's other abilities.

2.1.5 Extent of shortening of life

The concepts 'terminal phase' or 'concrete expectancy of death' played an important role in the discussion of euthanasia in the Netherlands. There was great resistance against the use of this concept as criterion for the admissibility of euthanasia. This, however, does not imply that such a concept would not be of importance in making of a decision. This is an important consideration, particularly for physicians.

To avoid the use of these two controversial concepts, the relevant question in this investigation asked instead the length of time by which, in the physician's opinion, the patient's life had in fact been shortened by the action taken. This question was answered in most instances, both during the interviews and in the standard questionnaire, albeit with some uncertainty.

There is no doubt that any estimate of the extent to which life was shortened can be only very general. In practice physicians are very reluctant to give an estimate of the length of time the patient may be expected to live. The estimates of the extent to which life was shortened as reported in this investigation certainly have no absolute value and should be interpreted with the greatest of caution. If, however, in a large number of cases the physicians indicated that life was shortened by a maximum of hours or days, the cautious assumption can be made that the patient was dying. If, in another type of decision, physicians indicated that life was shortened by weeks or months, it may be assumed that seriously ill patients were involved who were not yet dying.

2.2 Study design

2.2.1 Estimates

The primary goal of the three studies reported on here was to describe the current practice of end-of-life decisions in the Netherlands in quantitative terms. Therefore, much effort went into devising a study design that would give reliable estimates of the frequency of these decisions in medical practice. The degree of reliability of estimates is not only important for answering questions about numbers of cases of euthanasia and other important decisions. It is at least as important to clarify what are common situations and what are exceptions. Moreover, apart from sufficient numbers to get reliable estimates of frequency, sufficient in-depth knowledge was needed.

To record the numbers of end-of-life decisions it is essential to obtain reliable estimates of the total number of deaths connected with these decisions. For instance, physicians can be asked whether they have ever performed euthanasia and, if so, how often this has happened in the past two years. However, in order to present an estimate for the whole of the Netherlands, it is essential to know, out of the total number of deaths, the percentage on which the physicians' statements in the sample are based. This latter information cannot always be obtained.

It follows that the next step is to take a clearly defined sample from the total number of deaths occurring in the Netherlands within a given period of time and to discover whether euthanasia or other important end-of-life decisions played a major role. A minimum of several thousand deaths should be studied to obtain a sufficiently large number of important end-of-life decisions.

To enable detailed and profound interviews to be held with physicians and to be able to take a sample of several thousand deaths, this investigation was split into three part-studies.

I A sample was drawn from a population of physicians, to be defined further. These physicians were approached and asked to participate in an interview (retrospective study, physician interviews).

II A sample was drawn from all deaths in the Netherlands within several months and the attending physician was asked to supply a limited amount of data about this death. The resulting death certificate study was performed by Statistics Netherlands.

III The physicians who had been interviewed (study I) were also asked to record a small amount of data on any death occurring in the subsequent six months in which they would be the attending physician. This constituted the prospective study.

The fact that three studies were performed implied that there were three estimates, whether or not different, given in response to each of the questions to be compared. Ideally, the decision as to which estimate is the most plausible would be made based on the validity of the study and of the question. This was indeed the method applied with respect to the incidences of the various end-of-life decisions. As far as the further sub-divisions were concerned the following was decided. The best basis for quantitative estimates would be study II, with its representative sample of recent deaths. Generally, the numbers from that study will be mentioned. The figures from study III will only be mentioned if estimates differ markedly from study II. Study I will be used to give further details that are not available in studies II or III.

A detailed justification of the estimates can be found in appendix E of the first study report.[5]

2.2.2 Retrospective study: physician interviews (study I)

A sample was drawn from general practitioners, nursing home physicians and clinicians practising in the Netherlands, the latter to the extent to which they are involved regularly in problems related to end-of-life decisions. The specialties involved were: internal medicine, pulmonology, cardiology, neurology and surgery. 89% of all hospital deaths fall under these specialties. As nearly one half of all deaths occur in hospitals and non-hospital deaths are almost 100% covered by general practitioners and nursing home physicians, this approach to selection of physicians covered about 95% of all death cases. Information about the 5% thus excluded was obtained from the death certificate study and from discussions with some experts mentioned below.

Addresses were selected from existing registries. These registries are complete as far as names of physicians are concerned. The selection criterion was that respondents had practised medicine in the registered field and at the same place for at least two years. We had to draw a sample of 599 addresses in order to reach the number of interviews envisaged. Of this sample, 138 persons failed to satisfy the selection criterion (the registry did not always contain sufficient information). A further 14 were not interviewed because the address proved to be wrong and they proved impossible to trace. Of the remaining 447 physicians, 41 (9%) refused to partake in the study. One interview yielded useless information. This means that of the invited physicians 91% participated: 152 general practitioners, 203 clinicians and 50 nursing-home physicians.

The interviews were conducted by 30 experienced physicians and 5 academics from other disciplines who were abreast of developments in health care, in the period from October 1990 to February 1991. The interviewers all underwent an intensive training. The mean duration of the interviews was 2½ hours.

To extrapolate the results to the total number of deaths in the Netherlands weights were derived, taking into account the stratification of the sample and the non-response rate. Selection effects due to the sampling procedure and non-response could not be found. Thus, we consider the results of this study to be representative for the Dutch physicians from the disciplines sampled. The incidence estimates given below are corrected for the 11% hospital deaths that remain 'invisible' with this sampling procedure.

The interview questionnaire contained 122 pages. Items of the interview included:

- characteristics of the physician, such as specialty, type of practice, religion;
- requests for euthanasia and physician-assisted suicide involving the physician in the period just elapsed;
- considerations about acceding or not to this kind of request in relation to its medical, social and legal context;
- other relevant situations in which decisions as to performing life-terminating acts or omissions were taken (to withdraw or withhold life prolonging treatment);
- factual examples of situations in which the physician took an end-of-life decision (the last performed case of each type of end-of-life decision);
- wishes concerning the nature and contents of regulations concerning euthanasia and other acts terminating life;
- considerations, in relevant cases, as to reporting or not reporting in the death certificate that a non-natural death was involved;
- one case-report worked out by the interviewer on the most illustrative end-of-life decision arising during the interview.

In the interviews the term euthanasia was used because in that setting apparent misconceptions could be corrected. In the next two studies this was not the case.

2.2.3 The death certificate sample (study II)

To strengthen the quantitative basis of the investigation a sample was drawn from individual deaths. The best basis for such a sample is the death certificate file of Statistics Netherlands. This file includes the data for all deaths of residents of the Netherlands. For all inhabitants of the Netherlands, the cause of death is reported to Statistics Netherlands. The name of the patient is not mentioned on the cause-of-death form, but the name of the reporting physician is.

The Medical Officer in charge of the cause-of-death statistics drew a stratified sample of 7,000 cases from all deaths occurring from the first of August to the first of December 1990. The cause-of-death forms of all 41587 deaths that occurred during this period were examined by two physicians and assigned to one of five strata: in cases where the cause of death precluded the possibility of any kind of end-of-life decision (e.g. a car-accident resulting in instant death) the case was assigned stratum 0 and no questionnaire was sent. If the chance of an end-of-life decision was deemed to be high, the case was classified as stratum 4. The sample-fraction for stratum 4 was six times as high as for stratum 1 (0.5 and 0.083 respectively). A procedure was devised to ensure complete anonymity for all responding physicians and for the deceased persons. All Dutch physicians received a mailing explaining the design and the aims of the studies and the method by which complete anonymity would be guaranteed.

Of all questionnaires that were mailed, 76% was returned. Nearly all questionnaires had been completed carefully, and often contained additional information. The results of this study are based on 5197 completed questionnaires. This study was performed by researchers of Statistics Netherlands in close cooperation with the Department of Public Health of the Erasmus University Rotterdam.[6]

The questionnaire (see appendix) consisted of 24 questions. It was built around the questions in paragraph 2.1. Thus the terms 'euthanasia' and 'physician-assisted suicide' were not used. Instead, a combination of positive answers to questions 7 and 12 led to the total number of euthanasia and physician-assisted suicide, while a positive answer to question 7 and a negative to question 12 were counted as life-terminating acts without the patient's explicit request.

2.2.4 The prospective study (study III)

All physicians who were interviewed were asked to participate in a prospective study. This entailed having the physician complete a questionnaire identical to the questionnaire used in study II following the death of each patient within six months after the interview.

A prospective study posed several advantages. First, there would be few lapses of memory as the physician would be completing the questionnaire fairly soon after a patient died. Second, the interview study provided additional information supplied by these physicians and the prospective study could strengthen the quantitative bases of the interview study. Third, the carefully planned selection of respondents may be considered representative of 95% of all deaths in the Netherlands.

Of the 405 respondents of the interviews 322 participated, resulting in a 80% response. Because of the very limited time available for our study, we had to stop collecting questionnaires by June first 1991. On average, the respondents participated during 23 weeks. Together they described 2257 deaths and the decisions that they had (or had not) made regarding these patients. The expected number of deaths for this group of physicians during this observation period was 2220. This means that the physicians who participated in this study have produced nearly complete information. Weights were derived, based on those of study I, taking into account the extra non-response in this study and the differences in observation period between respondents, and small differences between studies II and III.

It was to be expected that certain situations in which decisions were taken would not occur sufficiently frequently to be reflected in the three part-studies described above. For such cases, which fall into special categories because of patient characteristics (e.g. being unable to make a decision) or illness characteristics (e.g. AIDS), complementary information was obtained from a number of experts from the areas concerned. Areas concerned include neonatology, other paediatric specialties, psychiatry and AIDS. No further attention is paid to these special groups in this thesis.

2.3 Privacy and data protection

Utmost care was given to the protection of privacy of the deceased, the participating physicians and the relatives and to ensuring the security of the data obtained in the course of the investigation. In the case of the sample of death cases, Statistics Netherlands made arrangements such that absolute anonymity of both physician and deceased patient could be guaranteed. Procedures concerning mailing and assessment of data made it impossible to track down the identity of either physician or deceased patient.

All data from the interview study and the prospective study were made anonymous upon their receipt. Here, too, it was impossible to trace back the data to particular respondents or patients except by a procedure that was known only to the investigators. The procedure for safeguarding the data was presented in writing to the respondent and was signed by the interviewer. The commitment was made that nobody could obtain any data, except in anonymous form and only for the purpose of scientific study. The Minister of Justice guaranteed immunity against legal prosecution based on the results of the studies.

2.4 Cooperation of the medical profession

Good cooperation by the medical profession was a prime requirement for success of this investigation. Credibility of the results would be seriously damaged should the response rate be low. Several steps were taken to encourage acceptance by the medical profession.

1 Protection of the privacy of physician and next of kin and the guarantees for the protection of data as discussed in the previous section were a prime condition for broad acceptance.

2 The Chief Medical Officer of Health and the Chairman of the Royal Dutch Medical Association (KNMG) wrote a letter addressed to all physicians in the Netherlands informing them of this investigation. They asked the physicians to cooperate if invited to do so.

3 Publicity in the general media was purposely kept to a minimum before and during the investigation. On the other hand, the study was carefully presented in the Dutch medical journals prior to its start.[7,8] These communications were apparently read widely. Reprints were sent to respondents in advance of the interviews.

4 A brief recommendation by the Chief Medical Officer of Health and the Chairman of the Royal Dutch Medical Association was enclosed with all invitations for interviews and questionnaires mailed by Statistics Netherlands.

5 Almost all interviews were conducted by physicians.

Moreover, the Royal Dutch Medical Association put the condition that it would support this investigation only if an instruction procedure concerning reporting and police actions in cases of euthanasia was produced. The commitment by the Minister of Justice that such guidelines would be produced probably contributed to the willingness of the medical profession to cooperate.

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Part II
Incidence

3 Euthanasia and other medical decisions concerning the end of life*

3.1 Introduction

Medical decisions concerning the end of life are being increasingly discussed in many countries. In the United States the discussion has focused on non-treatment decisions. In the Netherlands euthanasia has been at the centre of public debate since the early 1970s and this debate has attracted much international attention. Although euthanasia is, legally speaking, a criminal act in the Netherlands, prosecutions are rare provided physicians abide by strict guidelines.[1-3] Even so in cases of euthanasia the physician often declares that the patient died a natural death. The true number of deaths by euthanasia in the Netherlands is not known and this has given rise to much ill-founded speculation.[4]

A reform in the law has been proposed by several groups. Should euthanasia (strictly defined) be decriminalised altogether, as proposed by some members of the Dutch parliament; or should it remain a criminal act in principle but with clear rules about when not to prosecute; or should the present situation continue, with no new legislation? The government that took office in 1989 decided to postpone the decision until more reliable information would be available about the euthanasia in the Netherlands. To provide this information a commission was set up in January, 1990, chaired by prof. J Remmelink, at the time attorney-general of the Dutch Supreme Court, and we were asked by this commission to do a nationwide study among physicians and to report within a year. The commission also asked Statistics Netherlands to study a sample of deceased persons.

The study was not to be restricted to euthanasia in the sense in which it is used in the Netherlands - i.e., the intentional termination of life by somebody other than the person concerned at his or her the request - but was to address three forms of medical decision that might hasten the death of a patient. These were non-treatment decisions, the alleviation of pain and/or symptoms with high dosages of opioids, and euthanasia and related decisions, together called 'end-of-life decisions'. The aims of the nationwide study were to produce reliable estimates of the incidence of euthanasia and other end-of-life decisions; to describe the characteristics of patients, doctors, and situations involved; to assess how far physicians are acquainted

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* Van der Maas PJ, Van Delden JJM, Pijnenborg L et al. Lancet 1991;338:669-74

with the criteria for acceptable euthanasia; and to determine under which conditions physicians would be willing to report a death by euthanasia as such. This chapter addresses the first and second of these goals.

In order to gain insight into the backgrounds of euthanasia and other end-of-life decisions, detailed interviews with physicians were considered indispensable. On the other hand, the quantitative basis of the study would be considerably strengthened by a sample drawn from individual deaths. We decided to combine the advantages of detailed interviews with physicians with those of an investigation of a sample of individual deaths by setting up three studies (see chapter 2).

3.2 Results

3.2.1 Incidence

The three studies yielded similar estimates of incidence (table 1). Detailed analyses of cases permitted an overall figure for each end-of-life decision ('best estimate'). The percentage of deaths with an end-of-life decision was 35.4% (study III) or 39.4% (study II), with a best estimate of 38%. Studies II and III showed that about 30% of all deaths were acute and unexpected. In the remaining 70% there was enough time to take medical decisions, and in more than half of these cases (54%) an end-of-life decision is taken.

Euthanasia (terminating life at the patient's request) occurred in 1.7% (II), 1.9% (I), or 2.6% (III) of all deaths. Analysis of the response patterns in the substudies suggests that in study III some cases would fit better in the category 'alleviation of pain and symptoms' (APS). A best estimate is that

Table 1 Estimated incidence of end-of-life decisions, as percentage of all deaths*

End-of-life decision	Study I§	Study II	Study III	Best estimate
Euthanasia and related end-of-life decisions		2.7% (2.3-3.1)	4.7% (3.7-5.8)	2.9%
Euthanasia	1.9% (1.6-2.2)	1.7% (1.4-2.1)	2.6% (2.0-3.5)	1.8%
Assisted suicide	0.3% (0.2-0.4)	0.2% (0.1-0.3)	0.4% (0.2-0.9)	0.3%
Life-terminating acts without explicit and persistent request	†	0.8% (0.6-1.1)	1.6% (1.1-2.2)	0.8%
APS	16.3% (15.3-17.4)	18.8% (17.9-19.9)	13.8% (12.2-15.5)	17.5%
NTD	‡	17.9% (17.0-18.9)	17.0% (15.3-18.9)	17.5%
Total end-of-life decisions		39.4% (38.1-40.7)	35.4% (32.9-38.1)	38.0%

* Percentages refer to the total of deaths in The Netherlands (128,786 in 1990). Numbers in parentheses are 95% confidence intervals (Poisson method).

† Material in study I did not allow computation of this percentage.

‡ This percentage in study I is not comparable with that of study II and III because cases of living patients as well as dead patients were discussed.

§ Based on answers to questions on end-of-life decisions taken in previous 12 and previous 12-24 months.

1.8% of deaths in the Netherlands are the result of euthanasia with some form of physician involvement. Assisted suicide, meaning that a physician intentionally prescribes or supplies lethal drugs but the patient administers them, occurs in 0.2%-0.4% of all deaths, with 0.3% as best estimate.

In 0.8% of all deaths drugs were administered with the explicit intention to shorten the patient's life, without the strict criteria for euthanasia being fulfilled. In more than half of these cases the decision had been discussed with the patient, or the patient had expressed in a previous phase of the disease a wish for euthanasia if his/her suffering became unbearable. As table 1 shows the total of euthanasia and related end-of-life decisions amounts to 2.7% (II) or 4.7% (III) of all deaths. Detailed comparison of the three studies and the comments of respondents convince us that the 2.0% difference consists of cases that should not be considered as euthanasia and related end-of-life decisions but as being in a boundary area where APS with high dosages of opioids has the concomitant goal of shortening life. APS, at least accepting the risk of life-shortening, occurred in 13.8%-18.8% of deaths. 17.5% is the best estimate and cases in the boundary area are included in this 17.5%.

Non-treatment decisions (NTD) were taken in 17.9% (II) or 17.0% (III) of all deaths (best estimate 17.5%).

3.2.2 Euthanasia and assisted suicide: characteristics

At interview physicians were asked if they had ever practised euthanasia at the explicit and persistent request of the patient or had assisted in suicide. 54% confirmed that they had, and 24% had done so at least once during the previous 24 months (table 2). Of the general practitioners 62% had ever done so, of the specialists 44%, and of the nursing home physicians 12%.

Thirty-four per cent of the respondents said that they had never practised euthanasia or assisted in suicide but could conceive of situations in which they would be prepared to do so. The remaining 12% said that they could

Table 2 Physician's practice and attitudes regarding euthanasia or assisted suicide (%)*

Euthanasia or assisted suicide	General practitioners (n=152)	Clinical Specialists (n=203)	Nursing-home Physicians (n=50)	Total (n=405)
Ever performed	62	44	12	54
Had done so during previous 24 months	28	20	2	24
Never performed but would under certain conditions	28	40	60	34
Never would but would refer to another physician	6	9	26	8
Never would perform or refer	3	8	2	4
Total	100	100	100	100

* Percentages based on the weighted data so row totals cannot be directly computed as weighted averages of separate entries.

not conceive of any such situations but more than half (8%) said that they would be prepared to refer patients requesting euthanasia or assistance in suicide to a colleague with a more permissive attitude. In other words a large majority of physicians in the Netherlands see euthanasia as an accepted element of medical practice under certain circumstances. In the more urban western part of the Netherlands, significantly more doctors have ever performed euthanasia than in the other areas.

Table 3 contains information on age and sex of the deceased, based on study II. The results of the other two studies are very similar. The table also shows in what percentage of all deaths in a specific subclass an end-of-life decision was taken. For instance, in 38% of all deaths in the age group 65-79 an end-of-life decision was taken. This percentage does not differ very much between age groups or between the sexes. Table 3 also provides age and sex distribution for deaths under the three main types of end-of-life decisions and for all deaths in the Netherlands in 1990. In euthanasia and related end-of-life decisions, the patients tended to be younger and were more likely to be male than females.

When cause of death is taken into account the percentage of deaths in which an end-of-life decision was taken differed considerably (table 4), varying from 59% for all cancer deaths to 21% in cardiovascular disease (stroke in this study was considered to be a disease of the nervous system) and 12% for injury, suicide, and violence. In the subtype euthanasia and related end-of-life decisions, cancer was especially prominent (68% as opposed to 27% for all deaths).

One central question for each end-of-life decision was about the patient's involvement. The information about euthanasia and assisted suicide presented here is based on 187 cases described in interviews, because these yield detailed insight into the background.

Table 3 Age and sex of patients (%), Study II

	No	Died with end-of-life decision	Euthanasia and related end-of-life decisions (n=204)	APS (n=1166)	NTD (n=991)	Total with end-of-life decision (n=2361)	Deaths in the Netherlands*
Age							
0-49	363	32	14	6	7	7	8
50-64	797	40	24	17	9	14	13
65-79	1999	38	38	40	32	36	37
80+	2038	42	25	37	53	43	42
Total	5197	39	100	100	100	100	100
Sex							
M	2664	36	61	48	45	48	52
F	2533	43	39	52	55	52	48

* Figures for 1990 (128,786 deaths). Source: Statistics Netherlands.

In 96% of instances of euthanasia and assisted suicide the physicians stated that the patient's request was explicit and persistent. (The finding that there always was a request of some sort is circular since such a request is at the core of the definition of euthanasia in the Netherlands). In 94% the request had been made repeatedly; in 99% the physicians felt sure that the request had not been made under pressure from others; and in all cases they were convinced that the patient had sufficient insight and knowledge of the course of disease.

The patients made the request for reasons of loss of dignity (mentioned in 57% of cases), pain (46%), unworthy dying (46%), being dependent on others (33%), or tiredness of life (23%). In only 10 of the 187 cases was pain the only reason.

Life-termination by administering lethal drugs without an explicit and persistent request from the patient is probably the most difficult end-of-life decision. Our study suggests that this happens in about 0.8% of all deaths. In more than half of these cases the decision has been discussed with the patient or the patient had in a previous phase of his or her illness expressed a wish for euthanasia should suffering become unbearable. In other cases, possibly with a few exceptions, the patients were near to death and clearly suffering grievously, yet verbal contact had become impossible. The decision to hasten death was then nearly always taken after consultation with the family, nurses or one or more colleagues. In most cases the amount of time by which, according to the physician, life had been shortened was a few hours or days only. In this respect these cases resemble APS more than euthanasia. In euthanasia in 70% of all cases life was shortened by at least one week and in 8% by more than six months (study I).

We found that in the Netherlands over 25,000 patients per year seek assurance from their doctor that they will assist them if suffering becomes unbearable. Each year there are about 9,000 explicit requests for euthanasia or assisted suicide, of which less than one-third are agreed to. In most cases alternatives are found that make life bearable again, and in some instances the patient dies before any action has to be taken. Of the patients in the study whose request was refused, 14% had a psychiatric illness.

3.2.3 APS: characteristics

Physicians were asked if, to alleviate pain and/or symptoms, they had ever decided to give such dosages of opioids that they had to accept the risk of shortening the patient's life. Eighty-two per cent replied affirmatively (general practitioners 82%, specialists 81%, nursing home physicians 86%). Twelve per cent replied in the negative but thought it conceivable that they would do this; 7% said that they would never do so.

APS seems to be the most important end-of-life decision in 17.5% of all deaths. In 65% (study I) to 80% (studies II and III) of these cases the physician accepts that his action will probably shorten life. Interviews showed that in 6% of cases life-termination was the primary goal while in the other cases it was secondary. In most cases life had been shortened not at all (about one-third of cases) or by only a few hours or days but in some instances the estimate was weeks or even months. The patients are slightly younger than average and more often female, compared with the age and sex distribution of all deaths (table 3). Cancer is the most prominent disease, although less so than it was in euthanasia and related end-of-life decisions (table 4).

In about 40% of the cases the decision to increase dosages and the possibility that this might hasten the end of life had been discussed with the patient. When it had not, such discussion had usually (73%) been impossible because the patient was incompetent.

3.2.4 NTD: characteristics

When asked if they had ever decided to withdraw a treatment or not to start one, knowing that it might have prolonged the patient's life, 62% of respondents said that they had (general practitioners 51%, specialists 80%, nursing home physicians 98%).

NTD's were the most important end-of-life decision in 17.5% of all deaths. In about half these cases the physician accepted that treatment forgone probably would have prolonged life. In the other half not prolonging the patient's life was an explicit goal. Especially when treatment is not started with the explicit goal of not prolonging life, the estimate of life forgone can be quite considerable - over a week in about one third of these cases and over six months in 3%. NTD's usually relate to older patients (table 3) and to females slightly more often than males. The distribution of cause of death

Table 4 Causes of death (%), Study II

	No	Died with end-of-life decision	Euthanasia and related end-of-life decisions (n=204)	APS (n=1166)	NTD (n=991)	Total with end-of-life decision (n=2361)	Deaths in the Netherlands*
Cancer	2174	59	68	54	29	44	27
Cardiovascular disease	1103	21	9	15	19	16	30
Diseases of nervous system	572	43	2	9	18	13	12
Pulmonary disease	379	37	6	6	9	7	8
External	134	12	0.3	113	1.3	1.2	4.1
Other	835	43	15	15	24	19	19

* Figures for 1990 (128,786 deaths). Source: Statistics Netherlands.

also differs strongly from that found in the other types of end-of-life decisions, cancer having no predominant place. This may partly be explained by the fact that at older ages cancer forms a smaller fraction of all causes of death. A second explanation is that NTD's are not so much based on disease-specific considerations as on a general judgment about the possibilities of improving wellbeing by life-prolonging treatment.

In 30% of cases the NTD had been discussed with the patient; in 63% it had not (7% of respondents did not answer the question). In 88% of all cases where the NTD had not been discussed with the patient, the patient was incompetent.

3.2.5 Types of physicians

General practitioners claimed to have taken an end-of-life decision in about one-third of the deaths of patients for whom they were primarily responsible. The proportion was 40% for specialists and over 50% for nursing home physicians. Euthanasia and related end-of-life decisions were reported more often by general practitioners, while few were reported by nursing home physicians. On the other hand, NTD's were taken twice as often by nursing home physicians as by general practitioners. An APS was reported by general practitioners and specialists in about the same fraction of all deaths, while the nursing-home physicians report a higher percentage.

The finding that in nursing homes euthanasia and related end-of-life decisions is rare while an NTD is frequent can at least partly be explained by the fact that patients in nursing-homes are often already extremely fragile and any intercurrent illness, if not treated promptly, might cause death. Another part of the explanation could be that nursing home physicians are very reluctant to agree to euthanasia and related end-of-life decisions.

3.3 Discussion

This research shows that reliable data on euthanasia and other end-of-life decisions can be collected. The three different sources of data collection yielded similar results and the physicians cooperated irrespective of their opinions about euthanasia and other end-of-life decisions. Only 9% of the physicians selected refused to participate in the interviews, mainly because of lack of time (an interview lasted 2½ hours on average). Of those who were interviewed 80% also took part in the prospective study, giving nearly complete information on all deaths among patients for whom they had been responsible. Of 7,000 questionnaires 76% was returned. No financial compensation was offered for the time spent, which would have been many hours in studies I and III. The impressive cooperation of the Dutch medical profession may be interpreted as an indication that euthanasia and other end-of-life decisions are seen as important issues that deserve investigation and discussion - indeed many respondents commented to this effect, mentioning that these decisions are among the most difficult aspects in medical practice.

Quantitative studies on euthanasia nearly all stem from the Netherlands. We know of no such studies on APS; the few on NTD are mainly from the United States. In the Netherlands there have been several studies on requests for euthanasia in general practice. The estimates varied from 0.25-0.8 requests per general practitioner per annum.[8-10] For general practitioners in Amsterdam this number was 3.[11] In our study the comparable figure works out at 0.8. In their study on the frequency of euthanasia in the Netherlands, based on information from general practitioners, Van der Wal et al.[12] concluded that euthanasia and assisted suicide occurs in 2,000 cases yearly in general practice. The corresponding figure from our study is 1900. Other estimates of numbers of deaths by euthanasia range from 5,000 to 20,000 cases per year, but they are all based on inferences from small and incomplete data.[4,13-16] We know of no published estimates of the percentage of all deaths in which a NTD was taken but Neu and Kjellstrand found that 22% of all deaths in a dialysis ward were caused by stopping long-term dialysis[17], a study in intensive care patients showed that 45% of deaths were preceded by the withholding or withdrawal of treatment[18], and in a study of non-treatment of fever in extended-care facilities 81 of 190 patients were found not be treated, of whom 48 died as a result of this non-treatment.[19]

Our study supports the notion that the euthanasia debate should be placed into the much broader context of end-of-life decisions. In countries where life expectancy is long and standards of medical care are high, patients and physicians will be confronted with questions about refraining from further treatment, even if that treatment might prolong life and this is likely to arise more often as life-prolonging medical techniques become more and more abundant. This in itself should not be denounced: it is an inevitable consequence of the development of medicine. New ways of administering opioids can make life more tolerable and may even prolong life, and the possibilities for a dignified death without intolerable pain or dyspnoea have improved. But sometimes a balance between pain alleviation and life-shortening has to be found. As cardiovascular death rates decrease in western countries there will be more deaths from cancer and physicians will be confronted more often with end-of-life decisions.

Requests for euthanasia and, to a lesser extent, for assistance in suicide by patients with a fatal disease are not rare in the Netherlands. Many patients want the assurance that their doctor will assist them to die should suffering become unbearable. We found that about two-thirds of these requests never end up as a serious and persistent request at a later stage of the disease, and of the serious and persistent requests about two-thirds do not result in euthanasia or assisted suicide since physicians can often offer alternatives. Many physicians who had practised euthanasia mentioned that they would be most reluctant to do so again, thus refuting the 'slippery-slope' argument. Only in the face of unbearable suffering and with no alternatives would they be prepared to take such action. Many respondents mentioned that an emotional bond is required for euthanasia and this may be one of the reasons why euthanasia was more common in general practice where doctor and patient have often known each other for years and the doctor has shared part of the patient's suffering.

It appeared that requests for euthanasia or assisted suicide, in cases where this request was fulfilled, are indeed explicit and persistent and hardly ever made under pressure from others. Sometimes the death of a patient was hastened without his or her explicit and persistent request. These patients were close to death and were suffering grievously. In more than half such cases the decision had been discussed with the patient or the patient had previously stated that he would want such a way of proceeding under certain circumstances. Also, when the decision was not discussed with the patients, almost all of them were incompetent. It is very important that patients with a fatal illness express their wishes with respect to end-of-life decisions in advance and to form an opinion they will often need help from the physician.

From a physician's standpoint euthanasia will be restrained by the physician's desire, where possible, to find alternatives but it is not impossible that the number of requests for euthanasia (and for NTD's) will increase. Euthanasia and assisted suicide were more often found in deaths in relatively young men and in the urbanised western Netherlands, and this may be an indication of a shift towards a more demanding attitude of patients in matters concerning the end of life.

End-of-life decisions will become an issue of increasing importance for doctors because of demographic shift towards older populations, an increasing proportion of cancer deaths, a growth in the number of life-prolonging technologies, and possibly, generational and cultural change in attitudes of patients. The medical care of fatally ill patients demands a combination of medical skills and human qualities. The decision process in which the patient, his/her proxies, the nurses, the doctor and others become involved is very intimate. It is possible, however, to identify underlying structures and patterns. Many respondents indicated that the quality of their end-of-life decisions, and especially the decision process about euthanasia, had benefited from the public discussion in the Netherlands. End-of-life decisions should receive increasing attention in research, in teaching, and in public debate. An open discussion which starts from the premise that end-of-life decisions are being taken and have to be taken in any country with high standards of medical care and with an involved medical profession, will contribute to a better quality care for the dying.

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4 Dances with data*

4.1 Introduction

Many authors have commented upon the first findings of the Dutch study on end-of-life decisions. This study was performed for the Remmelink committee and was described by us elsewhere.[1] Some of the remarks concerning our data give evidence of misunderstanding and therefore need some comment in order to prevent further confusion.

Since many arguments follow the same pattern they can be categorized in four groups:
- simple misrepresentation of data;
- reordering of data;
- interpretation of the data;
- accusations.

In this chapter we will discuss these reactions one by one. We do not intend to give an exhaustive discussion. We will restrict ourselves to giving one or two examples of each type of reaction and point to some misunderstandings that have caused such reactions or that may follow from it.

4.2 Simple misrepresentations

Some commentators have taken the number of 2300 given by us as referring to the incidence of both euthanasia and assisted suicide and subtracted the 400 cases of assisted suicide that are mentioned separately in our report.[2] Thus they present 1900 as the euthanasia incidence. In fact however, 2300 is the annual incidence of euthanasia alone (1.8% of all deaths), to which the 400 assisted suicide cases should be added (0.3%) to reach a combined number for euthanasia and assisted suicide of 2700 (2.1%). This is only a minor point, since these small differences will not have much weight in a normative debate.

4.3 Reordering of data

Quite a few writers add cases from different end-of-life decision categories to the euthanasia number as defined by us (i.e. as active and voluntary) to prove that in fact euthanasia (in their definition) occurs much more often than

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* Van Delden JJM, Pijnenborg L, Van der Maas PJ. Bioethics 1993;7:323-9

we reported.[3] Usually they add up the following types of end-of-life decision: euthanasia, assisted suicide, life-terminating acts without explicit request of the patient, those decisions to alleviate pain and symptoms (APS), and non-treatment decisions (NTD) which were performed with the explicit purpose or partly with the purpose to hasten the end of the patient's life.

We find adding this last group (NTD) most confusing. Normally, opponents of active euthanasia defend the moral difference between killing and letting die.(4) They need this demarcation line in order to evade vitalism in which life must be prolonged as much as possible. Since nearly everyone agrees that some life and death decisions are sometimes morally proper, one has to draw a line somewhere and, according to the opponents of active euthanasia, the killing and letting die distinction is able to fulfil this task. Those who tend to accept active euthanasia, on the other hand, oppose the moral significance of this divide and conclude that logic forces us to accept at least some cases of active killing as the moral equivalent of some cases of letting die.[5] And now exactly the opposite happens: opponents of euthanasia lump together killing and letting die, referring to all of them as euthanasia cases.

But let us take a closer look at the reasoning process of the commentators. One step is often omitted, but can easily be reconstructed, namely that calling all these cases euthanasia means that they are all instances of wrongful killing. In spite of the lack of an adequate definition by most commentators of wrongful end-of-life decisions, one can safely state that the intention of the doctor is central to this whole line of reasoning. All cases brought together have one thing in common: the (primary or secondary) intention of the physician to hasten the end of the patient's life.

We should stress that we do not deny that the division between the different types of end-of-life decisions is not always as clear as between black and white. That is why we described some boundary areas between different types of end-of-life decisions.[6] Still, we think one misses the point if one lumps all these cases together because (a) intentions cannot carry the full weight of a moral evaluation on their own, and (b) although the formulations of the intentions are the same, the 'sameness' of the intentions can be questioned.

To our own judgement intentions can only be part of the moral evaluation of a situation (a). This is so because intentions are essentially private matters. Ultimately only the agent 'decides' what his intentions are, and different agents may describe the same actions in the same situations as performed with different intentions. The changes between descriptions of the intention need not even be inter- personal but can also be intrapersonal: what seems to be done at one time with one purpose might easily be felt differently at a later stage. What, then, is to count as the definitive description? One consideration might serve as an example: no physician who performs euthanasia does so with the sole intent to kill his or her patient. His or her intention can always be described as trying to relieve the suffering of his or her patient. This is exactly what infuriates Dutch physicians when, after reporting the case they are treated as criminals and murderers.

We have been criticized for including the extent of lifetime forgone as variable because of the uncertainty which surrounds this variable, but surely intentions are at least as fragile as this type of estimate. Those who add up all the above mentioned categories in fact tell us to rest the entire moral evaluation completely on this ground. Intentions, decidedly weak however, simply cannot bear this weight. For a moral evaluation, more is to be taken into account, such as the presence of a request of the patient, the futility of further medical treatment, the sequelae of the decision to stop treatment (e.g. will this cause heavy distress?), the interests of others involved such as family and so on.

Those authors[7] add to their 'euthanasia' number the 5800 cases of NTDs in which the patient explicitly requested to withhold or withdraw a treatment must have missed at least two decades of ethical debate. One can not but conclude that they want to respect an autonomous wish of a patient about his or her own death only if that patient decides that he or she does not want to die. Moreover, the question can be raised whether ignoring the patient's wish and focusing on the intention of the physician does not lead those authors to an untenable position. They would (if they want to be consistent) have to accept any NTD, even those to which the patient is opposed, as long as the doctor does not think about hastening the end of life of the patient. Surely, this can only be justified in cases of medically futile treatment.

All medical decisions and especially those concerning the end of life should be justified by good reasons. Neither the fact that the end-of-life decision implied an act or an omission, nor the intention of the doctor provide a sufficient basis for the conclusion that good reasons existed for the decision.

But even if one could morally evaluate an action simply by looking at intentions (we now turn to our (b) claim), that would still not mean that one can add up different actions on the basis of intentions. Again an example: in 6% of the cases of alleviation of pain and symptoms the intention was described as the explicit purpose to hasten the end of life. In the case of euthanasia the intention was described in the same wording. If the context is taken into account, however, one will soon realize that in the case of euthanasia the decision was made to hasten the end of life and then a means was sought. In those cases of APS, however, there is an ongoing medical treatment which fails to achieve its palliative goal. The physician then sees himself confronted with the need to use higher, possibly lethal dosages. Then there may be a point at which the physician realizes that he or she actually hopes that the patient dies. So the physician answers us that his purpose (at least partly) was to hasten the end of life. Those cases prompted us to speak of a boundary area around euthanasia. But are the intentions one and the same as in the euthanasia case? Not necessarily. In the euthanasia case the physician would surely try another drug if the first failed to bring about death, whereas in the second this would never happen. One misses this relevant point if one uses too narrow a concept of intentions by leaving out context. A similar problem originates from adding up all cases in which there was no explicit request of the patient. These cases include non-treatment decisions in which medically futile therapy was withdrawn or withheld and in which no shortening of life resulted. Surely their moral status is not completely determined by the absence of a request of the patient.

In conclusion, adding up cases from different end-of-life decision categories leads one astray because it is based on unacceptable simplifications. We have tried to analyze medical decisions concerning the end of life by answering four questions: what did the physician do (or not do); what was his or her intention when doing so; was this action chosen at the request of, or after discussion with, the patient; and if not, was the patient capable of a decision or not? Also, by means of the three substudies we were able to validate the results. We believe this detailed analysis provides a better starting point if one wants to examine the cases from a moral point of view.

4.4 Interpretations

Sometimes the numbers we presented are interpreted as proof for the existence of a slippery slope. Those arguing for this especially mention the 1,000 (0.8%) Life-terminating Acts Without Explicit Request of the patient (LAWER).[8] We take it that they refer to the empirical version of the slippery slope argument. We really cannot see how these cases can provide proof for the existence of a slippery slope nor how they can be an indication for the place on the slope at which the Dutch now find themselves. To demonstrate a slippery slope one would need to show that something changed after introducing a certain practice and for this at least two investigations would be required. Even then it is doubtful that this would yield conclusive proof either for or against.[9] At this moment however, we simply do not know whether this type of end-of-life decision occurred less or more often in the past. Nor can we safely predict the incidence in the near future. Nor do these numbers provide any comparison with other societies where euthanasia is not decriminalized.[10]

Although we have predicted an increase of the incidence of the total group of end-of-life decisions in the future, that does not imply that LAWER cases will increase in number as well. For all we know, starting a public debate about these cases as is currently going on in The Netherlands might be a good way of reducing the number of LAWERs, for instance by motivating patients and physicians to discuss end-of-life matters earlier in the course of a fatal disease.

4.5 Accusations

One comment goes further. After claiming that different cases should have been brought under one heading, the authors claim that the committee not only was wrong in failing to do so but actually deliberately 'brought similar practices under dissimilar headings to keep the numbers low'.[11]

We should stress that we are not making the same mistake which many commentators have made, that of not distinguishing between the investigators and the committee. Yet on this point the committee so clearly followed our structure of the study that this incrimination cannot but be taken as concerning us too.

We do not think the authors have any hard ground to rest their claim upon. As will be clear from the preceding, there are good reasons to defend the structure we used. Following that structure and the related definitions simply yielded the results as we presented them. All cases are reported and everyone can read and check exactly what we found. If someone wants to start reasoning using other definitions, we can see no problem in that as long as his definitions are made clear. However, to state that we deliberately present a distorted picture not only is wrong but leads us to the conclusion that, apparently, the authors could not find more substantial arguments to support their rejection of our study. This we find confirmed by the many misleading 'mistakes' that the authors make in describing the report. To name a few[12]: the authors suggest that the committee itself decided to broaden the scope of the study. Instead, the task that the cabinet assigned the committee was to do more than only investigate terminating life. The authors state that there are 1,000 patients whose death was caused by physicians without any request at all. In fact, 600 (59%) of these patients were involved in some way or other, although not in the sense of explicitly requesting their end of life to be hastened. Another example: one of the reasons stated by doctors for performing a life-terminating act without explicit request of the patient was not prolonging the suffering of the patient. The authors 'translate' this into 'one should not postpone death'. Finally, the authors overlooked the fact that decisions not to use futile treatments were not excluded from the NTD category. We can only hope that the truly interested reader will take the trouble of reading the Lancet article or the English version of the report itself[13], instead of relying on this faulty description.

4.6 Conclusion

Medical decisions concerning the end of life are a difficult matter and they evoke much emotional response. What is needed, however, is an open debate in order to improve the moral quality of decision making, not 'dances with data'. The central question in this debate should be, as Callahan aptly notes[14], whether medicine should involve itself only in that kind of 'suffering which is brought on by illness and dying as biological phenomena' or whether it should concern itself with the wellbeing of the patient. Apart from the fundamental question as to what types of suffering are to be considered as biological phenomena, in The Netherlands most doctors, ourselves included, think the medical profession should do the latter.

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10 In The Netherlands euthanasia is not legalized but decriminalized: physicians who performed euthanasia and adhered to the rules of due care can be reasonably sure that they will not be prosecuted.

11 Ten Have HAMJ, Welie JVM. Euthanasia: normal medical practice? Hastings Center Report 1992;22(2):34-8, at p. 36.

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Part III
The decision process

5 Withdrawal or withholding of treatment at the end of life*

5.1 Introduction

Decisions to withhold or withdraw treatment from patients who are terminally ill have been made throughout the history of medicine. Hippocrates acknowledged the limitations of the art of medicine. Treatment sometimes must be forgone to avoid harm (primum non nocere).

There is a rapidly growing body of literature about decisions to withhold or withdraw treatment, collectively called *non-treatment decisions*. We see two reasons for this. First, the number of nontreatment decisions inevitably increases, absolutely and relatively, with the increase in chronic diseases in an aging population and the growing number of life-prolonging technologies (including drug therapy). Second, nontreatment decisions have to be made in a more explicit way because of increased patient involvement in medical decisions. In the traditional model of health care, physicians made decisions for their patients. In the current model, physicians increasingly make decisions together with their patients.

The purpose of this chapter is to provide empiric information on the occurrence and background of nontreatment decisions, valid for the population as a whole. In 1990 the Dutch government appointed a commission (the Remmelink-Commission) with the task to report on the practice of medical decisions concerning the end of life. The commission was charged with providing empiric information to clear up some important issues in the ongoing euthanasia debate. The explicit instruction was that it should not restrict itself to active euthanasia but also include other important end of life decisions, such as decisions to withdraw or to withhold life-prolonging treatment and decisions to alleviate pain or symptoms resulting in possible shortening of life. We were asked by this commission to do a nationwide study on these issues.

We define nontreatment decisions as all decisions involving withholding or withdrawal of potentially life-prolonging treatment. This does not imply that all treatment will be forgone. In most instances at least palliative treatment is continued. Our information is representative of all deaths in the Netherlands, including those in hospitals, in nursing homes, at home, and elsewhere.

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* Pijnenborg L, Van der Maas PJ, Kardaun JWPF et al. Arch Intern Med 1995;155:286-292

After the frequency of nontreatment decisions is presented, some patient and physician characteristics will be given. Patient involvement and some other aspects of the decision-making process leading to nontreatment decisions will be described, as well as the different types of intervention that were forgone.

5.2 Methods

In 1990 and 1991, the first nationwide investigation of medical decisions concerning the end of life was performed in The Netherlands. Three studies were undertaken: 1. detailed interviews with 405 physicians (interview study); 2. questionnaires mailed to the physicians of a sample of 7,000 deceased persons (death certificate study); and 3. information about 2257 deaths collected by a prospective survey among those physicians who participated in the interviews (prospective study).

The methods used in the three studies are described in more detail elsewhere.[1-3] Here we will focus on how information on nontreatment decisions was elicited.

Interview study (study I)

A stratified random sample of 405 physicians who had practised medicine in their present practice for at least two years was interviewed by 30 physicians and five nonmedical academics, all well acquainted with health care. The sample was stratified according to type of specialty. Of all invited physicians, 9% refused to participate in the interviews, mainly because of lack of time (an interview lasted 2½ hours on average). In total, 152 general practitioners, 50 nursing-home physicians, and 203 clinical specialists (cardiologists, surgeons, internists (including oncologists), pulmonologists, and neurologists, together covering 89% of all hospital deaths) were interviewed. Two sections of the interview dealt with nontreatment decisions: those at the explicit request of the patient and those without such a request. The physicians were asked to give some details about their most recent case in each category, if any. Advance decisions not to resuscitate were asked as a separate category and are reported on elsewhere.[4] In this chapter, the information is restricted to the deceased persons.

Death certificate study (study II)

For all inhabitants of the Netherlands, the cause of death is reported to Statistics Netherlands. The name of the patient is not mentioned on the cause-of-death form, but that of the reporting physician is. A stratified sample was drawn on those death certificates from August till November 1990.

Stratification was based on the probability that an end-of-life decision had been made. Therefore, the cause-of-death forms of all 41587 deaths that occurred during this period were examined by two physicians and assigned to one of five strata: when the cause of death precluded the possibility of any kind of end-of-life decision (eg, a car accident resulting in instant death), the case was assigned stratum 0, and no questionnaire was sent. When the chance of an end-of-life decision was deemed (eg, most cancer deaths), the case was classified as stratum 4. The sample fraction for stratum 4 was six times as high as for stratum 1 (0.5 and 0.083, respectively).[1,2]

Anonymous questionnaires, consisting of 24 questions, were sent to the attending physicians of their recently deceased patients. Of the mailed questionnaires, 76% were returned. The results of this study are based on 5197 completed questionnaires.

If, according to the physician, the death had been sudden and totally unexpected, no further questions were asked, except for a question about do-not-resuscitate orders. If an end-of-life decision had been made, some questions were asked about the characteristics of that decision. The end-of-life decisions that could have been made were as follows: nontreatment decisions, alleviation of pain and symptoms with probable life-shortening, and euthanasia and other end-of-life decisions with the explicit intention to hasten the end of life.[3] The two most important questions pertaining to nontreatment decisions were the following:

1 Did you or a colleague take one or more of the following actions, or ensure that one of them was taken, taking into account the probability that this action would hasten the end of the patient's life?

2 Was death caused by one or more of the following actions, which you or a colleague decided to take with the explicit purpose of hastening the end of life?

The 'following actions' in both questions were: a. withholding a treatment (yes,no) and b. withdrawing a treatment (yes,no). If one of the four answering categories (1a, 1b, 2a, 2b) was answered affirmatively, that specific death was considered to have been preceded by a nontreatment decision.

The sequence of questions about the occurrence of end-of-life decisions was constructed as a gradient of 'importance'. This gradient was based on the type of decision and on the physician's intention: 'taking into account the probability of hastening the end of the patient's life' or 'with the explicit purpose of hastening the end of the patient's life' (eg, question 2 was 'more important' than question 1). For the most important end-of-life decision, if any, details about the decision characteristics were asked.[1]

A weighting procedure was applied to derive valid estimates for the whole population of deceased persons. The weights were derived after subdivision of the sample according to stratum, place of death, cause of death, age and sex.[2]

Prospective study (study III)

All respondents of study I were asked to complete a questionnaire that was identical to that used in study II, for every patient in their care who had died within 6 months after the interview. Of the 405 interviewees, 322 (80%) took part. They described 2257 deaths and the decisions they had or had not made.

The best basis for quantitative estimates is study II because of its random sample of all death certificates, and the fact that this sample was 2.3 times larger than the one of study III. Significance of relationships between variables was tested by log linear regression analysis. Stratification effects were modelled using an offset variable.[5] Study III will be mentioned if its estimates differ markedly from those in study II, or when a further subdivision within clinical specialties was made. Study I will be used to give further details about nontreatment decisions that were not available in study II or III.

5.3 Results

Of all deaths, 30% were considered to be sudden and unexpected by the reporting physician. The proportion of sudden deaths varied with age, sex, and cause of death (Table 1). As might be expected, the proportion of sudden deaths was higher in younger age groups, in males, and in deaths from cardiovascular diseases, while it was low in cancer deaths.

For better insight in the distribution of nontreatment decisions, we restricted our analysis to nonsudden deaths (Table 1, column 4). The proportion of nontreatment decisions in all nonsudden deaths was 39%. It was higher in newborns (64%), and slightly higher in the group of patients aged 80 years or more (43%) and in females (43%). It was relatively high in diseases of the nervous system (48%) and relatively low in cardiovascular diseases (32%). Age, sex and diagnosis all independently contributed to the probability that in a particular death case, a nontreatment decision had been made (log linear regression analysis). About half of all nontreatment decisions consisted of not starting a possibly life-prolonging treatment; in the other half physicians had withdrawn treatment, or they had withdrawn some treatment as well as withheld some other treatment. This distribution did not differ significantly between sexes or disease categories. However, there was a clear relationship with age. In younger ages, a larger proportion of nontreatment decisions consisted of withdrawing a therapy that already had been started (61% in those aged less than 65 years and 43% in those older than 79 years).

Table 1 Age and diagnosis of died patients according to total number of deaths (vertical %) and according to non-treatment decisions in non-sudden deaths (horizontal %) (study II)*†

	All deaths Vertical %	Sudden deaths Horizontal %	Non-sudden deaths Horizontal %	Non-treatment decisions in non-sudden deaths Horizontal %	Non-sudden deaths without non-treatment decision Horizontal %
Total (n=5197)	100	30	70	39	61
Age		$p<0.001$†		$p<0.001$	
0-64 years (n=1160)	22	41	59	36	64
65-79 years (n=1999)	37	30	70	37	63
80+ years (n=2038)	41	24	76	43	57
Sex		$p<0.001$		$p<0.001$	
Male (n=2665)	52	33	67	36	64
Female (n=2532)	48	27	73	43	57
Diagnosis		$p<0.001$		$p<0.001$	
Cancer (n=2174)	29	8	91	37	63
Cardiovasc.diseases (n=1103)	31	52	48	32	68
Nervous system (n=572)	12	23	77	48	52
Pulmonary system (n=379)	7	23	77	39	61
Other diseases (n=969)	21	35	65	46	54

* All percentages are based on weighted data, so absolute numbers in the sample cannot be computed directly from percentages. Due to rounding errors percentages may not add up to 100%.

† Significance was tested with loglinear regression analysis.

The place of dying in the Netherlands coincided with the distribution of deaths over the different types of specialties: 42% died at home, 41% in a hospital, and 17% in a nursing-home (table 2). About two fifths of all hospital deaths occurred in internal medicine. The proportion of sudden deaths was not equally spread over the specialties. The cardiologists reported 54% of all their deaths as sudden and unexpected, and the general practitioners 38%, while the nursing-home physicians reported only 16% as such. Non-treatment decisions in non-sudden deaths differed also among specialists: for surgeons, 55%, for nursing-home physicians, 44% (study II; 55%) and for cardiologists, 28%. In some specialties, most nontreatment decisions consisted of stopping a treatment that had already been started (cardiologists, surgeons), while in others the decision not to start treatment was the most common nontreatment decision (nursing-home physicians, neurologists).

In 25% of all non-sudden deaths the non-treatment decision was the most important decision. From this last group we further analyzed the decision characteristics. Table 3 presents the distribution of those characteristics over three types of specialists: general practitioners, clinical specialists, and nursing-home physicians. It also shows the distribution over three levels of patient involvement: nontreatment decisions at explicit request of the patient,

Table 2 Deaths per specialty according to total number of deaths (vertical %), according to non-treatment decisions in non-sudden deaths (horizontal %), and according to the division of non-treatment decisions in 'withholding only' and 'withdrawal with or without withholding' (horizontal %). (study III)[*][†]

	All deaths Vertical %	Non-treatment decisions in non-sudden deaths Horizontal %	Non-sudden deaths without non-treatment decision Horizontal %	Withholding only Horizontal %	Withdrawal with or without withholding Horizontal %
Total (n=2257)	100	37[‡]	63	48	52
Type of specialty		p<0.001[†]		p<0.001	
Cardiologist (n=267)	8	28	72	32	68
Surgeon (n=102)	6	55	45	32	68
Internist (n=378)	17	34	66	43	57
Pulmonologist (n=257)	4	42	58	35	65
Neurologist (n=172)	5	38	62	55	45
General practitioner (n=618)	42	33	67	46	54
Nursing-home physician (n=463)	17	44	56	61	39

[*] All percentages are based on weighted data, so absolute numbers in the sample cannot be computed directly from percentages. Due to rounding errors percentages may not add up to 100%.

[†] Significance was tested with loglinear regression analysis

[‡] In study II this percentage is 39%, see table 1, last column.

nontreatment decisions after discussion with the patient or a previous wish, and nontreatment decisions without discussion with the patient or a previous wish. In 67 cases (7%) we had insufficient information about the patient's involvement in the decision. These cases were excluded from the table.

Nontreatment decisions were made at explicit request of the patient in 19% of cases of nontreatment, after discussion with the patient in 13%, after a previous wish in 9%, and without any involvement of the patient in 59%. In this last group the patient was not (totally) competent in 87% of cases, mostly because of diminished consciousness and/or dementia. *Competent* was defined as 'able to assess his or her situation and to make a decision about it adequately'. In 72% of these cases, the decision had been discussed with relatives. Of the remaining 13%, we could not establish the competence of the patient, because in the majority of these cases the physician answered the question? 'Why was the decision not discussed with the patient?' with 'discussing the decision would have done more harm than good' or 'this was clearly the best for the patient'. In a number of these cases, the patient was probably competent. In 58% of these cases, the decision had been discussed with relatives.

Compared with other specialists, when general practitioners made nontreatment decisions, it was relatively more often regarding competent patients (42%) and at their request (31%) of competent patients. Clinical

Table 3 Decision characteristics in non-treatment decisions as most important end-of-life decision (vertical percentages) (study II)*†

Decision characteristics	By general pract. n=295 Vert. %	By clin. specialist n=314 Vert. %	By nursing-home physician n=312 Vert. %	p†	At explicit request n=192 Vert. %	After discussion or previous wish n=211 Vert. %	Without discussion or previous wish n=521 Vert. %	p†	Total n=924 Vert. %
Disc., request, previous wish				***				***	
At explicit request	31	14	14		100	-	-		19
After discussion or previous wish	26	23	18		-	100	-		22
Without discussion or previous wish	43	62	68		-	-	100		59
Competence				***					
Competent	42	18	18		96	31	-		25
Not or not totally competent	46	75	74		4	65	87		67
Uncertain	12	7	8		-	4	13		9
Decision discussed with:‡									
Colleagues	31	78	38	***	61	57	49	**	53
Nursing staff	40	61	79	***	60	59	62	NS	61
Relatives	69	73	76	NS	81	72	70	*	72
None of these	18	5	8	***	4	8	12	**	10
Shortening of life				***				***	
< 24 hours	41	52	36		27	45	49		44
1-7 days	35	29	27		31	28	30		30
1 to 4 weeks	16	12	19		25	17	12		16
> 1 month	6	4	14		14	8	6		8
Unknown	2	3	4		2	2	4		3

* All percentages are based on weighted data, so absolute numbers in the sample cannot be computed directly from percentages. Due to rounding errors percentages may not add up to 100%.

† Significance was tested by loglinear regression analysis: *** p<0.001, ** 0.001<p<0.01, * 0.01<p<0.05, NS Not Significant

‡ More than one answer possible.

specialists most often consulted colleagues, nursing-home physicians most consulted the nursing staff, while general practitioners consulted a health care professional less often.

We asked the physicians to give an estimate of the extent to which life was shortened by the nontreatment decision. Any estimate of this nature can only be very general. However, this investigation showed that estimates differed markedly between different types of end-of-life decisions. The estimated amount of life shortening was up to 1 week in 74% of all cases and more than 1 month in 8%. The estimated shortening of life was slightly higher for nursing-home deaths and somewhat lower for hospital deaths.

When nontreatment decisions were made at request of the patient, the estimated shortening of life was much higher than when there had been no request: 1 week or more in 39% vs 19%.

In the interview study we asked the physicians what their most important reasons were for deciding to forgo treatment. More than one reason could be given. When nontreatment decisions were made at the patient's explicit request, the wish of the patient was of course an important reason (74%). When nontreatment decisions were not made at explicit request (the majority of these patients were incompetent), the most important considerations to forgo treatment were 'no chance of improvement' or 'the futility of further treatment' (together 72%). Scarcity of means hardly ever played a role in the decision. It was mentioned in two out of 225 cases (shortage of beds in an intensive care unit), but in both cases there were also other reasons for the decision.

In the interview study, we also asked what kind of interventions were withdrawn or withheld. Table 4 shows that chemotherapy and radiotherapy were relatively more frequently withheld or withdrawn at the explicit request of the patient. Antibiotics were relatively more frequently withheld or withdrawn when there had been no explicit request of the patient. For other types of intervention, no major differences were observed. Altogether, the forgoing of antibiotics and 'no (further) diagnostics or hospitalization' were the nontreatment decisions most often made. We also asked if the physician's attitude had changed since the beginning of his or her practice with regard to the continuation of life-prolonging treatments in terminally ill patients: 56%

Table 4 Interventions forgone in non-treatment decisions at explicit request or not at explicit request (vertical percentages) (study I)*

	At explicit request n=139 Vertical %	Not at explicit request n=225 Vertical %	
Antibiotics	16	37	p<0.001
Diagnostics or hospitalization	17	23	NS
Chemotherapy	25	5	p<0.001
Radiotherapy	16	1	p<0.001
Tube feeding	10	11	NS
Surgery	9	10	NS
Antiarrhythmic drugs and/or antihypertensic drugs and/or drugs for angina pectoris	8	11	NS
Other drugs, or drugs not specified	14	18	NS
Blood transfusion	9	5	NS
Mechanical ventilation	3	7	NS
Parenteral fluid	2	4	NS
Dialysis	2	3	NS
Other	4	6	NS
Total†	135	141	

* All percentages are based on weighted data, so absolute numbers in the sample cannot be computed directly from percentages.

† Total higher than 100% because more than one answer was possible.

said that their attitude had changed (in 81% toward less aggressive treatment, which means more nontreatment decisions at the end of a patient's life); 9% of the physicians who had changed their attitude said they now tried more treatments because of the increased life-prolonging possibilities; and 13% mentioned that the wish of the patient had become much more important in their decision making process. In most cases this had resulted in forgoing life-prolonging treatment, but sometimes the physician had continued some treatment only because of the patient's wish.

5.4 Comment

Before the results are discussed, their validity should be considered. The death certificate study (study II) and the prospective study (study III) showed nearly identical results, although the samples of physicians and death cases in each of these studies were obtained in a totally different way. The response rate for both studies was high. The distributions of age, sex, and diagnosis in studies II and III were comparable with those of all deaths in the Netherlands. However, in study II the response rates related to those who died in a hospital and those who died elsewhere differed (64% vs 81%). Detailed analysis did not show any bias resulting from response.[2] Furthermore, the total anonymity and immunity guaranteed to all physicians who participated in the study strengthen our conviction that the physicians answered honestly.

Although there is increasing literature on nontreatment decisions, there are still few empiric studies, no other study covers a large representative sample from the whole population. The study most comparable with ours is that of Faber-Langendoen and Bartels.[6] They found that in 52 of 70 patients who had died during a 2-month period at a university hospital, some intervention had been withheld or withdrawn. The forgoing of life-sustaining treatment often occurred in a sequential manner over several days. For 39 of the 52 patients of whom treatment was forgone, the initial decision included orders not to resuscitate and/or intubate. The most common decisions made synchronously with the initial decision were forgoing the administration of vasopressors, anti-arrhythmics, or dialysis, and the performance of surgery. In 40 of the 52 patients, interventions other than resuscitation and mechanical ventilation were withheld or withdrawn. Of the adult patients, 29% were able to participate in the initial decision.[6]

From study II we know that in 61% of deaths that occurred in a hospital, nontreatment decisions were made and/or a do-not-resuscitate order was issued.[4] This percentage is slightly less than in the Faber Langendoen and Bartels study (74%).

In a study done in an intensive care department, treatment was withdrawn or withheld in 45% of the 198 patients who died. Of these, 11% had earlier expressed a wish that their terminal treatment be limited. Only 4% had participated in the actual decision to limit treatment; the others were incompetent at the time the decision was made.[7]

Several other studies have dealt with special groups of patients. Of 704 patients who died in a hospital dialysis department, 22% died because dialysis was withdrawn. Nearly half of these were competent patients, all of whom had requested or agreed with the decision to withdrawn the dialysis. In the early 1970s, the physician had initiated the withdrawal decision in 66% of cases; in the early 1980s, this number had dropped to 30%, leaving the role of initiator to the patients or their proxies.[8] Dialysis patients and intensive care patients, however, are special categories, while our patient groups are representative of the total patient population. Brown and Thompson[9] studied patients in a nursing home. He reported that in 83% (n=48) of the 58 patients who died with fever, it had been decided not to give specific treatment. In a general medicine unit, some form of acute medical intervention was withheld in 82% (n=18) of the 22 patients who died with severe dementia.[10]

Physicians daily face the decision whether to start or continue a certain treatment. We found that decisions to withhold or withdraw possible life-prolonging treatment perhaps are not made daily but still occur in 39% of all nonsudden deaths. These decisions do not imply that all life-sustaining care is forgone or that only comfort care is given. For example, a physician could decide, together with the patient's relatives, not to give antibiotics to a severely demented patient. Nevertheless, tube feeding could be continued.

All these decisions were made by the physician at least taking into account the probability that life would be shortened. The response that life was probably shortened by more than a month in 8% of cases indicates that to forgo treatment can be a weighty decision. In the interview study several physicians mentioned that the decision was to avoid prolonging life rather than to shorten life. The correct terminology depends on whether or not the results of life-prolonging treatment in terminal patients are considered to be part of normal human life expectancy.

Our results illustrate interesting differences between medical practice in different specialties. In hospitals, the largest contrast is to be found between the cardiologist and the neurologist. Cardiologists reported that 54% of their patients die suddenly and unexpectedly, while for the neurologists this figure is only 19%. Cardiologists have also the lowest proportion of nontreatment decisions in nonsudden deaths, while surgeons have the highest percentage (28% vs 55%).

The difference in the proportion withholding treatment per specialty may have to do with a difference in prognostic certainty and with quality-of-life considerations. Both medical prognosis and quality of life may be so poor in nursing-home patients and neurological patients that no therapeutic improvement may be expected. This might explain the high percentage of decisions to withhold treatment. In cardiac and surgical patients, the prognosis, especially the short-term prognosis, and the chance of therapeutic improvement may be more difficult to predict, which would justify starting a treatment with uncertain outcome. This would explain the relatively high percentage of decisions to withdraw treatment.

The observed reasons for the physician to make a nontreatment decision depended heavily on the involvement of the patient in the decision-making process. When there was no explicit request from the patient, the reasons were mainly 'no chance of improvement' and the 'futility of further treatment'. The latter reason implies in most instances more than a pure medical judgment about the effectiveness of a certain treatment.[4,11-13] Therefore, we think that generally the competent patient should be consulted about nontreatment decisions. The physician has to explain what can be achieved, and then the patient has to make clear what value he or she attaches to the alternative outcomes. More accurate prognostic estimates of survival and, even more important, of quality of life during that period could facilitate proper decision making, but, of course, this does not provide absolute certainty in the individual case.[14,15] When the patient is no longer competent, surrogate decision making, the use of advance directives, and the advance appointment of a proxy decision maker are the only ways to come closer to the (expected) wish of the patient, although limitations have been pointed out in a number of studies.[16-20]

In 59% of all nontreatment decisions cases the patient was not involved in the decision making, mostly because of incompetence. In at least 13% of these cases, the decision was made by the physician under the heading of what one might call 'therapeutic privilege' or 'paternalism', although relatives had been involved in more than half of these cases. It is often not until a patient is unable to interact with others that the wisdom of further (aggressive) therapy is questioned.[21] But has patient involvement in nontreatment decisions changed at all during the last decades? Except for the study by Neu and Kjellstrand [8] there are no quantitative investigations that can answer this question. In our study, approximately half of all physicians said they had changed their attitude about life-prolonging treatments and moved towards less aggressive treatments in the course of their practice, and several mentioned that nowadays there is more patient involvement in non-treatment decisions.

It has been shown that physicians in the United States are much more concerned about providing overly burdensome treatment at the end of life than about undertreatment, but nevertheless they are reluctant to withdraw treatment because uncertainty about what the law, medical ethics and professional standards say on this matter.[22-25] The most likely consequence is that often treatment will be continued against the professional intuition of the physician, which can be seen as 'defensive medicine'. We think that, especially in the terminally ill, continuing or starting treatment should be argued just as rigorously as discontinuing or withholding treatment.

5.5 Conclusion

Non-treatment decisions in terminally ill patients are made often in medical practice (39% of all nonsudden deaths). They can be weighty decisions, requiring considerable expertise. This is illustrated by the fact that sometimes life is shortened (or not prolonged) by a considerable amount of time. The considerations are seldom purely medical. Most often a physician has to weigh medical and nonmedical burdens and benefits. For this to be done properly, the patient should be involved whenever possible. Patient involvement is often impossible because the discussion is postponed until it is too late, the patient being incompetent. Other requirements for a balanced decision are better prognostic knowledge, optimal palliative treatment, consultation of other specialists and the absence of defensive motives.

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6 Medical decisions at the end of life in cancer patients

6.1 Introduction

Dilemmas in the care of cancer patients receive increasing attention.[1] Nowadays cancer is the second cause of death in the industrialized world and the proportion of cancer deaths is still increasing. Progress in medical technology has resulted in an increase in life-expectancy, but sometimes also in a prolongation of suffering. Yet, improvements in palliative treatment have made it possible to reduce much suffering at the end of life. According to the World Health Organization, it is feasible to relieve pain sufficiently in more than 90% of cancer patients.[2] Nevertheless, in practice alleviation of pain and symptoms is still a problem, especially at an advanced stage of disease in which 60-90% of cancer patients report substantial pain.[3-5]

In terminally ill patients not only good palliative care has to be provided, but sometimes also important medical decisions have to be made. In 1990/91 we performed the first nationwide investigation on medical decisions concerning the end of life.[6-8] Four types of decisions were studied: 1. decision to withhold or withdraw probably life-prolonging treatment (in this chapter 'non-treatment decisions'), 2. alleviation of pain and/or symptoms with probable life-shortening effect (in this chapter: 'decisions for pain alleviation'), 3. euthanasia and assisted suicide (both at the patient's request) and 4. life terminating acts without explicit request of the patient.[9] Of all deaths in the study, 30% appeared to be sudden and totally unexpected. In 54% of the remaining cases, some end-of-life decision was made. We found that end-of-life decisions were taken significantly more often in cancer patients than in patients with other diseases. This chapter describes some characteristics of end-of-life decision-making in cancer patients.

6.2 Results

Cancer was the diagnosis at death in 29% of all deaths. The group of non-cancer deaths was representative of all other diagnoses at death, of which the most important were: cardiovascular diseases, diseases of the nervous system (including stroke) and diseases of the respiratory system, 31%, 12% and 7% of all deaths respectively. Cancer patients were younger than non-cancer patients, 73% being under 80, compared to 53% of the

Table 1 End-of-life decisions in cancer- and non-cancer patients (death certificate study)*

	Cancer n=2174 %	No cancer n=3023 %	All deaths n=5197 %
End-of-life decision made	59	31	39
Euthanasia/assisted suicide	4.6	0.8	1.9
Life-terminating acts without explicit request	1.7	0.5	0.8
Alleviation of pain and symptoms†	35 (46)	12 (17)	19 (25)
Non-treatment decisions†	18 (34)	18 (25)	18 (28)
No end-of-life decision made	41	69	61
Sudden death	8	39	30
Other cases where no end-of-life decision was made	33	29	31
Total	100	100	100

* All percentages are based on weighted data, so absolute numbers in the sample cannot be computed directly from percentages

† Between brackets: total percentage of this end-of-life decision including cases where also other important end-of-life decisions had been made.

non-cancer patients. Cancer patients were also more often male (57% versus 50%).

Table 1 presents the distribution of end-of-life decisions in the cancer- and non-cancer group. In 59% of all cancer patients and in 31% of all non-cancer patients an end-of-life decision was made. This difference can partly be explained by the higher percentage of sudden deaths in non-cancer patients, but it still exists within the group of non-sudden deaths (64% versus 52%, not in table). In 6.3% of cancer patients a drug was administered or supplied with the explicit intention to hasten the end of life (euthanasia or assisted suicide or a life-terminating act without the patient's explicit request), whereas this had been the case in 1.3% of non-cancer patients. Not surprisingly, pain alleviation was the end-of-life decision most frequently taken in cancer patients. It was the most important end-of-life decision in 35% of all cancer patients, while in another 11% it occurred together with other important end-of-life decisions, most often with non-treatment decisions. The proportion of deaths where a non-treatment decision was the most important decision, was equal in cancer and non-cancer patients, both 18%. This makes non-treatment decisions the most frequent end of life decision in non-cancer patients.

The respondents estimated that the life-shortening effect of the end-of-life decisions was less than a week in 75% of all cases; in 11% it was unknown. These figures did not significantly differ between cancer- and non-cancer patients.

6.2.1 Differences per specialty

Cancer patients died more often at home than in a hospital or nursing-home:

Table 2 End-of-life decisions in cancer- and non-cancer patients, according to specialty (death certificate study)*

	General practitioner		Clinician		Nursing-home physician	
	Cancer n=1196 %	No cancer n=1160 %	Cancer n=755 %	No cancer n=1011 %	Cancer n=215 %	No cancer n=771 %
End-of-life decision made	57	21	60	32	64	54
Euthanasia/ assisted suicide	6.7	1.3	2.9	0.7	0.8	0.0
Life-terminating acts without explicit request	1.2	0.1	2.6	0.9	-	0.3
Alleviation of pain and symptoms†	35 (45)	8 (10)	34 (46)	13 (18)	38 (46)	22 (29)
Non-treatment decisions†	14 (28)	12 (16)	20 (39)	18 (24)	26 (47)	32 (46)
No end-of-life decision made	43	79	40	68	36	46
Sudden death	6	54	9	31	10	18
Other cases where no end-of-life decision was made	37	25	31	37	26	28
Total	100	100	100	100	100	100

* All percentages are based on weighted data, so absolute numbers in the sample cannot be computed directly from percentages

† Between brackets: total percentage of this end-of-life decision including cases where also other important end-of-life decisions had been made.

50%, 40% and 10% respectively (39%, 41% and 21% respectively for non-cancer patients). Because the place of death determines what kind of specialist is responsible, this means that in half of all cancer deaths the general practitioner was the responsible physician during the final stage of the disease.

Table 2 shows some differences between specialties. Euthanasia was more often performed by the general practitioner than by the clinician, in cancer patients as well as in non-cancer patients, although the last difference was not significant. On the other hand, life-terminating acts without explicit request of the patient occurred more often in hospital. The proportion of cancer patients where a decision for pain alleviation as most important end-of-life decision was made differed not significantly between specialties. However, there were significant differences in the frequency of non-treatment decisions. At home, they were the most important end of life decision in 14% of cancer patients, while in the nursing-home this was 26%.

6.2.2 Patient-involvement

Table 3 shows the differences between cancer- and non-cancer patients with regard to patient-involvement: explicit requests of the patient for an end-of-life decision, discussion with the patient, or (in case of no discussion) a previous wish of the patient. Euthanasia and life-terminating acts without explicit request do not have to be discussed here further, because in the first

Table 3 Decisions for pain alleviation and non-treatment in cancer- and non-cancer patients: patient involvement and competence (death certificate study)*

	Alleviation of pain and symptoms		Non-treatment decisions	
	Cancer n=770 %	No cancer n=396 %	Cancer n=380 %	No cancer n=611 %
Decision discussed with patient	21	13	19	10
Decision at explicit request of patient	24	10	27	14
Not discussed, but previous wish	5	7	9	8
Not discussed and no previous wish, of which:	37	55	38	62
Patient not or not fully competent	61	75	83	91
Competence patient uncertain†	39	25	17	9
Unknown	14	15	7	7
Total	100	100	100	100

* All percentages are based on weighted data, so absolute numbers in the sample cannot be computed directly from percentages

† Explanation 'uncertain': see Results

there is always an explicit request (according to the definition generally used in The Netherlands) and in the second there is none.

Discussion with the patient or an explicit request from the patient for an end-of-life decision is much more common in cancer patients than in non-cancer patients. The differences in patient involvement cannot be explained by age or gender of the patient. They can be explained by the fact that more cancer patients than non-cancer patients were competent, i.e. they were able to assess their situation and to adequately make a decision about it (logistic regression analysis). Of all cases were the decision had been discussed with the patient, the patient was fully competent in 88% (decisions for pain alleviation) and 87% (non-treatment decisions) of cancer patients, and in 76% and 71% of non-cancer patients. Of all cases were no discussion had taken place, the competence was uncertain in a high proportion of cancer-patients: 39% in decisions for pain alleviation and 25% in non-treatment decisions versus 17% and 9% in non-cancer patients. In these cases the researchers were not able to establish the competence of the patient from the answers, partly because the answer to the 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 about this end-of-life decision would have done more harm than good'.

6.2.3 Reasons for euthanasia

In the interview study we asked several questions about the reasons for euthanasia. The most important considerations for performing euthanasia did not differ significantly between general practitioners and clinicians, the most prominent being the wish of the patient. The most important reasons the patients gave for their request for euthanasia, according to the physician, were 'unbearable situation'(70%), 'dread the future suffering'(50%), and 'unworthy dying' (46%). the frequencies in which these reasons were mentioned did not differ significantly between cancer- and non-cancer patients. Reasons that showed a difference were 'loss of dignity' (61% of cancer patients versus 34% of non-cancer patients), and 'pain' (52% versus 16%). There were no significant differences between the patients of the general practitioner and the clinician. Pain as only reason for euthanasia was mentioned in 3% of cancer patients versus 1% of non-cancer patients.

In 70% of cancer patients where euthanasia was performed, opioids had been given to alleviate pain and symptoms versus 25% in non-cancer patients, but the opioids had helped sufficiently in only 35% and 65% of those patients, respectively. Again, there were no differences between general practitioners and clinicians.

6.2.4 Borderline area

The decision to alleviate pain and or symptoms, with probably life shortening effect, was the most important end of life decision in 19% of all deaths (study II). In some of these cases it was the physician's explicit purpose also to hasten the end of life. In those cases, it is not always possible to make a strict distinction between pain alleviation and euthanasia or life-terminating acts without explicit request.

The total of euthanasia, assisted suicide and life-terminating acts without explicit request of the patient amounts to 2.7% of all deaths in study II and to 4.7% in study III. After detailed comparison of the studies we concluded that the 2% difference could be considered as an indication of the size of a borderline area between euthanasia and life-terminating acts without explicit request of the patient on the one hand and decisions for pain alleviation on the other hand. These 2% are included in the above mentioned 19%.[7]

6.3 Discussion

The first issue to be discussed is the validity of the studies. In the Netherlands 27% of deceased persons died of cancer in 1990, which is comparable to other well developed countries. The proportions of cancer deaths in study II and III were 29% and 26% respectively. The response rates in all three studies were rather high (see chapter 2), although in study II the response rates related to those deceased in hospital differed from those deceased elsewhere (64% versus 81%). Detailed analysis did not show any bias due to non-response. Furthermore, we could guarantee complete anonymity, and immunity against legal prosecution based on the data. Taking these facts together, we are convinced that the physicians answered honestly and that no serious biases exist in the material.

From the results, it can be concluded that terminal cancer patients differed from terminal non-cancer patients in several respects:

- They were younger, more often male, and died more often at home.
- Decisions for pain alleviation, euthanasia and life-terminating acts without explicit request of the patient occurred three to six times more often in cancer patients.
- Cancer patients were more often involved in the decision making process of an end-of-life decision.
- The general practitioner performed significantly more often euthanasia in cancer patients than the clinician, but the clinician performed more often life-terminating acts without explicit request of the patient.

A plausible reason for the fact that cancer patients die at home more often is that the course of the disease leaves sufficient time to arrange terminal home care. Also, since cancer patients are relatively young, the partner or other relatives may still be able to help.

Why are more end-of-life decisions made in cancer patients than in non-cancer patients? Most likely, cancer more often leads to intolerable suffering, and is more often accompanied by severe pain. Moreover, the chronic course of fatal cancer and the frequent and intensive contact between patient and doctor during that period offer more opportunity for discussion and (anticipatory) decision making.

There is much literature about pain in cancer patients. Often, pain in cancer patients is not relieved sufficiently, leaving 60% to 90% of cancer patients with advanced disease with substantial pain.[3-5] In a study in the Netherlands in 1988, 45% of hospitalized cancer patients were found to be in pain.[10] Oster found that approximately 72% of patients dying of cancer were in pain, against 45% of patients dying of other diseases.[11] The barriers to optimal pain management include overconcern about narcotic addiction, addiction, and respiratory distress, lack of expertise in the administration of analgesics, lack of understanding of the pathophysiology of cancer pain, and lack of time for palliative treatment.[12-17]

It could be questioned if Dutch doctors are not too much concerned about the life-shortening side-effect of opioids, considering the large number of decisions for pain alleviation, where the physicians said that they took the life-shortening effect into account. In fact, respiratory depression is a rare side-effect of adequate pain management.[15]

It is often suggested that adequate alleviation of pain and/or symptoms and better personal care of the dying patient would make euthanasia unnecessary. On the other hand the World Health Organization states that in a small percentage (less than 10%) of cancer patients pain can not be relieved sufficiently.[2] This is compatible with the fact that in half of the 4.6% of cancer patients in which euthanasia was performed, pain was an important reason for their request. Furthermore, one should bear in mind that in only 3% of euthanasia cases pain was the only reason for the patient's request.

Recently, much attention has been paid to optimal pain treatment for cancer patients in the Netherlands. In 1990, the Ministry of Health distributed a 64 page booklet for every practising physician, with practical information about possibilities for pain treatment.[18] Most regional hospitals nowadays have a special pain-team, which can also be consulted by general practitioners. Of course, improvements are still possible.

The fact that the frequency of end-of-life decisions differs per specialty has probably several causes, of which differences in patient population and work situation may be the most important. Non-treatment decisions, for example, are typically made in older patients, which explains why the nursing-home physician makes such decisions more often. The general practitioner on the other hand will more frequently refer patients to the clinician, leaving the decisions to treat or not to treat to him. For euthanasia and life-terminating acts without explicit request the explanation of the differences between physicians is more difficult. The fact that euthanasia is more often performed at home may reflect the choice of the patient who requests euthanasia. The larger number of life-terminating acts without explicit request of the patient in hospital may reflect the larger proportion of patients who are dying under extreme suffering but who are not competent to express their wishes.[9]

Patient involvement in an end-of-life decision only makes sense if the patient is aware of his prognosis. In the past the withholding of this kind of information, especially for cancer patients, was no exception. In the Netherlands it is nowadays generally accepted that the patient knows his diagnosis. But, according to the results, this does not imply that a patient will always be involved in the process of a decision that might shorten or not further prolong life. In those cancer patients where decisions for pain alleviation or non-treatment were not discussed, a relatively high number of physicians answered that such a discussion could have harmed the patient or that this decision was the best for the patient. In a certain amount of these cases the patient was probably competent. It seems that there is still some reluctance on discussing end-of-life decisions openly with the patient.

6.4 Conclusion

In the future, the number of end-of-life decisions will increase, the absolute and relative increase of cancer deaths being an important reason. Therefore, the decision-making process in terminal cancer needs special attention. End-of-life decisions in cancer patients are not equally spread over the specialties, being partly patient-related and probably partly physician-related. Furthermore, although cancer patients are more often involved in the decision making process, there is certainly still room for improvement.

Further research is required into the reasons for the differences between specialties and the differences in patient involvement. This could contribute to a better training of physicians in the decision-making process at the end of the patient's life.

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7 Euthanasia: do doctors comply with the guidelines?*

7.1 Introduction

Guidelines developed in the past years play an important role in the discussion about euthanasia. Also, the reporting procedure has a prominent place in this discussion. This chapter contains the results on medical decisions concerning the end of life, as far as they relate to the guidelines and the reporting procedure. This investigation was commissioned by the Committee of Inquiry into the Medical Practice concerning Euthanasia, chaired by prof.mr. J. Remmelink. The investigation had four objectives:[1-3]
- Quantitatively correct estimates had to be presented of the incidence of euthanasia and other important decisions.
- Characteristics of the patients and physicians involved and circumstances under which decisions were taken had to be described.
- The amount of knowledge of physicians concerning the guidelines with respect to euthanasia and its translation into practice had to be investigated.
- Conditions had to be explored under which physicians would be prepared to report euthanasia truthfully.

The third and fourth objective of this investigation will be described in this chapter.

7.2 Results

Almost all physicians answered the question 'Are you aware of the existence of the guidelines with respect to euthanasia?' in the affirmative (table 1). The respondent was then asked to mention several guidelines. Table 1 summarises both the guidelines as formulated by the Royal Dutch Medical Association, by the National Health Council, or in the 1987 bill and the percentage of respondents mentioning one or more of these guidelines spontaneously. Respondents mentioned an average of 3.3 guidelines. Almost all respondents who were aware of the existence of the guidelines mentioned 'consultation with colleagues', about two thirds mentioned 'seriously considered request of the patient'; all other guidelines were mentioned less frequently. Of the physicians involved, 76% mentioned at least one of

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* Van der Maas PJ, Van Delden JJM, Pijnenborg L. Ned Tijdschr Geneeskd 1991;135:2082-8

Table 1 Respondents' knowledge of the guidelines with respect to euthanasia (physician interviews)

	General practitioner n=152 %	Specialist n=202 %	Nursing-home physician n=50 %	Total n=404 %
Aware of existence of guidelines	99	94	100	98
If above question is answered affirmatively:				
Guidelines mentioned*†:				
Voluntariness	42	40	49	42
Seriously considered request	71	54	76	66
Long-standing desire to die	16	15	47	18
Suffering not acceptable for patient	41	26	37	37
Consultation with colleague	90	87	94	89
Explanation of diagnosis, course of illness and alternative therapies	10	13	18	11
Relatives were informed unless patient did not wish this	15	23	2	16
Written report on decision-making	44	23	25	37

* More than one reply could be given to this question.

† The 8 mentioned guidelines are formulated by the RDMA, the National Health Council, or in the bill of 1987.

the three guidelines concerning the request of the patient ('voluntariness','seriously considered request','long-standing desire to die'). The fact that voluntariness was mentioned by fewer than half the respondents, however, does not necessarily mean that this would not be a grave consideration for the other respondents.

The fact that voluntariness regarding the request for euthanasia was considered obvious, is confirmed by the data of table 2. Respondents were asked to indicate their view of the degree of importance of several 'official' guidelines (that is the first 8 mentioned in table 1) and 'unofficial' guidelines on a scale from 1 to 5. The 5 categories were: unimportant, hardly important, more or less important, important, and very important. Most respondents who were aware of the existence of the guidelines felt that free choice, the carefully considered request and the technically faultless performance in particular were important or very important. Although all respondents mentioned consultation with colleagues as one of the guidelines, not all respondents found this important or very important. Of the general practitioners, 40% did not feel that consultation was (very) important.

Almost an identical distribution was found for replies to the separate question: 'Do you feel that a colleague should be consulted in all cases of euthanasia?'. Almost 40% of the general practitioners replied in the negative, as did 14% of the specialists and 10% of the nursing home physicians, respectively.

7.2.1 Compliance with the guidelines

Respondents were asked a great number of questions with the purpose of

Table 2 Opinion regarding the 'official' and the 'unofficial' guidelines for euthanasia (indicated are the number of physicians that found a particular guideline important or very important)

Guidelines	General practitioner n=151 %	Specialist n=201 %	Nursing-home physician n=50 %	Total n=402 %
'Official'*				
Voluntariness	98	97	98	98
Seriously considered request	99	97	100	99
Long-standing desire to die	75	69	90	74
Suffering not acceptable for patient	95	94	96	95
Consultation with colleague	60	79	90	67
Explanation of diagnosis, course of illness and alternative therapies	90	98	94	93
Relatives were informed unless patient did not wish this	72	73	80	73
Written report on decision-making	51	70	92	59
'Unofficial'				
Technically faultless performance	99	97	100	99
Incurable disease	78	89	66	81
No treatment alternatives	57	78	74	64
Patient dying	66	59	40	63
Nursing staff must be involved in decision-making	33	73	82	47
No unnecessary suffering for others	40	57	52	46

* The 'official' guidelines correspond with the guidelines mentioned in table 1.

detecting the extent to which they had complied with the guidelines on euthanasia and assisted suicide (table 3). In nearly all cases, the patient had made a voluntary request for euthanasia or assisted suicide. Moreover, virtually all cases involved a long-standing and carefully considered desire to die, as evidenced by the large percentage of repeated requests and the considerable percentage of patients who had a good understanding of their illness and prognosis.

In almost 80% of cases, no therapeutic alternatives were available to the patient. In those cases where alternatives were present, these were not applied by the respondent, as in almost all instances permission to do so was refused by the patient. A colleague was consulted in 84% of cases.

One of the strict guidelines proposed by the Cabinet in 1987 is that relatives of the patient must be informed, unless the patient does not want this. Table 3 shows that this guideline was followed in almost all cases.

The guideline on recording the decision-making process was complied with less stringently. Somewhat more than one half of the general practitioners and three quarters of the specialists kept adequate records.

In addition to euthanasia and assisted suicide there are also cases in which life is terminated without explicit request of the patient. Our best estimate is that physicians prescribe, supply or administer a drug with the explicit purpose of hastening the end of life without explicit request of the

Table 3 To what extent with the guidelines for euthanasia complied with?* (physician interviews)

	General practitioner n=94 %	Specialist n=87 %	Total n=187 %
Request of the patient			
Explicit request	97	91	96
Request made wholly by the patient	99	97	99
Repeated request	94	94	94
Patient had good insight into disease and prognosis	100	99	100
Alternatives			
No alternatives	77	84	79
Alternatives but patient no longer want them	17	16	17
Consultations			
Consult with colleagues	81	93	84
Relatives informed	97	85	94
Relatives not informed because there were none	-	9	2
Relatives not informed because patient did not want this	2	1	2
Relatives not informed for other reasons	1	5	2
Records			
Written records kept	54	74	60

* Nursing-home physicians are not mentioned separately but were included in the total.

patient in 0.8% of all deaths annually. In these cases, the guideline calling for an explicit and repeated request was not observed. Virtually all cases involved severely ill or terminal patients who were clearly suffering greatly and who were no longer able to make their wishes known. In more than half of these cases, the decision had been discussed with the patient, or the patient had at some time indicated his wish to have the end of life hastened. In several cases, there had been no consultation with others (family or relatives, colleagues). In a small number of cases there had been no consultation while this would have been possible. There was also a select number of cases where life had been shortened by more than half a year and, in the opinion of the physician, the patient clearly had not yet reached the terminal stage of his illness.

Intensifying the alleviation of pain and/or symptoms through administration by the physician of morphine or similar drugs in doses such that he at least takes into account the probability that the end of life will be hastened was a very frequent decision and the most important end-of-life decision in 17.5% of deaths.[1] In some of these cases, hastening the end of life was (partly) the explicit purpose. In the latter case, making a formal distinction between this action and euthanasia or acting to terminate life without explicit request of the patient is not always possible. In addition to situations meeting the definition of euthanasia, there are several decisions and actions that can be considered as part of the accepted actions of the medical profession. This boundary area between euthanasia or performing a life-terminating act without specific request on the one hand and intensifying the alleviation of pain and/or symptoms on the other hand can be estimated to comprise about 2% of all deaths. This 2% is part of the above mentioned 17.5%. In cases where life-shortening was the explicit intention of the alleviation of pain and symptoms, the patient had at some point expressed his or her wishes on this matter or had explicitly requested his or her life to be terminated.

7.2.2 Opinions about examining and reporting

Some two thirds of specialists and nursing home physicians answered in the affirmative to the question: 'Do you feel that each case of euthanasia should be somehow examined?' About 30% felt that this was sometimes, but not always necessary and a small minority felt that euthanasia need never be examined. It is not possible to determine whether all the respondents interpreted this question the same way. It could have been seen as referring only to legal examination (table 4). Those who felt that all or only some cases of euthanasia needed to be examined, were subsequently asked who should examine a case of euthanasia or assisted suicide in the first instance and who in the second instance, in cases that could not pass the examination in the first instance. In the opinion of specialists and nursing home physicians, especially physicians are the candidates of choice for performing the first examination. A medical ethics committee, an institutional committee of colleagues or an independent medical examiner would be suitable. If a case

Table 4 The opinion of specialists and nursing-home physicians on the questions whether euthanasia should somehow be examined

	Specialist n=199 %		Nursing-home physician n=50 %		Total n=249 %	
Do you feel that each case of euthanasia should somehow be examined?						
Yes	61		76		64	
No, but sometimes yes	31		22		29	
No, never	9		2		7	
Total	100		100		100	
Only for respondents answering 'yes' or 'sometimes' to the above stated question: Who should test in 1st or 2nd instance (see text)*						
	1st	2nd	1st	2nd	1st	2nd
Public prosecutor	7	25	25	49	10	30
Medical tribunal	2	17	4	31	2	20
Coroner	8	3	10	6	9	3
Health inspector	15	38	14	35	15	37
Medical-ethical committee	35	11	37	12	35	11
Institutional committee of colleagues	52	11	27	2	47	9
Independent medical examiner	30	16	35	6	31	14
Other	12	10	8	4	12	9

* More than one answer could be given to this question.

does not pass the first examination, a health inspector or public prosecutor should be considered for the next examination.

The question concerning the examining of cases of euthanasia was put in a different manner to general practitioners, who had been interviewed on the basis of an earlier version of the questionnaire.

The question 'Do you feel that each case of euthanasia should be examined legally?' was answered in the affirmative by 30% of general practitioners. The following question: 'Do you feel that in each case of euthanasia it would be sufficient to use in first instance a form of examination to be performed by colleagues according to a fixed protocol?' was answered in the affirmative by 69%. Some 15% of general practitioners added comments to their answers (e.g.:'yes, legally but not by a criminal judge').

All respondents were also asked what would be the conditions under which they would be prepared to report truthfully that euthanasia had been performed. The question was put as follows: 'What would be the conditions under which you feel that one can require a physician to report to the police, coroner or legal authority a case of euthanasia as an unnatural death?'

The answers are presented in table 5. Respondents had to formulate the conditions themselves. No possible answers were offered.

More than a quarter of the physicians felt that euthanasia should always be reported as unnatural death; 22% of physicians felt that this could never be demanded from a physician. One in three general practitioners mentioned as condition that relatives must not be questioned by police. One quarter of physicians mentioned prosecution as objection to reporting euthanasia.

In the proposals for a modified procedure (put forward by 20% of all respondents) emphasis was often placed on the fact that police must

Table 5 Under what conditions would physicians be prepared to report euthanasia as euthanasia to police, coroner or legal authority* (physician interviews)

	General practitioner n=149 %	Specialist n=201 %	Nursing-home physician n=49 %	Total n=399 %
Always	23	29	51	27
Only under the following conditions:				
If reporting does not lead to questioning of relatives by police	35	20	22	30
If reporting does not lead to prosecution	22	29	29	24
If reporting procedure is modified, i.e. (see text)	21	18	14	20
If reporting does not lead to confiscation of body	15	9	12	13
If guidelines were not applied	3	3	-	3
If considerable life-shortening was involved	2	4	-	3
Under no condition	26	17	8	22
Other	7	8	4	7

* More than one answer could be given to this question.

proceed with discretion. Many of the physicians making these kind of suggestions emphasise that they would be prepared to report euthanasia as such but do not wish to be considered as a suspect in a criminal act. Also, the uncertainty of what might happen to the physician is considered as an obstacle to making a report of unnatural death. Physicians indicated that they needed a careful, clearly formulated procedure that would not be drawn out for months on end.

7.2.3 Death certificate and reporting

After performing euthanasia or assisted suicide, three quarters of the general practitioners and about two thirds of the specialists reported these as cases of 'natural death' in the death certificate (table 6). Of the six cases reported by nursing home physicians, however, in only a single case was the cause of death reported to have been natural. The most important reasons for declaring death to have occurred naturally were: the 'fuss' of a legal investigation (55%), fear of prosecution (25%), the desire to protect relatives from a judicial enquiry (52%) and bad experiences in the past with stating unnatural death (12%). Moreover, the fact that 8 general practitioners and 15 specialists declared that, in spite of euthanasia or assisted suicide, they had experienced the patient's death as a natural one is noteworthy.

If no declaration of natural death was made, the coroner was contacted in 60% of the cases, the police in some 40% and the public prosecutor in some 40%. The inspector of health was contacted in only a small minority of cases. It is striking to note that general practitioners contacted the police much more often than the specialists. Specialist were far more likely to contact the public prosecutor.

Of the 97 cases in the interview study of life-terminating acts without explicit request of the patient, the death certificate almost always stated that the patient died a natural death. Only one general practitioner reported

Table 6 Death certificate in case of euthanasia or assisted suicide* (physician interviews)

	General practitioner n=93 %	Specialist n=85 %	Total n=184 %
No declaration of natural death made	25	35	28
In that case contact set up with†:			
Municipal coroner	65	45	60
Police	57	10	42
Public prosecutor	35	62	42
Inspector of health	9	4	8
Declaration of natural death made	75	65	72
Total	100	100	100

* Nursing-home physicians are not mentioned separately but were included in the total.

† More than one answer could be given to this question.

'unnatural death' to the public prosecutor. In this case the public prosecutor decided not to prosecute. The most important reasons for certifying that the death was a natural one were the 'fuss' of a judicial investigation (47%), the view that the death was in fact natural (43%) and the desire to protect relatives from a judicial enquiry (28%).

7.3 Discussion

This investigation provides answers to the questions about the opinions and the practice of physicians with regard to the guidelines and the reporting of euthanasia. Seven types of physicians were selected in the sample: general practitioners, nursing-home physicians, cardiologists, surgeons, and specialists in internal medicine, chest disease, and neurology. By interviewing these physicians systematically, the information obtained refers to 95% of all deaths in the Netherlands. To extrapolate the results to the total number of deaths in the Netherlands, weights were derived, taking into account the stratification of the sample and the non-response rate. Selection effects due to the sampling procedure and non-response could not be found, so the results are probably representative of Dutch physicians from the disciplines sampled. With regard to the opinions of the physicians, it should be kept in mind that physicians who have only few or no death cases in their practice, such as some types of specialists, were not interviewed. The division of the discussed opinions applies only for the seven mentioned types of physicians. Since these physicians come into contact with dying patients, their opinions about the guidelines and the reporting procedure is especially important.

It appears from the investigation that the interviewed physicians were aware of the existence of the guidelines, and that they could mention an average of 3.3 guidelines out of the 8 'official' ones. Moreover, it may well be that the respondent felt that one or perhaps even several of the guidelines were too obvious to rate a mention (e.g. the voluntariness of the request). However, demonstrating familiarity with a particular guideline does not mean that it is considered important or very important. For example, 89% of respondents mentions as guideline 'consultation with a colleague', whereas only 67% indicates it as (very) important. A written report is mentioned spontaneously in 37% of cases only, yet only 59% of physicians found this to be (very) important.

On the whole, it may be concluded that the decision-making process in respect of euthanasia is careful; the results of the interviews indicate as much. Moreover, a considerable amount of information other than the quantitative information obtained in the interviews points in the same direction: the decision for euthanasia or assisted suicide is never taken lightly.

Many respondents indicated spontaneously that the increasing openness around this subject and the fact that the forming of opinion has resulted in guidelines in the past years, has improved the quality of the decision-making process.

An important stumbling block is the written report, which failed to be made in 40% of cases. Another important limitation is the fact that no declaration of natural death was delivered in only 28% of all cases. These findings correspond closely with Van der Wal et al.[5,6] They conclude that the majority of physicians complies with the material guidelines adequately[5], whereas this is much less the case with regard to the procedural guidelines (obtaining advice of a colleague, written reports, and not delivering a declaration of natural death).[6]

Apart from euthanasia and assisted suicide, all other decisions concerning the end of life also require careful decision-making. Particular attention should be paid to the life-terminating acts without explicit request of the patient (0.8% of all deaths) and the 2% of deaths in which the boundary between 'the intensification of the alleviation of pain and symptoms' on the one hand and 'euthanasia' and 'life-terminating acts without explicit request of the patient' on the other hand is not clearly cut. In most of these cases there is only a minor shortening of life, according to the physician (some hours or days at the most), but in a small number of cases there is considerable life-shortening. It is precisely in these decision situations that extra carefulness is required.

It appears from this investigation that most physicians agree that cases of euthanasia should be examined. They would prefer examination by colleagues in first instance; a medical ethics committee, an institutional committee of colleagues or an independent medical examiner would be suitable. If a case does not pass the first examination, a public prosecutor or health inspector or the medical tribunal should be considered for the next examination.

It should be kept in mind that any examination procedure can only achieve its aim if at least two conditions are met. First, the procedure should be totally clear with respect to objective, criteria, steps of actions, (possible) consequences and total period of time. Second, physicians must receive training in dealing with euthanasia and other medical decisions concerning the end of life. This includes going through the decision-making process (together with others), determining the motives of the patient, and the evaluation of medical aspects and all other relevant factors, as in the end, the quality of medical decisions concerning the end of life is determined by human and professional qualities of the physician and the nurses, and regulation can only give some support at the most.

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8 Life-terminating acts without the patient's explicit request*

8.1 Introduction

The euthanasia debate in the Netherlands has focused whether or under what conditions a physician might be allowed to comply with a patient's request for such an action. It might seem self-evident that any life-terminating act without the explicit request of the patient should be considered murder. Yet there remains the uneasy feeling that some very important questions are being obscured. What is the responsibility of a physician towards a patient whom he has treated for many years and who is dying in great pain but unable to express any wish to be spared further suffering? Might not some doctors consider it their responsibility in such circumstances to shorten the patient's life by hours or days? The wish for clear-cut lines of demarcation is understandable but the suffering and death of a human being can give rise to a tension with generally accepted rules. This issue has been covered by studies done for the Dutch Commission of Inquiry into Medical Practice Concerning Euthanasia, which was set up in 1990 to look at all important 'end-of-life decisions'. One of these is a life-terminating act without the explicit request of the patient (LAWER). We found that this happens in about 0.8% of all deaths in the Netherlands (the figure for euthanasia is 1.8%). This finding[1,2] has disturbed many of those who have been following the euthanasia debate and we felt that more details of the circumstances of such events should be disclosed.

8.2 Methods

The methods used in the three studies - interviews with physicians, questionnaires to physicians attending patients who died, and a prospective study of respondents to the interviews - are described in chapter 2. Here we will focus on how information on LAWER was elicited.

Interviews

Questions on LAWER were introduced by pointing out that 'There are situations in which it is decided to perform a life-terminating act without the

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* Pijnenborg L, Van der Maas PJ, Van Delden JJM et al. Lancet 1993;341:1196-9

patient's request to do so. This can occur if the patient had made only vague remarks but not an explicit request. Other situations are those in which a patient is no longer able to make such a request or if the condition of the patient is evidently intolerable'. The interviewer was told to consider as 'acts' only the administration of drugs and not, for example, the withdrawal of artificial respiration. The interviewee determined what was non-explicit request - e.g., no request at all or a request that was not explicit.

There were 37 questions on the most recent LAWER-case (if any). The interviewer was instructed to work up a case report on the most illustrative end-of-life decision arising during the interview. Sometimes this was a case of LAWER. In total detailed information was available on 97 LAWER-cases.

Death certificate study and prospective study

The questions most pertinent to LAWER were: 'Was death caused by the use of a drug prescribed, supplied or administered by you or a colleague with the explicit purpose of hastening the end of life?' and 'Was the decision concerning that action taken upon an explicit request of the patient?' If the answers were 'yes' and 'no' respectively, that death was considered to be LAWER. The total number of LAWER cases in the death certificate study was 47 and in the prospective study 44.

All estimates are based on small numbers, for LAWER is a rare event. The numbers yielded by the prospective study are very similar to those from the death certificate study and any differences will be mentioned. More than half the cases in the interview study arose before 1985, and this study is the source of illustrative case histories only, unless otherwise specified.

8.3 Results

The frequency of LAWER was 0.8% in the death certificate study and 1.6% in the prospective study. This difference probably reflects a grey area between LAWER and the alleviation of pain with opioids at dosages that might have shortened life.[2]

At interview 27% of respondents said that they had performed LAWER at least once, 32% never have but could conceive of a situation where they would be willing to do so; and 41% never would.

Some characteristics of the patients (e.g., age, sex, diagnosis) and the physicians are summarised in table 1.

Information about the patients' wishes and competence the physicians' consultations with others, and the life-shortening effects of LAWER and euthanasia are compared in table 2. In 59% of all LAWER the physician had information about the patient's wishes (discussion with the patient and/or a

Table 1 Patient- and physician-characteristics of LAWER and to other end-of-life decisions (death certificate study)*

	% of LAWER (n=47)	% of other end-of-life decisions† E/AS (n=157)	APS (n=1166)	NTD (n=991)	% of non-acute deaths‡ (n=4007)
Age					
0-49	21	10	6	7	6
50-64	20	25	17	9	13
65-79	23	44	40	32	37
80+	36	21	37	53	44
Males	65	59	48	46	50
Diagnosis of cancer	60	71	54	29	39
Type of physician					
General practitioner	26	70	38	29	37
Specialist	69	29	40	42	43
Nursing home physician	5	1	22	30	20

* Percentages based on weighted data so percentages cannot be computed directly from absolute numbers

† E/AS= euthanasia or assisted suicide; APS = alleviation of pain and symptoms; NTD = non-treatment decisions

‡ Non-acute deaths form 70% of all deaths. In 54% of non-acute deaths an end-of-life decision has been made.

Table 2 Decision characteristics in LAWER compared with those in euthanasia and assisted suicide (death certificate study)*

Decision-characteristics	% of LAWER (n=47)	% of euthanasia or assisted suicide (n=157)
Discussion, request, previous wish		
Discussed, explicit request	-	100
No explicit request, but discussed or previous wish	59	-
No discussed and no previous wish	41	-
Competence		
Competent	36	99
Not competent	56	1
Unknown	8	-
Decision discussed with:		
Colleagues	70	84
Nursing staff	66	38
Relatives	83	89
No-one	2	-
Shortening of life		
< 24 hours	42	18
1 day to 1 wk	44	40
1 to 4 wk	6	25
More than 1 mo	8	17
Unknown	-	1

* Percentage based on weighted data so percentage cannot be computed from absolute numbers.

previously expressed wish) short of an explicit request. In all other cases discussion with the patient was no longer possible. In 56% of cases the patient was thought to be able to assess his situation and to make a clear decision. In 41% of cases where the decision had not been discussed with the patient (because that was not possible) and the patient had not expressed a wish previously, the family had asked for hastening of the end of the patient's life. In 70% of all cases the decision had been discussed with a colleague an in 83% there had been discussion with relatives. In 2% a physician had made the decision without discussing it with anybody. In 86% of cases life was shortened by few hours or days at most. The physician knew his patient on the average 2.4 years (specialist) and 7.2 years (general practitioner). 2.3% of the general practitioners and 31.3% of the specialists knew their patient less than one month (interview study).

8.4 Case histories

The spectrum of LAWER will be illustrated by three examples.

Case 1 (information on patient's previous wish)
An 81-year-old woman terminally ill with breast cancer and widespread bone metastases wanted to die at home. The general practitioner, who had known her for 8 years, visited her regularly. The pain became more and more difficult to alleviate with opioids. The patient repeatedly mentioned that if her situation were to become degrading or the suffering unbearable 'everything should be finished' but consciousness deteriorated rapidly and this was never an explicit request. When the decubitus became extensive and pain could no longer be relieved, the doctor, after discussions with a colleague, the home care nurse, and the patient's son, gave a very high dosage of opioids to shorten life. The patient died half an hour later. The doctor estimated that life was shortened by a week at most. As with other patients in this LAWER category the patient's wish was not perceived as an explicit request.

The fact that something was known about the patient's wish about life-ending was not always the most important consideration. As in this case, the hopelessness of the situation, the unbearable suffering, and the futility of further medical treatment were usually the most important factors (interview study).

Case 2 (no information about patient's wish)
A 75 year-old-woman, 3 years after her first stroke, was admitted with a basilar artery thrombosis. She was totally paralysed and her consciousness

deteriorated rapidly. Bronchitis developed and worsened despite antibiotics. That there was no chance of improvement was confirmed by a colleague, and asphyxia seemed imminent. The patient had never expressed a wish about life-ending, but the physician knew that patient very well. Her family first mentioned life-ending and the decision to do this was discussed with a colleague, nurses and husband. The most important considerations were the avoidance of a prolonged terminal phase and the threat of asphyxia. After high-dose opioids the patient died within an hour and her life was estimated to have been shortened by less than 24 hours.

Case 3 (no information about patients' wishes; life-shortened by at least 1 month).
A few cases are exceptions to the more typical cases 1 and 2, and the most important of these are where life was shortened by at least a month (8%, prospective study 0%). A 64-year-old man with a brain tumour was permanently unconscious and frequent seizures could not be controlled. He was not on opioids. No treatment alternatives or chance of improvement remained, and this was confirmed by another physician. After discussion with a colleague, nurses, and the patient's wife - the main arguments being the very poor quality of life with no chance of improvement, further treatment being futile - the specialist gave potassium chloride by intravenous drip. Death ensued within 3 minutes. Here the patient's life was shortened by 1-6 months.

8.5 Discussion

LAWER, largely ignored until recently, complicates the euthanasia debate, but before we try to interpret our findings we must discuss their credibility. For the study as a whole no indication of selection bias has been found.[2] The fact that the study was supported by government, the Royal Dutch Medical Association, and by the chief inspector of health, that anonymity and immunity were guaranteed and that physicians were interviewed (2½ hours on average) by experienced colleagues all support our impression that respondents answered honestly. The only other investigation of the incidence of LAWER, also in the Netherlands[4], was based on a questionnaire survey and indicated 100 cases a year in general practice. Our estimate is 270 and this is probably a reliable figure because it comes mainly from a sample of death certificates and does not rely solely on 'most recent case' questions. The case described in JAMA in 1988[5] could be defined as LAWER but one important difference between this case and most cases in our study is that 'Debbie's' physician saw her for the first time the day, that her life was cut short while in our study the physician had usually known his patient for months or even years.

There are two ways to describe LAWER - that it is a physician killing a person who has become defenceless or that it is a response to the injustice that a patient unable to make an explicit request has to suffer to the end even when his or her doctor, who may have been responsible for this patient for a long time, and perhaps the relatives also feel confident that the patient's wishes would have been for life to be ended.

A doctor's duty to preserve life and to alleviate suffering are thus in conflict. In discussing this dilemma it is also important to keep in mind that the life-shortening effect in LAWER is smaller than that in euthanasia on request. Almost all LAWER cases involve patients with only a few hours or days to live.

Why is there no explicit request from the patient? A patient's situation may deteriorate rapidly and unexpectedly and he or she may become incompetent before there has been an opportunity to discuss the possible future course of action. Another reason may be that older patients (and their spouses) often expect the doctor to 'do what is best' and in extreme situations patient and family may expect the physician to act as a sort of proxy-decisionmaker between doctor and patient. For younger generations this may be different. A third cause may be that it takes courage, an open mind and time from doctors and patients alike to discuss death and the acceptance of terminal illness and the possibility of great pain may come slowly or not at all. Physicians indicated that the public debate about euthanasia in the Netherlands has meant that open discussion between doctor and patient has become easier. Situations in which nothing is known about the wish of the patient are likely to become less common while advanced directives, and the assignment of proxy-decisionmakers will become more common.

End-of-life decisions will increase in importance with demographic shifts towards older populations, with the increasing proportion of cancer deaths and with the growth in life-prolonging technologies. However, this does not mean that LAWER will increase too. In the debate that followed publication of our earlier findings the existence of LAWER was often taken to confirm a 'slippery slope' once euthanasia on explicit request is accepted. Our studies do not permit conclusions about trends[6-8] but comments from our respondents about the increasing possibilities for open discussion convince us that future increase in end-of-life decisions may well go together with a decrease in LAWER.

But it is unlikely to disappear since there will always be some situations in which terrible suffering, which can end only when the patient dies, arises when the patient cannot give a clear judgement about the desired course of action. Many doctors in the Netherlands feel that in such exceptional situations LAWER can be justified. Safe-guards must include optimal palliative care, discussion with relatives, a colleague, and nurses, and reporting, and the absence of economic motives. In this last respect it must be noted that in the Netherlands 99.4% of the population is comprehensively insured for medical expenditures and 100% for the costs of long-standing illness. The ending of a patient's life never produces financial gain for the physician.

Legal regulation of euthanasia on request has proven very difficult, even in the Netherlands, and regulation of LAWER may even be impossible, making it likely that such acts will always remain an act against the law. Nevertheless, the answer to the question: 'LAWER: murder or medical practice?' must be 'Neither'. When all the safeguards are respected and only the best interests of the patient are taken into account, it is certainly not murder. Yet it is not normal medical practice either, and LAWER will always to be an exception to normal practice. We conclude, as in our previous articles[1,2] that open discussion, starting from the premise that end-of-life decisions have to be made in any country with high standards of medical care, will contribute to a better quality care for the dying. Such discussion may reduce the incidence of LAWER and will improve decision-making in those cases that, inevitably, remain.

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Part IV
Physician characteristics

9 End-of-life decisions in general practice*

9.1 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 in 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 chapter 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 the 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 practice 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 about the end of life and in the decision making process.

The methods are described in chapter 2.

9.2 Results

In 1990 about 129,000 deaths occurred in the Netherlands: 42% at home, 41% in a hospital, and 16% in a 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 1 shows some characteristics of patients according to the type of attending doctor. The mean age of patients who died in general practice was

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* Pijnenborg L, Van Delden JJM, Kardaun JWPF et al. 1994;309:1209-12

Table 1 Age, sex, and diagnosis of the died patients, according to type of physician (study II)*

	General practitioner n=2356		Clinician n=1766		Nursing-home physician n=986		Total n=5108	
	%	n	%	n	%	n	%	n
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
Sex								
Male	54	1280	55	963	37	363	51	2606
Diagnosis								
Cancer	36	1196	29	755	17	215	30	2166
Cardiovasc. diseases	34	544	33	383	19	165	31	1092
Nervous system	8	177	11	171	23	216	12	564
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.

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 are excluded from the denominator, the numbers were 54%, 54%, and 67%, respectively. Table 2 presents the distribution of end of life decisions made for each type of physician (excluding sudden deaths). Decisions about pain relief non-treatment were commonly made by all physicians. The withholding of antibiotics and no (further) diagnosis were the non-treatment decisions most often

Table 2 Decisions about the end of life made in patients who did not die suddenly, according to type of physician (study II)*

	General practitioner		Hospital doctors		Nursing-home physician		Total	
	%	n	%	n	%	n	%	n
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
Non-sudden deaths where no end-of-life decision was made	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 3 Reasons for not discussing the decision about pain relief or non-treatment with patient*, according to type of physician (study II)†

	General practitioner n=361		Hospital doctors n=360		Nursing-home physician n=398		Total n=1119	
	%	n	%	n	%	n	%	n
a Diminished consciousness	65	227	80	285	53	204	67	716
b Dementia	20	62	8	27	60	237	29	326
c Clearly the best for patient	34	129	18	72	13	53	21	254
d Would have done more harm than good	11	42	6	22	4	15	6	79
c or *d* 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.

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 the general practitioners, once in four years for the clinicians (selected specialties), and once in 14 years for doctors in nursing homes.

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

Table 3 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 cases the general practitioners answered that they had not discussed the decision 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 4 and 5 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 4 and 5 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 (single-handed or other), region, and degree of urbanisation. Logistic regression analysis showed that the competence of the patient, consultation of 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.

Table 4 Relation between the general practitioner's discussion with the patient about an end-of-life decision and selected characteristics of patients and physicians (study III).

Characteristic	% of general practitioners who discussed decision with patient
Age patient***	
Younger than 80 (n=112)	66
80 or older (n=70)	40
Competence of patient***	
Competent or competence uncertain† (n=122)	80
Not competent‡ (n=58)	9
Consultation of a colleague***	
Yes (n=76)	84
No (n=104)	36
Extent of life-shortening***	
Less than a week (n=127)	47
A week or more (n=53)	79
Age of general practitioner**	
Younger than 50 (n=129)	64
50 or older (n=53)	38
General practitioner religious*	
Yes (n=75)	45
No (n=105)	64
Size of practice*	
Less than 2500 persons (n=115)	63
More than 2500 persons (n=67)	45

Chi-square test: *** $p<0.001$, ** $0.001<p<0.01$, * $0.01<p<0.05$

† In cases in which the competence was uncertain researchers were not able to establish the competence of patient from the 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 the patient must have taken place before the patient became incompetent.

The consultation of a colleague was significantly (P<0.05) related to the characteristics mentioned in table 5 (data from study III). Logistic regression analysis showed that discussion with the patient, younger age of the patient, shortening life by more than a week, and working in group-practice were all significantly and independently associated with the proportion of decisions in which a colleague had been consulted.

9.3 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.

Table 5 Relation between the general practitioners' consultation with colleagues about an end-of-life decision and selected characteristics of patients and physicians (study III).

Characteristic	% of general practitioners who discussed decision with colleagues
Age patient***	
Younger than 80 (n=111)	57
80 or older (n=69)	19
Competence patient***	
Competent or competence uncertain† (n=120)	54
Incompetent‡ (n=58)	19
Discussion with patient***	
Yes (n=101)	63
No (n=79)	15
Extent of life-shortening***	
Less than a week (n=125)	33
A week or more (n=53)	64
Size of practice*	
Less than 2500 persons (n=115)	49
More than 2500 persons (n=65)	31
Type of practice*	
Single-handed (n=102)	34
Other (n=78)	53

Chi-square test: ***$p<0.001$, ** $0.001<p<0.01$, * $0.01<p<0.05$

† In cases in which the competence was uncertain researchers were not able to establish the competence of patient from the 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 the patient must have taken place before the patient became incompetent.

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.

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 possibility 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 interview 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 long-standing 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 decision 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. That is perhaps why they more easily assume that they know what is the 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 from the United States than from Canada 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 patient dying at home 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.

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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10 Euthanasia: physicians' attitudes and practices

10.1 Introduction

Quite a number of articles have been written on the physicians' attitudes towards euthanasia. Recently, too, articles have started to appear on the euthanasia practice. No comparison between attitudes and practice of euthanasia, however, has ever been attempted. In 1990-1991 we performed the first nationwide study on end-of-life decisions in the Netherlands. The first results were published elsewhere.[1,2] In this chapter, physicians' attitudes and practice towards euthanasia will be studied by first comparing the characteristics of physicians who considered it inconceivable that they would ever perform euthanasia and of those for whom this is not inconceivable, and subsequently by comparing, in the latter mentioned group, the characteristics of physicians who have and those who have not actually ever performed euthanasia. Apart from some socio-demographic characteristics such as age, gender, specialty, and region of practice, other possibly explanatory variables such as religion, number of years of practice and number of deceased per year were also included in two descriptive models.

10.2 Methods

The interview questionnaire consisted of 122 pages about euthanasia and other medical decisions concerning the end of life. Euthanasia in the Netherlands is defined as an intentional act to terminate the life by a person other than the person involved, upon request of the latter. When we talk about 'euthanasia' in this chapter, we are actually referring to 'euthanasia or physician-assisted suicide', as the latter case differs from euthanasia only in respect of the person who administers the drug. The methods of the interview study were described in chapter 2. The questions about euthanasia were: 1. 'Have you ever performed euthanasia?' and 2. (if not) 'Can you conceive of situations in which you would be prepared to perform euthanasia?' Physicians who had already performed euthanasia at some time were assumed to find the decision conceivable.

To model the conceivability and practice of euthanasia two series of logistic regression analysis were performed. Stratification weights were used to calculate percentages and odds. Standard errors and significance tests (probability ratio tests, $p<0.05$) were based on numbers in the original sampling population.

Model I describes the probability of a physician conceiving of a situation in which he will perform euthanasia, and model II describes the probability of a physician actually having performed euthanasia at some point, given he can conceive of such a situation.

The explanatory variables that were used in the models were the following: type of specialty, age and gender of physician, region of practice, experience (number of years of practice, number of deceased in practice per year, number of requests for euthanasia per year), and religion (type of religion, role of religion with respect to euthanasia).

10.3 Results

Of the respondents, 87% were men, and 73% were under the age of 50. As regards their religious affiliation, 17% were Roman Catholic, 16% were Protestant, 5% described themselves as Christians, 5% had another affiliation, and 57% had no affiliation; for 43% of those with a religious affiliation, religion had played an important role in their thinking on euthanasia, for 28% it was somewhat important, and for 30% it was not important (table 1). The physicians in the sample did not differ from the total population of physicians in the Netherlands in terms of sex, age, and region of practice.

10.3.1 Conceivability of performing euthanasia (model I)

Twelve percent of all physicians could conceive of no situation in which they would perform euthanasia. Model I shows the relation with some physician characteristics (table 2). Type of specialty was related to this ($p=0.006$); the odds ratios of the general practitioners and the internists were 3.5 times as high as the odds of the nursing-home physicians, indicating that a larger proportion of this first group might be willing to perform euthanasia. The conceivability of performing euthanasia was also significantly related to age, gender, region of practice, and the importance attached to religion ($p<0.05$). A larger proportion of physicians under 50, of female physicians, of physicians working in the northern part of the Netherlands, and of physicians without any religion could therefore conceive of situations in which they would perform euthanasia. Furthermore, a positive relation was found between having received at least one request for euthanasia and the conceivability of performing euthanasia. There was no relation to the number of deceased per practice per year. Nor was the model improved by including faith (Roman Catholic, Protestant etc.).

Table 1 Sample characteristics

	n	%*
Specialty		
Nursing-home physician	50	7
General practitioner	152	65
Cardiologist	34	4
Surgeon	34	8
Internist (incl. oncologists)	68	10
Lung specialist	33	3
Neurologist	34	4
Age		
50 or older	104	27
Younger than 50	301	73
Gender		
Male	346	87
Female	59	13
Region		
South	84	22
West	196	47
East	80	20
North	45	11
Has had request last year		
No	242	58
Yes	162	42
Role religion in medical practice		
Religion is very important	72	18
Is religious, but no important role	111	25
Is not religious	221	57

* All percentages are based on weighted data, so percentages cannot be computed directly from absolute numbers in the sample.

Multivariate logistic regression analysis revealed that, except for age of the physician ($p=0.065$) and region of practice ($p=0.051$), all the variables mentioned were significantly and independently associated with the proportion of physicians that considered performing euthanasia conceivable in some situations. Overall, the variables 'role religion' and 'requests for euthanasia' were the strongest determinants ($p<0.001$).

10.3.2 Practice of euthanasia (model II)

Of the physicians to whom performing euthanasia was not inconceivable, 61% had actually ever done so. Column 3 of table 2 shows the univariate odds ratios. Having performed euthanasia at some time, if conceivable, was related to type of specialty, the importance attached to religion, and having had one or more requests for euthanasia ($p<0.05$). Age and gender of the physician no longer played a statistically significant role. There was also no significant relation to the number of deceased per practice per year. Once

Table 2 Model I: Odds of the conceivability of performing euthanasia, for type of specialty and selected (socio-demographic) characteristics. Model II: Odds of having performed euthanasia at any time, given the fact that is conceivable for the physician, for type of specialty and selected (socio-demographic) characteristics

	Model I (performing euthanasia conceivable) n=400		Model II (given euthanasia conceivable, ever performed) n=341	
	Univariate odds	Multivariate odds	Univariate odds	Multivariate odds
Specialty	p=0.006	p=0.004	p<0.001	p<0.001
Nursing-home physician	1.00	1.00	1.00	1.00
General practitioner	3.70	5.58	11.17	12.02
Cardiologist	0.73 NS	0.99 NS	1.82 NS	1.04 NS
Surgeon	2.04 NS	2.02 NS	3.65	2.82 NS
Internist (incl. oncologists)	3.51	4.35	9.59	12.07
Lung specialist	2.46 NS	1.98 NS	9.30	5.93
Neurologist	1.64 NS	1.96 NS	3.34	2.30 NS
Age	p=0.014*	p=0.065	p=0.313*	†
50 or older	1.00	1.00	1.00	
Younger than 50	2.08	1.36 NS	1.30 NS	
Gender	p=0.007	p=0.002	p=0.165	†
Male	1.00	1.00	1.00	
Female	4.00	7.11	0.66 NS	
Region	p=0.001	p=0.051	p=0.002	p=0.061
South	1.00	1.00	1.00	1.00
West	1.24 NS	0.81 NS	2.91	2.28
East	0.68 NS	0.59 NS	1.41 NS	1.28 NS
North	12.53	8.65	1.72 NS	1.33 NS
Has had request last year	p<0.001	p<0.001	p<0.001	p<0.001
No	1.00	1.00	1.00	1.00
Yes	4.35	4.93	5.92	7.52
Role religion toward euthanasia	p<0.001	p<0.001	p<0.001	p=0.007
Religion is very important	1.00	1.00	1.00	1.00
Is religious, but no important role	3.10	3.92	0.94 NS	1.11 NS
Is not religious	7.88	8.83	2.57	3.86

* A classification into more or other age-groups did not improve the models.

† This variable is not included in the multivariate model, because it had no significant role in the univariate model.

again, a distinction according to religion (Roman Catholic, Protestant etc.) did not further improve the model.

Multivariate logistic regression analysis revealed that type of specialty, the number of requests, and the role of religion were significantly and independently associated with the proportion of physicians that had ever performed euthanasia, given this was conceivable to them. Region of practice had no significant influence in the multivariate model (p=0.061). Overall, the variables 'type of specialty' and 'requests for euthanasia' were the strongest determinants (p<0.001). None of the interaction terms were significant.

10.4 Discussion

The results show that the physicians' attitudes toward euthanasia differ from the practice of euthanasia, as far as a number of socio-demographic characteristics of physicians is concerned. These characteristics will be reviewed, in an attempt to interpret the differences between the two models.

Type of specialty plays a more important role in model II than in model I (comparing the multivariate odds). For example, the odds for the conceivability of performing euthanasia are 5 times higher for the general specialties (general practitioners and internists) than for the nursing-home physicians, but given the fact that euthanasia is conceivable, the odds for the general specialties for ever actually performed it are 12 times higher. The difference between the models must at least have to do with differences in patient population between the specialties. It is known that euthanasia is relatively more often performed in cancer patients, who are on average younger than the age of 80. Therefore, the chance of a nursing-home physician or cardiologist being confronted with possible euthanasia cases is lower than in other specialties. Hence model II suggests that, if a physician can conceive of a situation in which he would perform euthanasia, the type of patients he treats determines to a major extent whether or not he will ever actually perform euthanasia.

The fact that age of the physician does not play a role in either model after correction for other variables, could be due to three effects: an age-effect, a period-effect, and a generation-effect. Unfortunately, it is impossible to disentangle these three effects completely, because our study is cross-sectional. However, some statements can be made. We shall restrict ourselves to model II. An age-effect must exist, as the chance of having performed euthanasia is higher for older, more experienced physicians than for younger. Because this is not seen in the model, one of the two other effects must have cancelled out the age-effect. If an age plus a period effect should be operative, the combination of these effects should still have resulted in a difference between younger and older physicians. Because this is not the case, two possibilities remain: there is an age-effect plus a generation-effect, or all effects play a role.

The gender of the physician only plays a role in model I; a larger proportion of female physicians is able to conceive of situations in which they would perform euthanasia than male physicians. But from those who can conceive of such a situation, the odds for having ever performed euthanasia did not differ significantly between male and female physicians. Because women do not perform euthanasia more than men (not in models), apparently a larger proportion of female physicians can conceive of (extreme) situations in which they would be prepared to perform euthanasia, but which do not occur in practice.

The region in which a physician's practice is located also shows some interesting findings. The fact that a larger proportion of physicians working in the northern part of the Netherlands can conceive of situations in which they would perform euthanasia could perhaps partly be explained by the fact that the first euthanasia court case which received supportive media in the Netherlands came from the north.

The variable 'has had a request for euthanasia last year' is difficult to interpret. The higher the number of severely ill patients in a certain practice, the higher the chance of requests for euthanasia. On the other hand, a physician with a positive attitude towards euthanasia can expect more requests. Probably, the last explanation is more valid, because the number of patients per practice played no significant role in either univariate model, and because, given a request, the number of requests did not further improve the models.

The role of religion with respect to euthanasia plays a more important role in model I than in model II. Apparently, for physicians who can conceive of situations in which they would perform euthanasia, their religious point of view still plays a role as far as whether or not they had ever actually performed euthanasia, but other factors such as the type of patient probably become more important.

As was stated in the beginning, quite a number of articles on attitudes and practice of euthanasia have been written. A large study in Victoria, Australia also indicated that male and female doctors did not differ significantly with respect to the question of whether they had ever taken active steps to bring about the death of a patient who asked the doctor to do so.[3] Religion did play a role, but, as in our study, there were some doctors from every religious group who had performed euthanasia. There was a preponderance of support to take active steps sometimes especially among younger doctors, just as in our study. In a relatively small study done in South Australia there were no significant differences between physicians who had ever or never taken active steps to bring about death, according to age, sex or religious affiliation.[4] In Alberta, Canada, the willingness to practise active euthanasia if it were legalized was significantly and independently related to gender, and to religious affiliation and activity. In contrast to our study, here, a larger proportion of male physicians was willing to practise euthanasia.[5] In a small study in a Midwestern city in the US, the number of years in the profession was related to disagreement with euthanasia, but this disagreement was based on a highly disputable vignette.[6,7] In a larger study in Washington state, attitudes toward euthanasia varied significantly among the studied specialties. There were no differences with regard to gender.[8] Finally, in one area in the United Kingdom no significant associations were found between the physicians' age, sex or religious beliefs and the question of whether they had ever complied with a patient's request for active euthanasia.[9] Although the questions about attitudes and practice between these studies differed slightly, it may be concluded that there seem to be differences between countries.

In all these studies, no comparison was made between attitudes and practice. In our study, it became clear that attitudes towards euthanasia do not always coincide with actual practice: euthanasia being conceivable does not mean that the physician will also actually perform euthanasia. In other words, saying that one can conceive of a situation in which one would perform euthanasia may mean that one is in principle prepared to comply with a serious request for euthanasia ('yes, if...'), but also nearly the opposite ('never, unless...'). Even more important is the fact that the variables influencing these two issues are not the same. Therefore research into physicians' attitudes is useful, but not sufficient to draw conclusions about potential practice in the community.

10.5 Conclusion

It can clearly be seen that the conceivability of euthanasia and actually having performed this have different meanings. The presented models are restricted to some physician characteristics as explanatory variables. Undoubtedly, the diagnosis, the prognosis and other patient-characteristics also play an important role in the practising of euthanasia. Attitudes as well as practice vary significantly among the studied specialties. The age of the physician, corrected for other variables, plays no role in this context. Nevertheless, this may imply that younger generations will perform euthanasia relatively more often.

The conclusion is that research on the physicians' attitudes towards euthanasia in relation with some (socio-demographic) characteristics is not sufficient to gain a proper impression of the practice of euthanasia in relation to these characteristics, and vice versa.

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Part V
The euthanasia debate

11 Changes in Dutch opinions on euthanasia, 1966 through 1991*

11.1 Introduction

The Netherlands appears to have a worldwide reputation for tolerant policies on controversial issues such as abortion, drug abuse, and euthanasia. In a comparative survey of 15 countries, including the United States and Canada, the Dutch turned out to have by far the most permissive orientation.[1] 'Tolerant' in this context has positive connotations for some and negative for others, who interpret this tolerance as a loss of fundamental values that inevitably lead to a disintegration of society.

Policies must have at least some basis in public opinion and in opinions of the relevant professional groups. This is especially the case in an extremely value-laden topic such as euthanasia. Values such as the sanctity of life and human self-determination are involved as well as medical-professional ethics that may been seen as more or less derived from such values. In this chapter, we examine the development of public opinion on the issue of euthanasia and the changes in opinion that occurred among a representative sample of Dutch physicians during their medical practice.

The data that are presented in this chapter only refer to euthanasia, which is defined in the Netherlands as an intentional act to terminate life by a person other than the person involved, upon request of the latter.[2] Essential in this description are the physician's intention to end the patient's life and the request of the person on whom euthanasia is performed. Thus, euthanasia does not include the other medical decisions concerning the end of life, such as the alleviation of pain and symptoms with opioids in such dosages that the patient's life might be shortened, decisions not to treat, assisted suicide, and life terminating acts without explicit request. From an analysis of three studies, which we have reported previously[3] we estimate that euthanasia occurs in the Netherlands in 1.8% of deaths. Nearly all such cases of euthanasia concern patients who are terminally ill. In our surveys[3], physicians reported that in 87% of euthanasia cases the patient would have lived for a month at most, while another 12% would have lived for six months at the most.[3] Other medical decisions concerning the end of life, as described above, occur in approximately 36% of deaths, of which life-terminating acts without explicit request in 0.8% of deaths, and assisted suicide in 0.3% of deaths.

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11.2 Surveys of Public and Physician Opinions

The data concerning the development of public opinion in the Netherlands stems from a number of surveys on a range of socio-cultural subjects, held in 1966, 1970, 1975, 1980, 1985, and 1991. These data were made available by the Social and Cultural Planning Office of the Netherlands.[4] Respondents were selected following a three step procedure: first a random sample of municipalities was drawn; within these municipalities a sample of addresses was drawn; and from the persons living at each address a respondent was selected according to a standard procedure.

For the period 1966 through 1991 each survey contained one question about euthanasia, asked during a personal interview: 'What should a doctor do, when a patient asks him to put an end to his suffering by administering a lethal injection?'. There were four possible answers: 'Give the injection', 'not give the injection', 'depends', and 'don't know'. The numbers of respondents ranged from 1656 and 1851 for the different years. The group of respondents ranged in age from 16 to 70 years, representing the adult Dutch population in terms of age, sex and region. The response rates ranged from 79% to 83%.

The information about physicians' opinions was collected as part of a nationwide study on medical decisions concerning the end of life, which was performed in 1990 and 1991 and previously reported.[3,5-7] We asked a stratified sample of 405 physicians in a personal interview about their practice of and opinions on euthanasia and other end-of-life decisions. Participants were selected from registries of licensed physicians of the Dutch Institute for Primary health Care, the Dutch Association of Nursing Home Physicians, and the Inspectorate of Health. The registries were ordered according to province, and within each province alphabetically according to name. Based on sample fractions 1/n, every n-th physician was selected as respondent in each sample. Stratification was according to type of specialty. The sample consisted of general practitioners, nursing home physicians, cardiologists, surgeons and specialists in internal medicine, chest diseases and neurology. These specialties together cover about 95% of all deaths in the Netherlands and also about 95% of all euthanasia cases.[3,5] To make the results more representative for the total group of the above mentioned specialties, the data were weighted according to the sampling fractions for the different strata (specialties).

To be included in our study, physicians had to be practising in the same specialty and location for at least two years.

Of all physicians invited (N=599), 194 were not included in the study: 138 did not meet the selection criteria; 41 refused to participate, mainly because of the required time investment (the interviews lasted 2.5 hours on average);

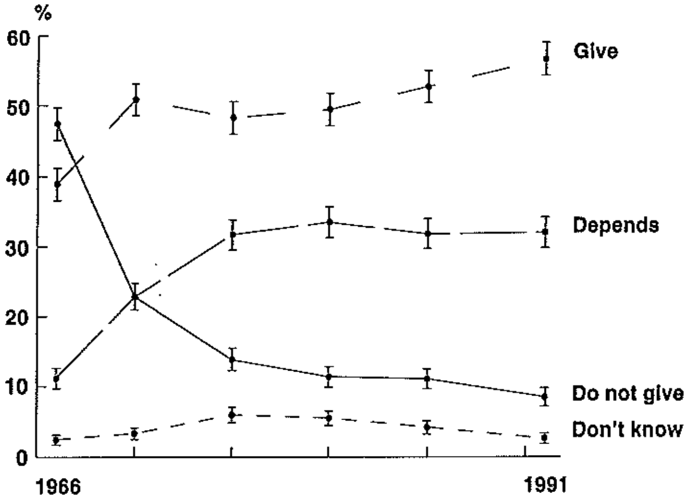
14 addresses were incorrect; and 1 interview did not provide useful information.

One of the questions during the interview was: 'Have your own opinions about euthanasia changed during the whole period that you have been practising medicine?'. From four respondents no information on this question was available. In Dutch 'euthanasia' refers only to euthanasia on the patient's explicit request. During the interviews, this was stated by the interviewers to avoid any confusion.

11.3 Results

11.3.1 Public opinion

Figure 1 summarizes the percentages of respondents' answers to the question regarding euthanasia. Between 1966 and 1975, significant changes in public opinion occurred (95% confidence intervals varied between 1.4% and 2.4%). In 1966 nearly half of all respondents said that a physician should not give the lethal injection. Four years later less than one quarter of the respondents adhered to this position. The percentage not supporting euthanasia continued to drop gradually to 9% in 1991. The



From: Study on Cultural Changes

Figure 1 Distribution of answers to public opinion interview question: 'What should a doctor do when a patient asks him to put an end to his suffering by administering a lethal injection?' during the period 1966-1991. (Confidence intervals are represented by crossbars).

Table 1 Distribution of answers and respondent characteristics from Dutch public opinion interviews conducted in 1966 and 1991. Question: 'What should a doctor to when a patient asks him to put an end to this suffering by administering a lethal injection?'

	1966								1991							
Respondent characteristics	Give		Depends		Do not give		Do not know		Give		Depends		Do not give		Do not know	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Total	679	39	196	11	828	47	43	3	965	57	546	32	145	9	45	3
Male	313	39	90	11	390	48	15	2	426	57	236	32	64	9	16	2
Female	366	39	106	11	438	47	28	3	539	56	310	32	81	8	29	3
17-39	311	38	86	11	403	49	21	3	518	59	280	32	53	6	24	3
40-64	311	39	89	11	370	47	19	2	379	55	226	33	72	10	15	2
65-70	57	42	21	15	55	40	3	2	68	51	40	30	20	15	6	5
No religion	347	56	87	14	175	28	14	2	657	67	278	28	32	3	19	2
Roman Catholic	176	33	52	10	288	55	11	2	190	53	126	35	30	8	12	3
Dutch Reformed	96	33	35	12	149	52	7	2	69	38	74	41	28	16	9	5
Calvinist	42	17	18	7	181	72	10	4	25	23	46	42	37	34	2	2
Other religions	18	31	4	7	35	60	1	2	24	36	22	33	18	27	3	4

From: Dutch Study on Cultural Changes 1966-1991

percentage of respondents who agreed that euthanasia should be given on request increased steeply between 1966 and 1970, but afterwards only gradually increased, reaching 57% in 1991. The largest part of the decrease in the percentage of respondents who did not support euthanasia was compensated for by the increase in the percentage of respondents who said the answer would depend on the specific situation.

Opinions did not vary according to gender; they varied only slightly according to age (Table 1). In 1991, all age groups reported a shift toward supporting euthanasia or toward allowing euthanasia depending on specific circumstances. The age group 17-39 included the highest percentage of respondents who answered in the affirmative (59%). Although the numbers for the 65-70 age-group are relatively small, the respondents had the highest percentage who said that the doctor should not give the injection (15%). This age trend reversed between 1966 and 1991.

The largest differences were found between members of different religious groups. After being relatively restrictive in the 1950s and 1960s the distribution of the opinions of members of the Roman-Catholic church was now nearly identical to that for the whole population of the Netherlands. Persons who did not belong to a religious group have been much more permissive than members of religious groups during the entire period. Members of the Dutch Reformed church remained more restrictive and members of the Calvinist churches remained the most restrictive. The percentage of respondents of both of these groups that would allow euthanasia increased only slightly. However, the percentage of Dutch Reformed and Calvinist respondents who said that their answer would depend on the specific circumstances increased.

11.3.2 Physicians' opinions

Before 1990, empirical information about the practice of euthanasia in the Netherlands did not exist. Similarly, reliable data about physicians' opinion on euthanasia was lacking during that period. For an understanding of the physicians' opinions about euthanasia it is important to know something about the actual practice of euthanasia in the Netherlands. The physicians we interviewed were asked if they had ever practised euthanasia at the explicit and persistent request of the patient. Forty-nine percent confirmed that they had practised euthanasia, and 22% had done so at least once during the previous 24 months. Fifty-seven percent of the general practitioners, 43% of the clinicians, and 10% of the nursing home physicians reported performing euthanasia. Five percent of physicians reported ever assisting in suicide, but not performing euthanasia.

Thirty-eight percent of respondents said that they had never practised euthanasia, but could conceive of situations in which they would be prepared to do so. The remaining 13% said that they could not conceive of any such situation.

The physicians answered the question if their opinion on euthanasia had changed as follows: 61% said they had not changed their opinion, 25% said they had become more permissive, and 14% said they had become more restrictive.

All physicians who answered that they had changed their opinion were asked to elaborate (Table 2). Fifty percent of respondents who had become more permissive and 20% of those who had become more restrictive referred to their own experience with dying people. The reason most frequently offered by those who had become more restrictive was that better palliative medical care was available. Twenty percent of the more restrictive physicians cited the development of guidelines and legal policy as reasons for their change in opinion. Only 6% of those physicians who moved towards a permissive position cited those reasons; they mentioned increased discussion more often as a reason (15%).

Of the 55 respondents who had become more restrictive, 29 (66%) reported performing euthanasia (Table 3). Of the 100 respondents who became more permissive, 44% reported performing euthanasia and 47% said that they had never performed euthanasia but could conceive of a situation in which they would be prepared to do so. Of the 246 respondents whose opinions had not changed, 48% had performed euthanasia. Of the

Table 2 Explanations given by physicians for their change in opinion on euthanasia

	n	%*
More permissive (n=100)		
Experience	50	50
Increased societal discussion	15	15
Guidelines/protocols/legal policy	6	6
Wish of patient now more important	8	8
From 'never' to 'sometimes'	11	11
Medicine has its limits	3	3
I won't do it myself, but understand it better now	9	9
Religion has become less important	4	4
Other	6	6
More restrictive (n=55)		
Experience	11	20
Increased societal discussion	3	5
Guidelines/protocols/legal policy	11	20
Physician's emotions and judgment	7	13
From 'always' to 'sometimes'	4	7
Medicine has improved (better palliative care)	13	24
Request not always well-considered	6	11
Danger of slippery slope	4	7
Terminal phase unpredictable	3	5
Other	6	11

* Total higher than 100% because more than one answer was possible.

Table 3 Physicians' practice and attitudes regarding euthanasia*

	More permissive		More restrictive		No change		Total	
	n	%	n	%	n	%	n	%
Ever performed euthanasia	40	44	29	66	106	48	175	49
Never performed, but would be willing under certain circumstances	47	47	17	20	99	38	163	38
Never performed and believe it not conceivable to ever do so	13	9	9	14	41	14	63	13
Total	100	100	55	100	246	100	401	100

* All percentages are based on weighted data, so percentages cannot be computed directly from absolute numbers in the sample.

Table 4 Changes in physicians' opinions about euthanasia in relation to the number of years they have practised medicine*

Years of medical practice	More permissive		More restrictive		No change		Total	
	n	%	n	%	n	%	n	%
2-9	24	14	24	17	89	69	137	100
10-19	49	27	25	14	117	59	191	100
≥20	27	39	6	9	40	52	73	100
Total	100	25	55	14	246	61	401	100

* All percentages are based on weighted data, so percentages cannot be computed directly from absolute numbers in the sample.

52% who had never performed euthanasia, 14% reported that it was not conceivable that they would ever do so.

We noted an association between the number of years that the physicians had practised medicine and those who reported changes in their opinion (Table 4). While most physicians have not changed their opinions, physicians who had practised medicine more than 20 years reported moving toward a more permissive position. Those who had practised medicine for a relatively short time (2-9 years) more often moved towards a more restrictive position. The largest opinion shift could be seen in Roman Catholic physicians, of whom 27 (37%) said that they had become more permissive. Twenty-five (25%) physician-members of other religious groups and 48 (23%) non-religious physicians reported a similar shift in opinion.

11.4 Discussion

Before discussing the results of the public and physician surveys, their validity and limitations should be considered. With the relatively high response rates the results of the public opinion surveys can be generalized to the overall adult Dutch population.[4] Due to the relatively large numbers in the sample, the confidence intervals are small. The most important limitation was that only one question about euthanasia was asked in each survey. In addition we did not assess socio-economic characteristics other than age, sex, and religious affiliation.

For the physician survey, the percentage of those who refused to participate was low (9%). All physician participants were promised anonymity and immunity against legal prosecution and letters were sent to all Dutch physicians from the Chairman of the Royal Dutch Medical Association and the Chief Medical Officer recommending participation. These actions may have contributed to the low refusal rate. We expect the risk of recall bias to be low. Some physicians may not completely remember their initial opinion about euthanasia, but it is very unlikely that a physician would forget having performed euthanasia.

We cannot offer any specific explanations for the large shift in public opinion that occurred between 1966 and 1970. It was not until 1973 that the first case of euthanasia was tried in court and subsequently attracted wide attention. Since then, an ongoing public debate has ensued, which intensified during the 1980s. The smaller shift in the 'depends' and 'do not give' answers between 1970 and 1975 thus might be related to the media attention for the 1973 court case. The defendant in this case, a women physician who administered her seriously ill mother a lethal injection at her persistent request, attracted much public support.

The opinion shift before 1973 probably should be seen in the light of parallel shifts with respect to opinions on church membership, religious beliefs, the importance of the family, and divorce.[4]

The causes of these changes in attitudes, which occurred simultaneously in many Western countries, are subject to much speculation. A number of Dutch and US authors cite an association between the economic growth of the 1950s and 1960s and the subsequent individualization process of the 1960s as one of the reasons for the movement away from traditional, institutionalized value systems.[8-10]

As to the development of public opinion on euthanasia, a number of similarities between the United States and the Netherlands exist. From an assessment of public opinion surveys conducted in the United States between 1950 and 1991, Blendon et al[11] reported a shift towards more permissive attitudes regarding the legalization of euthanasia. They reported that the percentage of respondents who answered 'yes' to the question, 'When a person has a disease that can not be cured, do you think doctors should be allowed by law to end the patient's life if the patient and his or her family requested it?', increased from 36% in 1950 to 63% in 1991. With regard to euthanasia, not including assisted suicide, 24% would consider asking their physicians to end their lives if they 'were beyond recovery and in great pain.'[11] Like the shift seen in the Netherlands, the greatest amount of change occurred before 1973 when 53% answered yes to the question. This change in US public opinion occurred during a time of changes in attitudes toward religious practices, sexual morals, divorce, and abortion. In both countries, public attitudes toward morality, religion, social behaviour and individual responsibility shifted to a more liberal, permissive plane between 1965 and 1975.[9,12,13]

Of the 155 (39%) Dutch physicians who had changed their opinions on euthanasia, 61 (39%) explained this change by referring to their experience with dying patients. Such responses may represent a tension between those with the relevant experience and those without. Since most people rarely or never will assist others in their death, they may never be confronted with an extreme situation that may induce people to request for euthanasia. In addition, there are a number of medical specialties, such as ophthalmology, dermatology and orthopaedics, in which a patient's death and a long terminal illness are rare. In fact, in the Netherlands, 95% of all deaths are covered by 7 specialties.[3]

The fact that 39% of Dutch physicians who had practised for 20 years or more reported changing to a more permissive position, while only 14% of those who had practised for a relatively short time reported becoming more permissive, may be interpreted as an interesting generational association or an effect of experience with dying patients.

Dutch physicians who considered themselves to be Roman Catholic had more often changed towards a more permissive position than Protestants, members of other religious and non-religious groups. The official doctrine of the Roman Catholic church rules out any form of euthanasia.[14] On the other hand, in the Reformed and Calvinist churches, where church doctrine has no absolute authority and the final responsibility remains with the individual[15], the positions remain more restrictive, although there was a shift towards the 'depends'-position.

The 'depends'-answer, which was given by one third of all respondents in 1991, may, with some caution, be seen as an indication that according to these respondents a patient's request is not sufficient justification for performing euthanasia.

Euthanasia is an issue that involves the entire society, which makes the development of public opinion in this area extremely relevant. However, euthanasia pre-eminently involves the medical profession, making the opinion of physicians just as important. To make progress in the euthanasia debate there should at least be some agreement between the opinions of the general public and of the medical profession. But even if general public and medical profession agree on the acceptability of euthanasia under certain circumstances, legal regulations and ethical principles do not provide simple decision rules.

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12 The Dutch euthanasia debate in international perspective

12.1 Introduction

Why does the Netherlands have such a special position in the international euthanasia debate? This question apparently does not have a quick straightforward answer, as the issue has been discussed for at least a decade already in a variety of contexts. Exploration of this question might shed new light on the cultural, legal, ethical and emotional backgrounds of euthanasia. The answer is important for the Dutch who feel that they take the issue of euthanasia very seriously but are often regarded as deviant by others who take the euthanasia issue just as seriously. It is also important for those who want to draw lessons from the experience in the Netherlands.

Therefore, we decided to explore this question in a further depth with the help of a number of experts from different countries, representing a variety of disciplines: physicians, lawyers, ethicists, philosophers, and social scientists. This chapter attempts to integrate the various opinions of the experts, taking into account the importance that respondents attach to certain opinions.

12.2 Methods

We invited 44 respondents to take part in our study. Five respondents said that they were not able to participate, either because they thought they would not be able to answer the questions or because of lack of time. From five respondents who intended to participate, no answer was received, resulting in a total response percentage of 77%.

The selection of the respondents was not based on a representative sample of any kind but was intended to cover the main relevant disciplines (medicine, law, ethics, philosophy, and sociology), and a number of different countries (Australia, Canada, Germany, the Netherlands, United Kingdom, United States). All respondents were selected on the basis of their expertise regarding euthanasia. They were expected to be familiar with the Dutch situation, and, for Dutch respondents, with the situation in at least one other country. Table 1 presents the distribution of the respondents per nation, and per discipline.

Table 1 Sample characteristics.

	n=34
Discipline*	
Medicine	13
Law	8
Ethics/philosophy	11
Psychology/sociology	4
Other	2
Country	
The Netherlands	23
United States	6
Australia	2
Canada	1
United Kingdom	1
Germany	1

* More than one answer possible

We asked the respondents to answer two questions:

1 'What, according to you, is the explanation of the fact that the current discussion on euthanasia in the Netherlands differs from the discussion in other countries?'

2 'Do you think that the current euthanasia practice in the Netherlands differs from other countries?'

The procedure was more or less based on the Delphi method, and proceeded as follows:

1 The respondents received the above mentioned questions.

2 The answers to question 1 were arranged forming ten main topics (history, church and religion, culture and society, geography and demography, physician and patient and health care, moral principles, legal aspects, definition of euthanasia, politics, media). The information was categorized according to topic, taking into account as far as possible the range of opinions, as well as the frequency with which the different issues were raised. The answers to question 2 were also summarized.

3 Each respondent received the combined and condensed text and was invited to give comments. The respondents were also asked to indicate which three topics, according to them, were the most important for the answer to the first question.

4 The text was revised, taking into account the comments.

To get an indication of the position the respondents choose in the euthanasia debate, the respondents were asked to respond on the statement: 'On the whole, I find the practice of euthanasia in the Netherlands...(acceptable-unacceptable)', with answering categories on a five-point scale.

All the opinions presented in the results reflect those of the respondents.

12.3 Results

The majority of the respondents indicated they found the questions very difficult, because the answers can only be based on speculation without sound scientific support. All the respondents agreed that there was a difference in the euthanasia debate between the Netherlands and elsewhere, although there may be some similarities with certain countries. It was also pointed out that there were large differences between other countries, which would make a general comparison difficult. One respondent stated that in comparison with other countries there had not been any very serious discussion at all in the Netherlands.

Most non-Dutch respondents said that they mainly compared the Netherlands with their own country. Dutch respondents mainly drew comparisons with the United States, the United Kingdom and Germany. As a matter of fact a sizeable proportion of the answers was not directed at any comparison between the Netherlands and other countries but tried to describe the history of the Dutch euthanasia debate itself.

One respondent pointed out the risk of providing explanations that are too ethnocentric, when such a question is answered by the Dutch themselves.

The word 'differ' in the question could be interpreted in several ways. The debate can differ with respect to content and form but also with respect to the participants, its course and the conclusion. From the answers it was evident that 'differ' generally was understood as 'more permissive' or 'more open'. The answers on the statement about the acceptability of the euthanasia-practice in the Netherlands are presented in table 2. As could be expected, Dutch respondents found this practice more acceptable than non-Dutch respondents.

Inevitably, categorizing the answers in ten groups results in some overlap. Where relevant, cross references will be made. The combined complete text of the respondents was 8 times as long as the present chapter. Although this reduction unavoidably resulted in the loss of some detail, it gained considerably in coherence. The respondents mainly agreed with the summarized text, although there was some disagreement. A number of respondents were strongly opposed to some statements indicated in the text such

Table 2 Respondents' opinions about the next statement: 'On the whole, I find the practice of euthanasia in the Netherlands:...'

	n=34
Very acceptable	12
More acceptable than unacceptable	13
Neither acceptable, nor unacceptable	1
More unacceptable than acceptable	4
Very unacceptable	4

as: 'One respondent mentioned...'. However, we kept those in the final text to do justice to all respondents.

12.3.1 Question 1: The euthanasia debate

History

Since its emergence as an independent nation in the 17th century, the Netherlands has had a strong position in international trade. This strong mercantile orientation requires flexibility, adaptation and the avoidance of conflicts. Although the war of independence with Spain (1568-1648) also had strong religious motives, the government attempted to avoid serious religious quarrels, which might harm business. This is one of the reasons why the Netherlands became a refuge for dissidents and religious groups who were oppressed or expelled elsewhere, such as the French Huguenots, free thinkers such as Spinoza and Descartes, the Sephardic Jews from Portugal and the Ashkenazi Jews from Eastern Europe.

Although the religious tradition was strongly calvinistic and clergies were often very intolerant in their teaching, tolerance in religious matters and freedom of thought prevented one dominant view from being imposed on others by force of law. Moral and religious issues remained a continuous source of public debate. Since the 19th century, there was a simple solution for persons with dissident religious views: they were always allowed to found a new denomination.

Turning to the more recent history, the Netherlands, despite its liberal tradition, was not the first country to start the discussion of more liberal euthanasia legislation. That discussion started in the United States, Germany and the United Kingdom at the turn of the century.[1] In the Netherlands the discussion only began during the sixties, the decade in which emancipation and liberation of the individual in all aspects of life was the dominant cultural development. This may have contributed to the rather immediate public support for euthanasia. An important additional aspect was that the Netherlands did not have a Nazi past as did Germany. Especially Dutch physicians as a group have an impeccable record of non-cooperation and resistance against the Nazis, which makes them trustworthy in the eyes of the public.[2]

A number of Dutch respondents pointed out the role some individuals have played in the development of the Dutch euthanasia debate. Of course, historical explanations always have to find a balance between structural and individualistic components. However, the fact that since the seventies a number of key persons in the religious, political, medical and legal system have acknowledged the existence of situations which can be defined as unbearable or as involving unacceptable suffering, which could allow for termination of life upon request, formed a strong impetus. They joined the euthanasia debate in the professional as well as in the public media without being afraid of an ensuing disintegration of society. As a result euthanasia became an important issue for public debate. The verdict in the euthanasia case of 1973 may thereby have acted as a catalyst (see 'legal aspects'). For example, it led to the establishment of the Dutch 'Right to Die' Society.

In 1985, the State Commission on Euthanasia, installed by the government, recommended the legalization of euthanasia by a margin of 13 votes against 2.[3] This recommendation had, as with the formulated point of view of the Board of the Royal Dutch Medical Association in 1984[4], a great influence on the course of the euthanasia debate in the Netherlands. Among other things, the Commission advised that the definition of euthanasia be restricted to situations in which there had been an explicit request of the patient (see 'definition of euthanasia').

Church and religion

Many respondents referred to the role of religion and churches in the Netherlands. As was indicated above, the emergence of the Netherlands as a powerful nation coincided with the dominance of protestantism, as well as with a certain tolerance towards other philosophies of life. The strong calvinist tradition in the Netherlands accentuates the individual's responsibility in all aspects of life, ranging from one's own conscience and personal salvation to public matters. This individualism went hand in hand with a strong social control.

Some mentioned that Dutch Roman Catholicism still retains calvinist characteristics, especially with respect to the concept of individual responsibility and the related resistance to official church dogma. The Dutch Roman Catholics during the 1960s played a role of emancipation vis-a-vis Roman dogma and Vatican authority. From that time quite a number of Dutch Catholics supported euthanasia.

Neither Protestants nor Roman Catholics have a dominant political or moral position in the Netherlands at present. Moreover the separation between state and church in the Netherlands has been a reality for a long time. This excludes the direct influence of the churches in matters of legislation. Although the US and the UK also have a long-standing separation between church and state, church leaders still have a significant influence on public debate. This seems important in the general opposition to euthanasia in those countries. Perhaps some of the complexities of the current American debate on euthanasia reflect the considerable ambivalence and disagreement within the American society today about the proper role of religion in public life and public discourse.

All Western societies are much further secularized and individualised than they were in the fifties, but the level of secularization differs strongly among countries. In the United States for instance a much larger proportion of the population still considers itself to be church member than in the Netherlands or the United Kingdom.[5] A general consequence of secularization is the awareness that you live your own unique life and that there is no hereafter. This probably makes it more difficult to discern a meaning in suffering.

Culture and society

As was mentioned in the section on history, the Dutch national character produces an at times surprising combination of pragmatism and principle. There is often much discussion on matters of principle, but at the same time people are prepared to look for pragmatic solutions. Thus, the existence of moral problems is rarely denied, but some solutions may look hypocritical to others. This attitude can be seen in the discussion on very diverse issues, such as euthanasia, drug policy and abortion. The calvinism-inherited mentality largely guarantees the clarity and openness of the discussion, although the solutions may be less transparent (one dissenting respondent claimed that 'the Dutch cannot squarely face the facts and significance of euthanasia', and that 'practice has been allowed to run far ahead of any serious discussion of morality'). It may all have to do with the strong tendency towards consensus in public matters. This contributes, according to most respondents, to the moderate tone of the discussion. This tolerance with respect to public regulation seems to bear fruit in other areas. The Netherlands has, for example, the lowest abortion rates in the world[6], in spite of an open and tolerant abortion policy and thanks to open information on birth control and the easy availability of contraceptives.

The tendency towards consensus has prevented the polarization of the euthanasia debate which can be observed in many other countries. For instance, the United States may be considered as a religiously tolerant society, but its tolerance may be more constitutional and legal than social. Especially the churches and other religious groups, which form strong polarizing powers in the public debate in the United States, tend in the Netherlands to be included in the consensus formula. One respondent concluded there seems to be no seriously organized groups to oppose the changes that have taken place in Dutch law. Another respondent was convinced that within the Netherlands there is a polarization against Christian morals and organizations, which suppresses an even-handed presentation of the issues involved.

In the Netherlands moral standpoints and daily practice tend to be rather closely related. This means that publicly defended moral standpoints have to be realistic. This may explain the nearly complete absence of tabloids, sex scandals involving prominent persons, and moralizing discussions on drugs or AIDS.

The Netherlands is a country with relatively minor social inequalities. Health care is one area in which inequalities are relatively small. Basically there is equal access to health care for everyone (see 'physician, patient and health care'). On the whole the Netherlands is a non-violent society: murder and suicide rates are low (suicide rates are even decreasing) and death is not a daily fear or reality for the majority of Dutch people. This might have facilitated the euthanasia debate.

Geography and demography

The fact that the Netherlands is a small, densely populated country, with one language for the large majority of the people, where news can simultaneously reach all inhabitants, may have contributed to the rapid start and progress of the debate.

Physician, patient and health care

Nearly all respondents mentioned one or more aspects of the Dutch health care system as important. On some aspects there was complete agreement, on others there was less.

The Dutch health care system has at least two relevant characteristics: equal access and a generally long-standing doctor-patient relationship. Presently, economic motives and scarcity of health care provisions hardly play a role in end-of-life decisions.[7] Of all inhabitants, 99.4% are insured for medical expenses and 100% are insured for the costs of long-term illness. Therefore, the costs of long-term medical and nursing care will never become an unbearable financial burden for the family and are thus never reasons for euthanasia requests in the Netherlands. There are no financial motives for the physician either. There is no fee for euthanasia, and a doctor can not inherit from a patient whom he or she has treated in the final stages of life.

Virtually everyone in the Netherlands has a general practitioner with whom he or she generally has a very long-standing relationship. This relationship may become very personal during the terminal phase of disease, and generally includes the whole family. Discussing death and dying may be easier in such a situation. It is therefore not surprising that most euthanasia cases occur at home, by the general practitioner.

The euthanasia debate in the Netherlands was started by physicians and lawyers. This is very important for two reasons. First, the medical profession is a prestigious one with strong ties to the legal and political establishment.

The first euthanasia conferences were mainly organized by lawyers and doctors who tried to draw the attention of politicians to the increasing problems in the application of medical technology. Scarcity of health care resources was never an issue. Second, the medical profession asked for social standards for decisions concerning the end of life and did not keep the problem to itself. In other words, the discussion did not emanate from a crisis of confidence between the medical profession and the general public or other professional groups. And although the discussion was mainly directed at norms based on criminal law, there was no general feeling and no evidence that there were excesses that should be brought under more strict and legal control.

In most other countries the debate stresses the possibility of abuse. A non-Dutch respondent remarked that 'an outsider can not be certain why or how killing some of the seriously ill became established in all branches of society in place of a strict adherence to providing good humane and medical care' (see 'moral principles').

The decision of the general board of the Royal Dutch Medical Association (RDMA) to become involved in the public debate and to take a moderate standpoint was of major importance. So, in the Netherlands not only the majority of the general public support euthanasia under well specified conditions, as is the case in other European countries, Australia, and the United States as well, but also the large majority of the medical profession, which is not the case in many other countries.[8-15] However, this can only be part of the explanation, as in England in the 1930s prominent physicians and their organizations led the fight for the legalization of euthanasia without success.

On two important health care aspects, patient autonomy and palliative care, there was disagreement between the respondents.

Many respondents mentioned the strong patient autonomy in the Dutch health care system. However, two respondents thought that Dutch doctors are still very paternalistic. This has a bearing on the question whether the physician or the patient controls the dying process.

Some respondents doubted whether Dutch physicians are sufficiently aware of the possibilities of palliative care. A lack of knowledge could be responsible for a certain tendency towards euthanasia. In contrast, others pointed out that the Dutch system of terminal care, whether at home, in a nursing-home or in a hospital is on the whole of high quality. Moreover, serious requests for euthanasia can not always be prevented with good humane and medical care.

Finally, the common sense mentality of the Dutch may have contributed to the acceptance of the limitations of medical technology and death as inevitable. The fact that one third of all births and 42% of all deaths still occur at home, independent of social status, may illustrate that birth and death are seen as natural events. However, one respondent thought that Dutch physicians in particular have a tendency towards intervening instead of letting nature take its course. Performing euthanasia instead of letting the patient die would fit this picture.

Moral principles

In all industrialized countries the traditional Judeo-Christian attention to the sanctity of human life has gradually shifted to the quality of life.[16] For the majority of people health is the prime value and is more and more identified with a happy and meaningful life. Together with the increasing importance of self-determination this has led to the acceptance of the fact that a severely ill patient may decide for him- or herself whether life is still worthwhile. Some pointed out that the calvinist tradition of individual responsibility in a period of secularization may turn into an extreme form of self-determination, resulting in extreme individualism and perhaps even hedonism. Others disputed this hypothesis; besides individual responsibility, social cohesion exists to a large extent. In health care, this not only appears from the social insurance system, but also from the relationship between patients and doctors and from an extensive offer of volunteers for the care of chronic patients.

The Dutch seem to be less afraid of the so-called slippery slope than others. According to several Dutch respondents this has to do with the organisation of the Dutch health care system (equal access, long-standing relationship between patient and physician, social control by relatives and nurses), and the confidence that, just as with abortion, an open approach and good regulation do not lead to undesirable or unwanted consequences. Several non-Dutch respondents said that the Dutch seem to close their eyes to the fact that they have already begun to slide down the slope.

Legal aspects

This section combines comments on the Dutch legal system, Dutch law and specific court cases. According to many respondents the latter have played an important role. The euthanasia case that was brought to court in 1973 had a strong influence on the current euthanasia debate. The defendant was a physician who had shortened, at her persistent request, the life of her mother, who was terminally ill and suffering very much. The sentence was a conditional imprisonment of one week. The court agreed with some of the arguments that had been brought to the defence by the expert witness. The present criteria for careful euthanasia still contain a number of elements that were introduced by the defence in that case.

Dutch criminal law contains a paragraph on 'necessity' (conflicting duties, force majeure). This made it possible to keep euthanasia in the criminal law but at the same time to accept it under specific circumstances. Although euthanasia falls under the criminal code - there are even separate paragraphs about killing on request and assisting in suicide - the legal debate was not primarily concerned with crime.

Another important aspect is that the Dutch administration of criminal justice is not based on the legality principle which implies that all cases should be prosecuted, but instead on the principle of expediency.[17,18] This principle implies that there can be cases in which prosecution of a possibly criminal act would not serve the public interest. The principle of expediency leaves room for public policy in the area of criminal justice. Thus, also the judgement whether not-prosecuting would serve the public interest is the responsibility of criminal justice.

The number of medical malpractice suits remains rather low in the Netherlands. On the whole the Dutch put trust in the medical profession. There are no strong incentives to practice defensive medicine. Therefore, Dutch physicians are perhaps more willing to make euthanasia decisions, even if it would entail some risk of legal prosecution initiated by complaints of the family.

The definition of euthanasia

The present definition of euthanasia in the Netherlands is restricted to life-terminating acts *at the explicit request of the patient*. The reasons for restricting the definition of euthanasia were threefold.[19] In the first place it was meant to help clear up the euthanasia debate. Second, self-determination was taken as a starting point, which makes the request the central issue. Third, while the intentional life-termination without the request of the patient is considered to be murder in the Dutch penal code, intentional life-termination following explicit and serious request, mentioned in a separate section of the law, is, although punishable, not called murder. The definition of euthanasia was intended to connect with this section of the law.

The restricted definition of euthanasia was adopted by the Health Council, the Royal Dutch Medical Association, and the State Commission on Euthanasia.[3,4,20] Several respondents mentioned that this restricted definition of euthanasia indeed had clarified the debate and had made it possible to give this form of euthanasia a more or less legal basis under strict criteria. Some mentioned that this restriction also had its drawbacks. One consequence was that patients who are unable to put forward a request for euthanasia in the Netherlands have remained outside the main discussion for a long time, in contrast to many other countries. The withdrawal of life-sustaining treatment, e.g., in comatose patients, was a major issue in the United States long before becoming so in the Netherlands.

The lack of consensus about the definition of euthanasia and other end-of-life decisions probably has complicated the international euthanasia debate. One respondent went so far as to say: 'I sometimes believe that the differences between countries may have as much to do with confusion and misunderstanding, as with serious ethical disagreement', with which two others explicitly disagreed.

Politics

Dutch society used to be rather strongly organised along the lines of religion and philosophy of life. In politics this is still more or less the case; The major parties are Social Democrats, Christian Democrats, Liberals, and Liberal Democrats. Traditionally relatively few Christians were members of a non-denominational political party, and if they were, they had a relatively liberal philosophy of life. The non-denominational parties thus could afford to propose rather liberal euthanasia legislation, without risking the loss of a sizeable number of votes. Nevertheless, a bill proposed by the Liberal Democrats, which would legalize euthanasia at request was never accepted, because the Christian Democrats formed a majority coalition with first the Liberals and then the Social Democrats, which precluded such legislation. This might be seen as another example of consensus politics, resulting in a combination of principle and pragmatism.

Media

In general the media play an important role in the shape and style of any public debate. They share perceptions and concepts which for many participants form the only information upon which to base their opinion, because they lack direct experience with the problems that are being discussed. As an example, the euthanasia trial of 1973 was turned into a radio play. Public opinion was very much in favour of the defendant. People were convinced of the good faith of the doctor, irrespective of whether they considered such an act morally acceptable. Two other cases in which the carefulness of the doctor was doubted, were seen as exceptions to a generally accepted picture of careful euthanasia practice.

Two respondents believed that the Dutch community is poorly or selectively informed about euthanasia. A number of other respondents postulated, however, that the Dutch are very much aware of the true practice of euthanasia in their country, and that they do not depend on distorted information from abroad.

12.3.2 Question 2: The euthanasia practice

All respondents indicated that in the absence of quantitative empirical data from most other countries than the Netherlands they could only hazard a guess about differences in euthanasia practice between the Netherlands and other countries. Studies from the United Kingdom and Australia suggest that 12% to 20% of physicians have at some time practised euthanasia at the patient's explicit request.[11,13,14] In the Netherlands, 54% of all physicians have ever performed euthanasia.[8] In the face of the criminal penalties attaching to active euthanasia in the US, almost any response of physicians to research surveys must be viewed as of questionable validity, and response rates are usually too low to allow confident interpretation.

All respondents knew of cases of euthanasia in their own country. Overall, most respondents hypothesized that euthanasia at the patient's explicit request would be more frequent in the Netherlands than in other countries. According to them, this had to do with the openness of the euthanasia debate and the acceptance and availability of euthanasia in the Netherlands. Although euthanasia as an ethical issue is widely discussed in many countries, specific requests for euthanasia and the actual performance are only rarely openly discussed in those countries. In the Netherlands the patient is aware of the options and dares to ask for them, and the chance of prosecution of the physician is low. The result of the fact that elsewhere euthanasia is not discussed openly is that no clearly formulated guidelines for careful decision-making and euthanasia performance have been developed.

The existence of life-terminating acts without the patient's explicit request that was reported in the 'Remmelink study' was mentioned as a marked difference between the Netherlands and other countries by three respondents.[21] However, the majority of respondents think it plausible that physicians, being placed in the same situation of 'necessity' as Dutch doctors, will act in quite the same way. But they will probably use other language (they have to use much innuendo) to prevent prosecution. Physicians may prefer to over-prescribe high doses of narcotic medications sufficient to cause respiratory depression and death. Such cases are not called euthanasia and are referred to as relief of suffering; but it is understood that death will result.

12.4 Conclusion

The answer to the question why the Dutch debate on euthanasia differs from other countries resulted, as could be expected, in a wide range of topics. Still, it seems that a rather coherent picture emerges, although it inevitably has some contradictory and speculative elements. The topics that were most

Table 3 The most important topics according to the respondents (n=33; three topics per respondent)

Topics	Times mentioned
History	11
Church and religion	10
Culture and society	22
Geography and demography	1
Physician, patient and health care	24
Moral principles	5
Legal aspects	15
Definition of euthanasia	6
Politics	2
Media	3
Total	99

often mentioned as having the most explanatory power for the differences between the Netherlands and other countries were differences in culture, differences in health care system, and differences in the legal system (table 3). We think that the results of this exploratory study warrants a much more thorough international comparative study into the socio-historical background of euthanasia. Finally, only time will tell whether the developments in the Netherlands are really unique, or whether by coincidence they have just happened ahead of other countries, or whether they are a one-time experiment which will be reversed in the future.

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Although we consider the information as presented to be a fair reflection of the diverse opinions of the respondents, this does of course not mean that each respondent agrees with every statement.

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Part VI
Conclusions and recommendations

13 Conclusions and recommendations

13.1 Introduction

This thesis explores the field of end-of-life decisions in Dutch medical practice, seen primarily from the physician's point of view. In the previous chapters detailed empirical information was given on the incidence of end-of-life decisions and the decision-making process. The physician's role and the patient's involvement were highlighted. Finally, the decisions were placed in a socio-historical context. In this chapter the qualities and the limitations of the investigation will be considered and the question whether the objective has been realised will be answered. After the conclusions, recommendations will be given to maintain and improve the quality of medical decision-making at the end of a patient's life.

13.2 Qualities and limitations of the studies

13.2.1 Qualities

Design

Three studies were performed, as described in chapter 2. Study I consisted of interviews with 405 physicians, Study II contained the responses to 5197 questionnaires filled out by physicians concerning deceased persons, and Study III was composed of information about 2257 deaths collected by a prospective study among those physicians who had been interviewed. The design of the samples was such that representative information on physicians as well as deaths could be obtained. The designs of the studies were complementary: studies II and III were meant to give quantitative information on end-of-life decisions, whereas study I was to provide greater insight into the decision-making process. In practice, data from all three studies were used, according to their original intentions.

Concepts

The decisions we intended to study 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 intention 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 were able to use the term euthanasia as such, as the setting allowed apparent misconceptions about the definition used[1] to be corrected. In general, the interviewed physicians concurred with the given concepts. Some problems, however, should be mentioned.

Some respondents had difficulties in indicating their intention where decisions to forego treatment or to alleviate pain with opioids were concerned. This was a matter to which they, in some cases, had given no prior specific consideration (see 13.3.3).

We knew that there would be a grey area between pain alleviation with opioids on the one hand and euthanasia and life-terminating acts without the patient's explicit request on the other. The interview study gave a first indication of the extent of this area. We explicitly defined euthanasia (only one intention possible: deliberately hastening the end of life) and asked questions such as 'Have you ever performed it?'. If this proved to be so, we went on to ask a number of questions about the physician's most recent experience in this area. In another section of the interview questionnaire we asked questions about the alleviation of pain and symptoms with opioids: 'Were you ever in a situation in which you were going to have to give such high doses of morphine... that the patient's life would almost certainly be shortened?' If so, one of the following questions concerned the intention of the physician in that case. A small number of physicians answered that the explicit intention had been to shorten the patient's life. This could not have been a case of euthanasia, as this would have been dealt with in the previous section. We concluded that these cases were part of the grey area between euthanasia and performing a life-terminating act without the patient's explicit request on the one hand and intensifying the alleviation of pain or symptoms with opioids on the other.

We were given a second indication that this grey area indeed exists by the difference in the number of affirmative answers to question 7 of two percent between the studies II and III[2]: 'Was the death caused by the use of a drug* prescribed, supplied or administered by you or a colleague with the explicit purpose of hastening the end of life?' (* This may mean one or more drugs; morphine is also sometimes used for this purpose). The conclusion was that it is possible to classify end-of-life decisions, when this grey area is taken into account.

The term 'life-shortening' deserves special attention. We were very reluctant to ask a question about this. It appears to be almost impossible to give an accurate indication of the time span of the terminal phase.[3] To avoid confusion about the term 'terminal phase', we introduced the shortening of life-estimate. This study showed that the extent of life-shortening estimated by the physicians differed markedly, depending on the type of end-of-life decision. This indicates that more is involved than a relatively casual estimate.

In the interview study, several physicians mentioned that where non-treatment decisions were concerned, the aim had been 'not to prolong life' rather than 'to shorten life'. The correct terminology depends on whether or not the results of life-prolonging treatment in terminal patients are considered to be part of normal human life expectancy.

Questionnaires

Two questionnaires were used: an interview questionnaire consisting of 122 pages for study I, and a questionnaire of 4 pages (24 questions, see appendix) which was to be filled out by the physician for the studies II and III. To go through the interview questionnaire took quite some time: two-and-a-half hours on average. At the end of the questionnaire the respondents were asked to comment on the interview. In many cases, they had found it exhausting and sometimes causing heavy emotions, but also very clarifying, meaning that they had considered it as a mirror for their own decision-making. A few remarked that questions about the emotions that some decisions had brought about were lacking.

An even closer connection between the questions in the two questionnaires could have facilitated the comparison between the studies. This was the case particularly for decisions on foregoing treatment or alleviating pain with opioids.

Response

The response rates in the three studies were high. Only 9% of the physicians selected refused to participate in the interviews, mainly because of lack of time. Of those who were interviewed, 80% also took part in the prospective study, giving nearly complete information on all deaths among patients for whom they had been responsible. Of the 7,000 questionnaires in study II 76% was returned.

The impressive cooperation of the Dutch medical profession may be interpreted as an indication that euthanasia and other end-of-life decisions are seen as important issues that deserve investigation and discussion. Indeed many respondents commented to this effect, mentioning that these decisions are among the most difficult aspects of medical practice.

Validity and reliability

All interviews except one yielded complete information, since every interview had been discussed with the researchers afterwards and any unclear details could be corrected by consulting the respondent again. The answers in study II also appeared to be very useful, although the physicians who participated in this study could not be consulted afterwards, because of complete anonymity.[4]

The studies II and III showed nearly identical results, although the samples of physicians and death cases in each of these studies were obtained in a totally different way. The interview study indeed provided the expected deeper insight in the decision-making process. A good example of this are the case-reports, worked out by the interviewer, on the most illustrative end-of-life decision arising during each interview. For a good understanding of the decision situation, these case-reports were indispensable.

The fact that the three studies showed far more similarities than differences, is a strong argument in favour of their validity. Furthermore, the response rates were rather high and the physicians cooperated irrespective of their opinions about euthanasia and other end-of-life decisions. Even though the response rates in study II differed for those dying in a hospital versus elsewhere (64% versus 81%) detailed analysis showed no bias due to non-response.

The fact that Van der Wal found the same incidences for euthanasia in family- and nursing-home practice[5,6], gave even more support to the reliability of the study results. Neither nationally nor internationally has this quality been questioned. Criticism was not directed at the quality of the data, but at the definition of euthanasia, that was restricted to active euthanasia *at the patient's explicit request.*[1] The estimates of the total number of end-of-life decisions were not disputed.

Complete anonymity and immunity against legal prosecution based on the research data were guaranteed. Furthermore, the study was supported by the government, the Royal Dutch Medical Association, and by the chief inspector of health. From many details on the interview questionnaires and the returned questionnaires we could infer that the responding physicians had answered the questions sincerely, and attentively. Taking all these facts together, we are convinced that no serious biases are likely to have arisen.

A detailed discussion of response and representativity can be found in appendix C of the first study report.[2]

13.2.2 Limitations

The most important limitation of the study was the type of respondents chosen. In the three studies performed, only physicians were approached. To answer the objective of the thesis, we could restrict ourselves to this group, because the final responsibility for end-of-life decisions is carried by them. However, the scope of the information gained could have been widened by including three other groups who would have been able to provide important additional insights: the (competent) patient, the patient's relatives, and the nurses.

Information from the patient or his relatives would have been helpful in further exploring the communication with the physician. It has often been demonstrated that this communication can be far from smooth. Explanations regarding the illness, for example, often appear not to be completely clear to the patient. It is thus obvious that in case of an end-of-life decision particularly high demands are made on the physician's ability to communicate. The possibility that the patient or his relatives feel that consultations had not been particularly satisfactory, while the physician had been of the opinion that everything had been satisfactorily arranged with good understanding on the part of everyone cannot be ruled out. This aspect requires further exploration in another study.

There is no doubt that nurses play an important role in end-of-life decisions, particularly in hospitals and nursing homes. Through their daily and intensive contacts with the patient they receive important signals earlier and can often evaluate the total situation better from a social point of view. Their position also needs further investigation.

The scope of our studies do not allow us to draw conclusions about the time (sequence) in the decision process: How much time was needed for the decision? How are different end-of-life decisions taken after one another? Another limitation is that the studies do not permit conclusions about time trends, because only one moment in time was measured. A so-called slippery slope can thus neither be affirmed nor denied (see 13.4).

Unfortunately, comparisons with the decision-making in other countries are impossible. So far, the Netherlands has been the only country in the world in which end-of-life decision-making has been quantified on a nationwide basis.

13.3 Conclusions

I think that the question of whether the objectives of this thesis have been realised can be answered in the affirmative. This thesis had four objectives:
1 Quantification of end-of-life decisions;
2 Description of the background of end-of-life decisions;
3 Analysis of the role of the physician in end-of-life decisions;
4 Exploration of the socio-historical perspective on euthanasia.
Not all results will be summarized here again. Some of the most important findings will be reviewed in the light of these objectives. At the end of these conclusions, the practice of medical decision-making at the end of a patient's life in the Netherlands will be tentatively appraised.

13.3.1 Quantification of end-of-life decisions

By exploring the field of end-of-life decisions we wanted to identify the place of euthanasia within the entire scale of medical decisions at the end of life. Moreover, we wanted to distinguish frequently occurring situations from exceptions. End-of-life decisions cover all decisions in which the physician took at least into account the probability that the end of a patient's life would be hastened. The four types of end-of-life decisions were: non-treatment decisions, decisions to alleviate pain or symptoms with opioids, euthanasia or physician assisted suicide, and life-terminating acts without the patient's explicit request. The incidence of end-of-life decisions could be measured well. Non-treatment decisions and decisions to alleviate pain with opioids were commonly made by all types of physicians (general practitioners, clinicians and nursing-home physicians). The other end-of-life decisions mentioned were made relatively infrequently (chapter 3).

13.3.2 Background of end-of-life decisions

Differences in background between end-of-life decisions could also be described. They concerned differences in physician-characteristics (see 13.3.3) as well as differences in patient-characteristics. The following can be said about the patient-characteristics. Non-treatment decisions are taken somewhat more often with older patients (chapter 5). The distribution of causes of death in non-treatment cases do not differ from the distribution found for the total mortality in the Netherlands. It appears that in such cases the type of illness is less important than the fact that treatment no longer contributes to the patient's well-being. Intensifying the alleviation of pain or symptoms with probable hastening of the end of life occurs relatively less often in the oldest age group (80+). More than half of the patients suffer from cancer (chapter 6). Euthanasia and related end-of-life decisions are also made mainly with respect to cancer patients. The patients are under 65 years of age in about half of these cases. The patients are somewhat more often males, contrary to other end-of-life decisions (chapter 3).

The remaining life-expectancy at the time of the decision-making was short on average: some days for non-treatment decisions, for pain alleviation-decisions with opioids, and for life-terminating acts without the patient's explicit request; some weeks for euthanasia.

Questions about treatment alternatives and the adequacy of pain alleviation had only been asked in the case of euthanasia decisions or life-terminating acts without the patient's explicit request (interview study). In a minority of cases, treatment alternatives had still been available. These alternatives had not been used, because the patient had refused this, because it would have prolonged the suffering, or because the gain to be expected was no longer acceptable in relation to the treatment. Pain apparently could not always be treated adequately despite opioids (chapters 3 and 8). We can not pass judgement on the quality of pain alleviation and other palliative care in the Netherlands from our study. In a different study it was shown that the prevalence of pain in cancer patients as an indication for the quality of pain alleviation is comparable with other countries, but improvements are possible.[7]

The patient's request for an end-of-life decision and/or discussion with the patient about an end-of-life decision is dealt with in the chapters 5 to 9. A well-informed patient and a carefully considered request are only possible if the patient is able to assess his situation and to take a decision about it adequately. In most instances this was no longer possible. In those cases, physicians had to make decisions about continuing or stopping treatment without the patient's participation.

13.3.3 Analysis of the role of the physician in end-of-life decisions

General practitioners take fewer end-of-life-decisions than clinicians and nursing-home physicians. Especially decisions on whether to withhold or withdraw life-prolonging treatment are taken less often. On the other hand, euthanasia or assisted suicide is performed relatively more often (chapter 9). This is what would be expected, since it is especially the general practitioner who has a long-standing and often intimate relationship with the patient.

The physician does not always discuss end-of-life decisions with the patient, mostly because of the patient's incompetence, but sometimes for 'paternalistic reasons', which is used here as a neutral term, not as a pejorative. It is important to place this aspect of the communication between physician and patient in a historical context. Only a few decades ago, patients were generally not told the truth about diagnosis or prognosis, let alone talked to about possible decision-making. Nowadays, older general practitioners do not discuss end-of-life decisions as often as younger general practitioners. This could indicate a generation effect (chapter 9). This difference could however also partly be explained by the fact that younger physicians have less experience and thus have to deal with more uncertainties, and as a consequence are more willing to discuss things. However, the fact that a younger physician does not consult with a colleague more often, possibly contradicts the last hypothesis.

The more far-reaching the decision, the more often a colleague was consulted. The question is whether all end-of-life decisions should be discussed with a colleague. It is difficult to make a general pronouncement in this regard. Consultation becomes more important if a diagnosis or prognosis is more uncertain, if the consequences of the decision are more extensive, and if there are more uncertainties about the patient's decision-making capacities.

The term 'intention' deserves further attention. As explained in chapter 2 the physician was asked if the end-of-life decision had been made 'taking into account the probability that the end of life would be hastened' or 'with the explicit intention of ending the patient's life'. If the decision had been to alleviate pain or symptoms with opioids, a third answer category was also offered: 'partly with the intention of ending the patient's life'. This description relates to a situation in which the patient's death was not foremost in the physician's mind, yet neither was death unwelcome. Some will argue that theoretically there can only be two groups: hastening the end of a patient's life either with or without the explicit intention of doing so. The responses to this question showed however, that practice, as always, is more complicated than theory.

When asked what the most important considerations were for an end-of-life decision, the physicians answered: the patient's wish, the patient's suffering, no chance of improvement, all medical therapy had become futile or was too burdensome, and the low quality of life. Economic considerations (e.g. scarcity of beds) had not or hardly ever played a role in the decision-making process. For most end-of-life decisions 'the hastening of the end of the patient's life' is not foremost in the physician's mind at all. 'Intention' must be seen as a relative term: it can only be part of the moral evaluation of a situation (chapter 4).

13.3.4 Exploration of the socio-historical perspective on euthanasia

Public opinion on euthanasia has changed in the Netherlands as well as in the United States during the past decades (chapter 11). The increase in the number of advocates of euthanasia occurred mainly during the sixties and early seventies, the decades in which emancipation and liberation of the individual in all aspects of life was the dominant cultural development (chapter 12). Physicians' attitudes towards euthanasia have also undergone change. The fact that physicians who have practised for a long time more often moved towards the more permissive position, as opposed to those who have practised for a relatively short time may be interpreted as an interesting generation effect (chapter 11).

The Netherlands has a very specific position in the international euthanasia debate. It is the country with the most liberal regulation of euthanasia in the world, and with the most open discussion regarding its practice, both probably interrelated. The question of why the Netherlands differs in this aspect from other countries is not easy to answer, but plausible roots may be traced back to the 17th century. The emergence then of the Netherlands as a powerful nation coincided with the dominance of Protestantism, as well as with a widespread tolerance towards other philosophies of life. This has probably contributed to a tendency towards consensus in public matters such as euthanasia (chapter 12). A thorough, internationally comparative, socio-historical study would be necessary to give a non-speculative answer.

Nowadays, a number of factors still distinguish the Netherlands from other countries. For example, the fact that the Royal Dutch Medical Association has not been opposed to euthanasia since the eighties, has been of major importance for the development of guidelines for the careful performance of euthanasia. There is enough evidence that euthanasia is also performed outside the Netherlands, but unfortunately it is rarely discussed in the open.

13.4 A tentative appraisal of the present end-of-life practice

The study for the Remmelink Commission was set up to collect facts on the practice of end-of-life decision-making. The task and purpose of the researchers was not to give judgements about the practice. The results had to be presented in such a way that the Remmelink Commission and others could base their opinions on facts. The present thesis is not subject to this restriction. Hence I will briefly present some personal opinions. They concern two major questions: *1.* Can the current practice (and procedures) be improved?, and *2.* Will the current practice by itself lead to unwanted future situations?

Present practice

Many years' discussion about end-of-life decisions in the Netherlands, intensifying in the last few years, has been fruitful.[8] On the whole, physicians are very seriously concerned with end-of-life problems. They think about it regularly, but do not always have a clear view of their own decision-making process. Perhaps this is more often the case in the relatively frequently made decisions to forego treatment or to alleviate pain or symptoms with opioids. The different elements of end-of-life decision-making at the moment do not seem to form an integrated part of the professional identity of physicians. The guidelines that have been developed for euthanasia have, as yet, not been further developed into a frame of reference for other end-of-life decisions. Several respondents in the interview study mentioned that the interview itself had already contributed to a clearer view on end-of-life decisions. Moreover, some respondents indicated after describing cases that had occurred several years ago, that due to present day acceptance of more open decision-making they certainly would have opted for a more explicit decision-making process had these cases occurred today. These facts show that improvements are possible.

It appears that, at present, decisions about euthanasia are generally made very carefully. It is such an emotional burden for a physician, that he must feel very sure about the whole situation (unbearable suffering, well considered request, no acceptable alternatives etc.) before proceeding to such an act. When a physician fails to comply in full with the guidelines, this mostly concerns procedural guidelines such as consulting a colleague, or reporting euthanasia as an unnatural death, and to a far less extent material guidelines such as, for example, the condition of the patient's unbearable suffering.[9]

I particularly expect improvement in end-of-life decision-making as regards discussion with the patient and consultation with a colleague. Some, less far-reaching decisions could perhaps be made without a colleague or maybe even without involvement of the patient under the terms of 'therapeutic privilege', but the general principle should be that the patient is to be involved, and in most cases also a colleague. These improvements could perhaps be achieved with certain procedures, but most improvement can be expected from an open, matter of fact, discussion on the subject as occasioned by this research, and from providing training to physicians and other health care professionals in end-of-life decision-making (see 13.5.2).

Slippery slope?

The question that repeatedly has been posed, is whether the Netherlands is on a slippery slope regarding end-of-life decisions. The structure of the argument is: to take position A, in itself morally acceptable or morally neutral, will or can lead to the morally unacceptable position B or to a total of unacceptable consequences B.[10,11] The discussion about the slippery slope has mostly been restricted to cases of 'life-terminating acts without the patient's explicit request': the fact that in the Netherlands, euthanasia is considered morally acceptable to the majority of people, has been thought to lead to morally unacceptable life-terminating acts without the patient's explicit request. These last decisions have been discussed extensively in chapter 8. They concerned terminally ill patients who, in the majority of cases, would have lived for another few hours or days. According to the physician, the suffering was such that the only way to reduce it was to hasten the end of the patient's life. The patients had expressed their wishes regarding life-termination at some point in time in more than half of these cases.

There are three points that need to be emphasized. Firstly, the fact that these cases were shown to occur was seen as evidence for a practice which is on the wane.[12-14] However, our study does not permit conclusions about time trends, because only one moment in time was measured. We simply do not know whether life-terminating acts without the patient's explicit request occurred more or less frequently a decade ago.

Secondly, in the debate resulting from these 'thousand cases', various totally different patient groups were mixed up. As mentioned above, most of these patients would have died within a few days. Life-terminating acts on patients whose life expectancy ranges from months to years, such as may be the case in newborns, mentally handicapped patients, demented patients, and permanently comatose patients can thus be considered as extremely exceptional.

Thirdly, in exceptional situations, prolonging a patient's suffering can be crueller than ending a patient's life. In these cases life-terminating acts without the patient's explicit request can be morally defendable. Thus, inevitably, these decisions will sometimes have to be made, not as a rule but as an exception to normal medical practice.

I do not want to argue that all cases in our study were morally acceptable. In some cases, especially some of those that occurred some time ago, the decision-making process could have been more extensive. And besides that, patients could have expressed their wishes in this regard more explicitly if physicians or patients had started discussing end-of-life issues at an earlier stage of the disease.

To see whether the number of these decisions is changing and to gain more insight into the background of the decision-making process, it would be worthwhile to set up a new study within another few years. Meanwhile, physicians, lawyers, and ethicists have to try to further clarify the limitations of acceptability of end-of-life decisions.

Safeguards for careful medical practice must include optimal palliative care, discussion with relatives, a colleague, and nurses, and the absence of economic motives. In this last respect it should be noted that in the Netherlands 99.4% of the population is comprehensively insured for medical expenses and 100% for the costs of long-standing illness. Thus, the costs of long-standing medical and nursing care can never become an unbearable burden for the family. Furthermore, the ending of a patient's life never may produce financial gain for the physician.

Given the fact that euthanasia and life-terminating acts without the patient's explicit request have to be carried out in very exceptional cases, they can perhaps only be tolerated by society in a context where on the whole all human life is valued highly and each human being is valued as equally important. In situations where the value of life becomes more uncertain due to violence, high suicide rates, disasters, economic uncertainties etc., the basis of mutual trust on which this decision-making should be founded cannot be sufficiently guaranteed.

13.5 Recommendations

13.5.1 End-of-life decisions: increasing frequency and difficulty

End-of-life decisions are an integral part of medical practice. As such, physicians will retain final responsibility regarding those decisions. The recommendations to be made in this section are directed at physicians who are or will be confronted with these decisions. Firstly, some arguments showing why physicians should pay (more) attention to end-of-life decisions will be given. Secondly, some improvements in the training of physicians in the knowledge, attitude and practice of end-of-life decision-making will be proposed.

It is very likely that end-of-life decisions will become an issue of increasing importance for doctors. The number of these decisions will increase for three reasons. It is a fact that, as a consequence of the ageing population, the number of deaths per 1,000 inhabitants will increase. In addition, an important change in the pattern of causes of death is taking place: the proportion of cardiovascular diseases is decreasing and that of cancer is increasing. Therefore, cancer will be the cause of death more frequently in the future. As described in chapter 6, end-of-life decisions are taken significantly more often in cancer patients. Moreover, medical technology is still progressing. As more possibilities of prolonging life become available, the physician will be confronted more frequently with decisions as to whether to initiate, to continue or to withhold treatment.

Not only the frequency of end-of-life decisions will increase, but perhaps also the difficulty of the decision-making. With the increase in the number of very old people, the number of patients unable to express their own wishes may also be expected to increase. On the other hand, there is a growing willingness of both physician and patient to talk about the end of life openly. As a consequence, the number of requests for or against euthanasia and assisted suicide will probably increase. This investigation showed that requests for euthanasia are made fairly frequently by relatively young people. This also holds for people for whom euthanasia or assisted suicide was performed. Physicians have to be able to cope with an increasing number of patients who want to decide on their own life and death, but who want the physician to assist.

13.5.2 Education in end-of-life decision-making

To all decision-making in medical practice, it is important that a physician has the knowledge, the right attitude, and enough experience. It can sometimes be difficult to build up experience, especially in case of exceptional decisions. Decision support is desirable in such cases. As I indicated in chapter 1, ideally, a protocol for decision support would be made for every far-reaching kind of end-of-life decision, assuming that every kind of end-of-life decision is morally defendable under certain circumstances. In recent years much attention has been paid to the protocolling of euthanasia. The Royal Dutch Medical Association formulated guidelines that are now more or less embedded in the law as 'points of attention'. There are no such guidelines for non-treatment decisions and decisions on pain alleviation with opioids. These decisions are generally considered as 'normal medical practice'. Nowadays, also 'normal medical practice' is a subject for protocols to improve the quality of medical decision-making.

Although guidelines for good practice at the end of the patient's life are desirable, the range of end-of-life decisions is too broad to address in one common protocol. However, the required professional skills can be presented in general terms.

Knowledge

Physicians must be familiar with all treatment alternatives. If they are uncertain about the available possibilities, they should consult a colleague. In the terminal phase, optimal palliative care is required. Since many physicians are only infrequently confronted with terminal patients, consultation with an expert physician may be necessary. Every hospital should have at least one such an expert to advise clinicians and general practitioners on palliative care. University hospitals should be top reference centres with regard to palliative care, as they are in other areas of medicine.

Physicians ought to be able to estimate a patient's prognosis in case end-of-life decision-making is considered. This is especially important when the reason to stop (further) treatment is because the expected burdens of that treatment outweigh the benefits. Predicting the outcome is not always easy, and often seems impossible in case of a capricious course of illness. Nevertheless, in our study most physicians were willing to give an estimate of the life-expectancy in terms of days, weeks or months. Prognostic knowledge is increasing constantly (e.g. in coma patients), but further research is necessary.

Attitude

Good practice also means having a right attitude. Assuming physicians only want the best for their patients, a number of virtues described in medical ethics could contribute to this. Physician ought to be honest, sincere and faithful; they should have respect for their patients; they should have patience and perseverance at the right moment; they ought to be modest, with feeling for their fellow men; and they ought to be open and ready to justify their decisions.[15]

Physicians should be conscious of their motives when making a decision concerning the end of life, also of their personal motives. In this latter respect, one may consider one's own attitude towards death, sympathy for the patient, uncertainty, and emotional burden. In what way do certain emotions play a role? Is it acceptable that they play a role? Physicians should be able to recognise their emotions, to admit them and channel them in the proper direction, to ensure that they can stand by their decision emotionally as well.

Practice

As in all areas of medicine, it is practice that makes the master. To gain experience in end-of-life decision-making other than by having to go through these decisions in practice, two forms of training are of interest. Firstly, all medical students and residents should receive medical ethics training in this field. Video and role plays could be very helpful in this aspect. Secondly, they should all acquire experience in areas in which the number of end-of-life decisions is relatively high (for example, oncology departments or nursing homes).

In practice, there are a number of persons who are close to decision-making process. The patient is, of course, at the centre of the decision-making. That means that the patient should be involved wherever possible. On what does 'possible' depend? Firstly, the patient must be able to communicate. In case of unconsciousness or coma, for example, this is impossible. The patient should also be able to assess his situation and to take a decision about it adequately. A physician should not assume too rapidly that the patient can not bear responsibility, or that discussion would do more harm than good. By talking with the patient in an early stage, and by taking time for discussing options more than once, the patient gets the opportunity to be well informed. Only then is the patient able to express a well-considered wish about the further course of action.

This wish should obviously be verified by the physician. What is exactly the motive of the patient? Do fear or uncertainties play a role? Unclear statements of the patient, like 'Doctor, you should help me if my life becomes worthless', must be clarified. What does the patient mean by 'helping'? When is life no longer worthwhile to the patient?

The patient indeed is at the centre of the decision-making, but ultimately the physician is the one who bears the final responsibility for the decision, even when the patient requested the decision. A decision is permitted only if all alternatives are considered. Burdens and benefits of each treatment should be weighed. If the patient is no longer able to make decisions, weighing these issues is no simple matter since it involves patient preferences. A judgement about the quality of the patient's life is inevitable in these cases.

Although up until now, the patient's family has not been discussed, they can also play an important role. They can contribute to the decision-making process, especially if the patient is no longer competent, provided the family is well-informed. If an end-of-life decision is requested by the family, their motives must be investigated.

Finally, the colleague-physicians have to be mentioned. They have to play an important role especially when the attending physician is uncertain about the diagnosis, the prognosis, the treatment alternatives, the patient's competence, or the deliberateness of the patient's request. The first three are the competence of the clinician, the other two require a physician who is well trained in looking at psycho-social, psychiatric and environmental aspects.

13.5.3 Further research

There are at least four fields that need further investigation in order to improve medical decision-making at the end of life.

Firstly, the answer of whether or not palliative care could be improved considerably in the Netherlands has not been answered yet. Comparative studies between countries, as well as comparative studies between different settings in one country are necessary. Moreover, intervention studies could be set up to ascertain whether protocolling of pain treatment could improve the decision-making process.

Secondly, further research in prognostic knowledge in different diseases and clinical situations is necessary, especially in the elderly who will make up an increasing proportion of patients in the near future.

Thirdly, further investigation into decision-making from the patient's point of view is required, especially regarding the aspects playing a role in the patient's decision to refuse (further) treatment or to ask for euthanasia.

Fourthly, a second 'Remmelink study' is recommended in a few years time, to see whether the decision-making process regarding end-of-life decisions has altered, and if so, what the reasons are for this change. To compare the end-of-life practice in the Netherlands with other countries, it would of course be very useful to start studies abroad.

13.6 Finally

It has been a privilege to participate in a scientific study on the medical practice of end-of-life decisions in the Netherlands. This research has yielded an unique amount of data, thanks to the enormous cooperation of thousands of physicians. The first study results played a role in the political debate around legislation of euthanasia in 1992. This thesis, however, is especially meant for the practising physicians confronted with terminally ill patients. Most of them started their career with the intention of curing people, or at least of keeping them as healthy as possible. In their training, only little time was spent on the fact that sometimes lives can not be saved, that people sometimes do not want to go on living, or that major decisions have to be taken without the patient being able to participate. Nevertheless, the task of physicians is not only to preserve the patients' lives, but also to support them at the end of life. In such a situation, the most important professional skills are: knowing when to refrain and when to act, being prepared to face and discuss these difficult decisions, and being prepared to account for them afterwards.

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Appendix The Standard Questionnaire

1	In respect of this death, where you acting as:	☐ specialist/specialist-in-training/ assistant-physician-not-in-training ☐ general practitioner/general practitioner-in-training ☐ nursing-home physician/trainee nursing-home physician ☐ in a different function to those named above
2	When was your first contact with the patient?	☐ before or at the time of death → go to question 3 ☐ after death → go to question 24
3	Was death sudden and totally unexpected?	☐ yes → go to question 22 ☐ no → go to question 4
4	Did you or a colleague take one or more of the following actions, or ensure that one of them was taken, *taking into account the probability* that this action would hasten the end of the patient's life: (please reply to all three questions, 4a, 4b and 4c)	
4a	withholding a treatment*?	☐ yes ☐ no
4b	withdrawing a treatment*?	☐ yes ☐ no
4c	intensifying the alleviation of pain and/or symptoms using morphine or a comparable drug?	☐ yes → go to question 5 ☐ no → go to question 6
5	Was hastening the end of life *partly the purpose* of the action indicated in question 4c?	☐ yes ☐ no
6	Was death caused by one or more of the following actions, which you or a colleague decided to take *with the explicit purpose* of hastening the end of life: (answer both 6a and 6b)	
6a	withholding a treatment*?	☐ yes ☐ no
6b	withdrawing a treatment*?	☐ yes ☐ no

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* In this study,, 'treatment' is taken to include 'tube feeding'

7	Was the death caused by the use of a drug** prescribed, supplied or administered by you or a colleague *with the explicit purpose* of hastening the end of life (or of enabling the patient to end his own life)?	☐ yes ☐ no
	If yes, who administered this drug** (= introduced it into the body)? (tick one or more answers)	☐ the patient himself in the doctor's presence ☐ the patient himself without the doctor being present ☐ you or a colleague ☐ a nurse ☐ another person in the doctor's presence ☐ another person without the doctor being present

If *at least one* of the items of questions 4, 5, 6 and 7 was answered with 'yes', go to question 8

If all parts of questions 4, 5, 6 and 7 were answered with 'no', go to question 22

Questions 8 to 21 relate to the *last 'yes' in answer to questions 4 to 7*

8	A question about that (last mentioned) action: in your estimation, by how much was the life of the patient in fact shortened by this action?	☐ more than six months ☐ one to six months ☐ one to four weeks ☐ up to one week ☐ less than 24 hour ☐ life probably was not shortened at all
9	Did you or a colleague discuss with the patient the (possible) hastening of the end of life as a result of the last-mentioned action?	☐ yes, at the time of performing the action or shortly before→ go to question 10 ☐ yes, some time beforehand (and not at the time of, or shortly before) → go to question 10 ☐ yes, I do not know when → go to question 10 ☐ no, no discussion → go to question 16
10	Who took the initiative to discuss the situation with the patient? (tick one ore more answers)	☐ the patient ☐ you or a colleague ☐ nursing staff ☐ the patient's partner ☐ (other) relatives of the patient ☐ pastor, spiritual adviser ☐ other persons ☐ do not know

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** This may mean one or more drugs; morphine is also sometimes used for this purpose.

11	At the time of the *discussion*, did you consider the patient able to assess his/her situation and to take a decision about it adequately?	☐ yes ☐ no, not or not totally able
12	Was the decision concerning the (last-mentioned) action taken upon an explicit request of the patient?	☐ yes → go to question 13 ☐ no → go to question 15
13	At the time of this *request*, did you consider the patient able to assess his/her situation and take a decision about it adequately?	☐ yes ☐ no, not or not totally able
14	Did the patient express this request repeatedly?	☐ yes
15a	Was there a written advance directive available?	☐ yes → go to question 15b ☐ no → go to question 21
15b	Did this play part in reaching the decision?	☐ yes → go to question 21 ☐ no → go to question 21

Only answer questions 16 to 20 if the answer to question 9 was 'no, no discussion'

16	Was it possible to discuss the situation with the patient at the time when the (last-mentioned) action was decided upon?	☐ yes ☐ no
17	Why was this decision not discussed with the patient? (tick one or more answers)	☐ patient was too young ☐ patient was too emotionally unstable ☐ this (last-mentioned) action was clearly the best one for the patient ☐ discussion would have done more harm than good ☐ patient was temporarily unconscious ☐ patient was permanently unconscious ☐ patient was in a state of diminished consciousness ☐ patient was demented ☐ patient was mentally handicapped ☐ patient was suffering from a psychiatric disorder ☐ other, if you wish you may expand on this at question 24

18	Did one of the following make an explicit request to hasten the patient's life: (tick one or more answers)	☐ partner of patient ☐ parents of patient ☐ guardian, or authorized representative of patient ☐ children of patient ☐ (other) relatives of the patient ☐ colleague ☐ nursing staff ☐ others ☐ no explicit request
19	As far as you know, did the patient ever express a wish for the end of life to be hastened?	☐ yes → go to question 20 ☐ no → go to question 21
20	How were you informed of this wish? (tick one or more answers)	☐ verbally by the patient ☐ by a written directive of the patient ☐ verbally by a colleague ☐ in writing by a colleague ☐ by relatives or other persons ☐ otherwise, if you wish you may expand on this at question 24
21	Did you or a colleague discuss with anybody else the (possible) hastening of the end of the patient's life before it was decided to take the last-mentioned action that was indicated by 'yes' in questions 4 to 7? (tick one or more answers)	☐ with one or more colleagues ☐ nursing staff ☐ partner of patient ☐ (other) relatives of patient ☐ pastor, spiritual adviser ☐ guardian, authorized representative of patient ☐ other persons ☐ nobody
22	Did you or a colleague clearly agree in advance that in the event of a (functional) cardiac and/or respiratory arrest no attempt would be made to resuscitate this patient? (a so-called Do Not Resuscitate decision)? (tick one or more answers)	☐ yes, with other doctors ☐ yes, with nursing staff ☐ yes, with the patient ☐ yes, with relatives of the patient ☐ not explicitly for this patient; however, implicitly based on the agreement that resuscitation will not in general be attempted in our institution ☐ no
23	Was there an explicit request to terminate life that was not carried out? (tick one or more answers)	☐ no, there was no explicit request that was not carried out ☐ yes, request by patient ☐ yes, request by relatives ☐ yes, request by other persons

24 If in your opinion your answers to the questions would benefit from further clarification, please provide this in the space below

Summary

This thesis explores the field of end-of-life decisions in medical practice in the Netherlands, seen primarily from the physician's point of view.

The four objectives for the investigation are: quantification of end-of-life decisions (chapters 3-4), description of the background of end-of-life decisions (chapters 5-8), analysis of the role of the physician in these decisions (chapters 9-10), and exploration of the socio-historical perspective on euthanasia (chapters 11-12). The data on which this thesis is based stems mainly from the study on euthanasia and other medical decisions concerning the end of life, that was performed for the 'Commission of Inquiry into the Medical Practice concerning Euthanasia', better known as the 'Remmelink Commission'. The Commission published its report in 1991. In the present thesis the material from the Remmelink study is further analyzed, new material is added, and interpretations and recommendations are given.

Chapter 2 presents the classification of end-of-life decisions and the study design of the Remmelink study.

The end-of-life decisions were classified on the basis of three questions: What did the physician do, what was the physician's intention in doing this, and did the patient request this end-of-life decision? Four types of end-of-life decisions were discerned: euthanasia and physician-assisted suicide, life-terminating acts without the patient's explicit request, alleviation of pain and symptoms with probable life-shortening effect, and non-treatment decisions with probable life-shortening effect.

Three studies were performed during the period 1990-1991. Study I consisted of interviews with 405 physicians: general practitioners, nursing-home physicians, and specialists from five specialties who are often confronted with dying patients. Random samples were drawn from physician registries. For study II a sample was drawn from the death certificate file of Statistics Netherlands, and the responsible physicians were contacted. This study contained the responses to 5197 questionnaires concerning deceased persons, filled out by these physicians. Study III was composed of information about 2257 deaths collected in a prospective study among those physicians who had been interviewed in study I.

The elaborate questionnaire of study I included among others detailed questions about the last occasion in which the physician had made an end-of-life decision. The concise questionnaire of studies II and III consisted of questions concerning the decision-making process in the final stages of a patient's life, in case an end-of-life decision had been made.

The response rates in the three studies were high: 91% in study I, 76% in study II, while 80% of the interviewees of study I participated in study III. The impressive cooperation of the Dutch medical profession may be interpreted as an indication that euthanasia and other end-of-life decisions are seen as important issues that deserve investigation and discussion.

The fact that the three studies showed far more similarities than differences, is a strong argument in favour of their validity. Complete anonymity and immunity against legal prosecution based on the research data were guaranteed. It could be inferred that the responding physicians had answered the questions truthfully and carefully. Potential biases have been explored, but were not found (see also chapter 13).

Chapter 3 presents the frequency of end-of-life decisions. About 30% of all deaths appeared to be sudden and unexpected, according to the physician. In the remaining 70% there was enough time to make decisions, and in more than half of these cases an end-of-life decision was made. Non-treatment decisions and decisions to alleviate pain with opioids were commonly made by all types of physicians. The other end-of-life decisions mentioned were made relatively infrequently: euthanasia in 1.8% of deaths, physician-assisted suicide in 0.3% of deaths, and life-terminating acts without the patient's explicit request in 0.8% of deaths. Initial requests for euthanasia were not rare (25,000 in 1990), but two thirds of these never evolved into a serious and persistent request. If they did, another two thirds did not result in euthanasia mainly because physicians could often offer alternatives.

It is concluded that physicians perform euthanasia less often than was previously supposed by some. A large majority of physicians sees euthanasia as an accepted element of medical practice under certain circumstances.

In *chapter 4* the discussion on the true incidence of euthanasia is evaluated. In the Netherlands, the accepted definition of euthanasia is the purposeful act of terminating life by a person other than the person concerned, upon request of the latter. Some have interpreted the term 'euthanasia' to include all medical decisions in which it is the physician's primary or secondary intention to hasten the end of the patient's life, including for example decisions to withhold antibiotics at the explicit request of a terminal cancer patient.

Such a different definition of euthanasia is of course possible, but concluding that all these decisions are instances of 'wrongful killing' is an unacceptable simplification. For a moral evaluation of end-of-life decisions, not only 'intention' has to be taken into account, but also the presence of a request of the patient, the futility of further medical treatment and other aspects.

Chapter 5 investigates the decisions to withhold or withdraw treatment at the end of life, collectively called non-treatment decisions. These decisions were made in 39% of non-sudden deaths. This percentage varied by specialty (28% to 55%). Non-treatment decisions were made more often in older, female patients. The decisions were made at the explicit request of the patient (19%), after discussion with the patient or after a previous wish (22%), or without any involvement of the patient (59%). Of this last group, 87% of patients were not competent to take a decision. Of all physicians interviewed, 56% had changed their attitude concerning life-prolonging treatment since the beginning of their practice, of which 81% toward more non-treatment decisions at the end of life.

It is concluded that continuing or starting treatment should be argued just as rigorously as discontinuing or withholding treatment. For this to be done properly, the patient should be involved whenever possible.

In *chapter 6* special attention is paid to the end-of-life decision-making in terminal cancer patients. It appeared that decisions for pain alleviation, euthanasia and life-terminating acts without the patient's explicit request occurred three to six times more often in cancer patients than in patients with other diagnoses at death. 'Pain' was an important reason for the cancer patient to ask for euthanasia, which is compatible with the fact that it is often terminal cancer patients whose pain cannot be relieved sufficiently.

Due to the fact that there will be a further absolute and relative increase of cancer deaths in the future, the number of end-of-life decisions is expected to increase. This warrants more training for physicians in the end-of-life decision-making in terminal cancer patients.

Chapter 7 describes whether physicians comply with the Dutch guidelines with respect to euthanasia, and it explores the conditions under which the physicians are prepared to report euthanasia truthfully. In nearly all cases of euthanasia the request was explicitly made. Virtually all cases involved a long-standing and carefully considered desire to die. In 79% of cases, no therapeutic alternatives were available to the patient. In almost all cases where alternatives were present, the patients refused their application.

Physicians acted somewhat less prudently with regard to the procedural guidelines: a colleague was consulted in 84% of cases, and written records were kept in 60% of cases. Most physicians agree that cases of euthanasia should be examined, under the condition that the procedure is transparent in terms of objectives, criteria, steps to be taken, and (possible) consequences.

Chapter 8 investigates the life-terminating acts without the patient's explicit request (LAWER). In 59% of LAWER the physician had some information about the patient's wish; in the remaining 41% discussion on the decision was no longer possible. In LAWER, patients tend to be younger and more likely to be male and to have cancer than in non-acute deaths generally. The physician knew the patient on average 2.4 years (hospital specialist) or 7.2 years (general practitioner). Life was shortened by between some hours and a week at most in 86%. In 83% the decision had been discussed with relatives and in 70% with a colleague. In nearly all cases, according to the physician, the patient was suffering unbearably, there was no chance of improvement, and palliative possibilities were exhausted.

It is concluded that although the number of end-of-life decisions probably will increase in the future, increasing possibilities for open discussion suggest a possible reduction in LAWER, even though there will always remain some situations in which a well-considered LAWER decision may have to be made.

Chapter 9 analyzes the role of the general practitioner in end-of-life decisions. 41% of all patients in the Netherlands die at home. General practitioners took fewer end-of-life-decisions than hospital specialists and nursing-home physicians (34%, 40% and 56% of all dying patients, respectively). Especially decisions to withhold or withdraw life prolonging treatment were taken less often. On the other hand, euthanasia or assisted suicide was performed in 3.2% of all deaths in general practice, against 1.4% in hospital practice. In 54% of the cases concerning pain relief or non-treatment, the general practitioner did not discuss the decision with the patient, mostly because of incompetence of the patient, but in 20% of cases for 'paternalistic' reasons. Older general practitioners discussed end-of-life decisions less often with their patients than younger ones. Colleagues were consulted more often if the general practitioner worked in group-practice.

The conclusion is that differences in work situation between general practitioners and hospital specialists, and differences within the group of general practitioners contribute to differences in the number and type of end-of-life decisions, as well as in the decision-making process.

In *chapter 10* the attitude of physicians towards euthanasia is compared with the practice. Performing euthanasia was not conceivable for 12% of physicians. Of those who could conceive of ever performing euthanasia, 61% had actually done so. Type of specialty (general practitioner, internist), gender of physician (female), importance attached to religion (none), and the number of received requests for euthanasia (one or more) were all significantly and independently contributed to the probability that a physician could conceive of ever performing euthanasia. Within the group of physicians who could conceive of a situation in which they would perform euthanasia, the gender of the physician was not related to the distinction between those who had never performed euthanasia and those who had ever done so. Differences in type of specialty became more prominent, indicating that differences in patient population per specialty probably influence the chance of performing euthanasia.

The findings demonstrate that conceiving of a situation in which euthanasia could be performed and having performed this at any time describe to different things. Therefore, research on the physicians' attitudes towards euthanasia in relation with some (socio-demographic) characteristics is not sufficient to gain a proper insight into the practice of euthanasia in relation to these characteristics, and vice versa.

Chapter 11 reports on the Dutch public and physicians' changes in opinions on euthanasia from 1966 to 1991. There was a major shift in opinion of the general public between 1966 and 1975. Opponents of euthanasia decreased from 49% to 15% in 1975, with a further decrease to 9% in 1991. The largest shift was towards a conditional acceptation of euthanasia. The opinion shift before 1975 probably should be seen in the light of parallel shifts with respect to attitudes toward religious practices, sexual morals, divorce, and abortion. Of the physicians, 39% had changed their opinion on euthanasia during their medical practice, 25% towards a more permissive position, 14% towards a more restrictive position.

One of the conclusions is that the physicians' confrontation with severe suffering in terminal disease tends to modify very clear-cut opinions in favour or against euthanasia.

In *chapter 12* the question is put forward why the Netherlands has such a special position in the international euthanasia debate. A number of experts from different countries, familiar with the Dutch situation, and representing a variety of disciplines, was asked to give their view. The answers covered, as could be expected, a wide range of topics. Still, a rather coherent picture emerged, although it inevitably had some contradictory and speculative elements. The topics that were most often mentioned as having the most explanatory power were differences in culture, differences in health care system, and differences in the legal system.

The results of this exploratory study warrants a much more thorough international comparative study into the socio-historical background of euthanasia.

The *concluding chapter* examines to what extent the objectives raised at the beginning have been realised. The most important findings are reviewed in the light of these objectives. In addition, the qualities and limitations of the investigation are discussed and the practice of medical decision-making at the end of a patient's life in the Netherlands is tentatively appraised. Improvements in the training of physicians regarding the knowledge, attitude and practice of end-of-life decision-making are proposed. Finally, suggestions for future research are given.

Samenvatting

In dit proefschrift worden de medische beslissingen rond het levenseinde in Nederland in kaart gebracht, bezien vanuit het oogpunt van de arts.

De vier doelstellingen voor het proefschrift zijn: kwantificering van deze beslissingen (hoofdstukken 3-4), beschrijving van de achtergrond van deze beslissingen (hoofdstukken 5-8), analyse van de rol van de arts in deze beslissingen (hoofdstukken 9-10), en onderzoek naar euthanasie in sociaal-historisch perspectief (hoofdstukken 11-12). De gegevens waarop het proefschrift is gebaseerd zijn voornamelijk afkomstig uit het onderzoek naar euthanasie en andere medische beslissingen rond het levenseinde, dat is uitgevoerd voor de 'Commissie Onderzoek Medische praktijk inzake Euthanasie', beter bekend als het 'de Commissie Remmelink'. De Commissie publiceerde haar rapport in 1991. In dit proefschrift wordt het materiaal van het Remmelink onderzoek verder geanalyseerd, wordt nieuw materiaal toegevoegd, en worden interpretaties en aanbevelingen gegeven.

Hoofdstuk 2 geeft de classificering van beslissingen rond het levenseinde en de onderzoeksopzet van het Remmelink onderzoek. De beslissingen werden geclassificeerd op basis van drie vragen: Wat deed de arts, wat was intentie van de arts hierbij, en wat was de rol van de patiënt bij deze beslissing? Vier typen beslissingen werden onderscheiden: euthanasie en hulp bij zelfdoding, levensbeëindigend handelen zonder het uitdrukkelijk verzoek van de patiënt, pijn- en symptoombestrijding met waarschijnlijk levensbekortend effect, en beslissingen om behandelingen te staken of niet in te stellen met waarschijnlijk levensbekortend effect.

Drie onderzoeken werden uitgevoerd gedurende de periode 1990-1991. Onderzoek I bestond uit interviews met 405 artsen: huisartsen, verpleeghuisartsen, en specialisten uit vijf specialismen die regelmatig worden geconfronteerd met stervende patiënten. Uit bestaande artsenregistraties werden aselecte steekproeven getrokken. Voor onderzoek II werd een steekproef getrokken uit het bestand van de doodsoorzaakverklaringen van het Centraal Bureau voor de Statistiek, en de verantwoordelijke artsen werden aangeschreven. Dit onderzoek bevat de antwoorden op 5197 vragenlijsten over overleden patiënten, ingevuld door deze artsen. Onderzoek III bestond uit informatie over 2257 sterfgevallen, komend uit een prospectief onderzoek onder de artsen die waren geïnterviewd in onderzoek I.

Onderzoek I bestond onder meer uit gedetailleerde vragen over de laatste keer waarin de arts een bepaald type beslissing had genomen. De beknopte vragenlijst uit de onderzoeken II en III bevatte vragen over het besluitvormingsproces, in het geval een beslissing rond het levenseinde was genomen.

De respons in de drie onderzoeken was hoog: 91% in onderzoek I, 76% in onderzoek II, terwijl 80% van de geïnterviewden uit onderzoek I deelnam aan onderzoek III. De grote medewerking van de medische beroepsgroep mag worden opgevat als een aanwijzing dat euthanasie en andere beslissingen rond het levenseinde worden gezien als belangrijke onderwerpen die onderzoek en discussie vereisen.

Het feit dat de drie onderzoeken veel meer overeenkomsten dan verschillen lieten zien vormt een aanwijzing voor hun validiteit. Volledige anonimiteit kon worden gegarandeerd, evenals het niet opvraagbaar zijn van het verkregen materiaal in het kader van eventuele rechtsvervolging. Geconcludeerd werd dat de artsen de vragen zorgvuldig en naar waarheid hadden geantwoord. Selectie-effecten ten gevolge van non-respons werden niet gevonden (zie ook hoofdstuk 13).

Hoofdstuk 3 beschrijft het voorkomen van beslissingen rond het levenseinde. Van alle sterfgevallen vond 30% plotseling en onverwacht plaats. In de overige 70% was er voldoende tijd om beslissingen te nemen, hetgeen in de helft van deze gevallen geschiedde. Beslissingen om behandelingen te staken of niet in te stellen, en om pijn- en symptoombestrijding te intensiveren werden frequent genomen. De andere typen beslissingen waren betrekkelijk zeldzaam: euthanasie in 1,8% van alle sterfgevallen, hulp bij zelfdoding in 0,3%, en levensbeëindiging zonder uitdrukkelijk verzoek in 0,8% van alle sterfgevallen. Verzoeken om euthanasie kwamen regelmatig voor (25,000 in 1990), doch slechts eenderde hiervan mondde uit in een uitdrukkelijk en herhaald verzoek. Eenderde van deze laatste leidde uiteindelijk tot euthanasie of hulp bij zelfdoding.

De conclusie is dat euthanasie minder vaak plaatsvindt dan eerder wel eens werd verondersteld. Wel ziet de overgrote meerderheid van de artsen euthanasie als een acceptabel onderdeel van de medische praktijk.

Hoofdstuk 4 gaat in op de discussie welke ontstond naar aanleiding van publikatie van de in hoofdstuk 3 gerapporteerde gegevens. Sommige auteurs wilden alle beslissingen waarbij bespoediging van het levenseinde mede of het uitdrukkelijke doel was als euthanasie opvatten. Hierdoor vielen bijvoorbeeld beslissingen om geen antibiotica toe te dienen bij terminale kankerpatiënten, al dan niet op uitdrukkelijk verzoek, onder de definitie van euthanasie. Vervolgens werden al deze beslissingen vaak beschreven als 'wrongful killing'. Voor een morele beoordeling van beslissingen rond het levenseinde dient echter met meer aspecten rekening te worden gehouden dan alleen intentie. Ook het al dan niet aanwezig zijn van een uitdrukkelijk verzoek van de patiënt, en de mogelijke zinloosheid van verdere behandeling dienen bijvoorbeeld in de afweging te worden betrokken.

In *hoofdstuk 5* worden beslissingen om behandelingen te staken of niet in te stellen nader onderzocht. Dergelijke beslissingen werden in 39% van alle niet-acute sterfgevallen genomen. Tussen verschillende specialismen varieerde dit percentage van 28% tot 55%. Ze betroffen vaker oudere, vrouwelijke patiënten. In 19% van de gevallen werden ze genomen op uitdrukkelijk verzoek van de patiënt, in 22% na overleg met de patiënt of na een eerder geuite wens van de patiënt, terwijl in de resterende 59% de patiënt niet bij de beslissing betrokken was. Van deze laatste groep was 87% van de patiënten niet wilsbekwaam. 56% van de geïnterviewde artsen zei dat hun opvattingen over de toepassing van levensverlengende behandelingen in de loop van de praktijk was gewijzigd. Hiervan zei 81% tegenwoordig minder vaak dergelijke behandelingen toe te passen.

De conclusie is dat het continueren van of beginnen met behandeling even zorgvuldig moet worden beargumenteerd als het staken of niet beginnen. Waar mogelijk dient de patiënt bij de besluitvorming te worden betrokken.

In *hoofdstuk 6* worden medische beslissingen rond het levenseinde van kankerpatiënten besproken. Intensivering van pijn- en symptoombestrijding, euthanasie, en levensbeëindigend handelen zonder uitdrukkelijk verzoek vinden bij kankerpatiënten drie tot zesmaal zo vaak plaats als bij andere terminale patiënten. Kankerpatiënten noemden vaker pijn als reden voor het euthanasieverzoek. Dit is in overeenstemming met het gegeven dat bij terminale kankerpatiënten de pijn soms niet voldoende kan worden bestreden.

Gezien de voortgaande absolute en relatieve toename van de aantallen sterfgevallen aan kanker mag een toename van het aantal medische beslissingen rond het levenseinde worden verwacht. Dit vraagt om een intensievere scholing van artsen op dit gebied.

Hoofdstuk 7 beschrijft in hoeverre artsen bekend zijn met de zorgvuldigheidseisen ten aanzien van euthanasie, hoe die in de praktijk worden gehanteerd, en onder welke voorwaarde artsen bereid zijn om euthanasie te melden. In nagenoeg alle gevallen van euthanasie betrof het een uitdrukkelijk verzoek van de patiënt. Ook was er sprake van een duurzaam en weloverwogen verlangen naar de dood. In 79% van de gevallen waren er geen behandelingsalternatieven meer voor de patiënt. Wanneer die er wel waren, had de arts er in bijna alle gevallen van afgezien deze toe te passen, omdat de patiënt dat niet toestond.

Artsen handelden iets minder zorgvuldig met betrekking tot de procedurele eisen: In 84% was overlegd met een collega, en in 60% was een schriftelijk verslag bijgehouden.

De meeste artsen vinden toetsing van euthanasie gewenst, op voorwaarde dat de procedure volstrekt helder is wat betreft doelstelling, criteria, te volgen stappen, (mogelijke) consequenties en totaal tijdsbeslag.

In *hoofdstuk 8* wordt het levensbeëindigend handelen zonder uitdrukkelijk verzoek (LHZUV) van de patiënt nader onderzocht. In 59% van de gevallen van LHZUV beschikte de arts over informatie omtrent de wens van de patiënt. In de resterende 41% was het niet meer mogelijk de beslissing met de patiënt te bespreken. In vergelijking met de verdeling over alle niet-acute sterfgevallen vindt LHZUV vaker plaats bij jongere, mannelijke patiënten, en bij patiënten met kanker. De arts kende de patiënt gemiddeld 2,4 jaar (klinisch specialist) respectievelijk 7,2 jaar (huisarts). In 86% van de gevallen bedroeg de levensbekorting tussen enige uren en hooguit een week. In 83% van de gevallen was de beslissing besproken met familieleden en in 70% van de gevallen met een collega. In vrijwel alle gevallen was er sprake van een ondraaglijk lijden, was er geen uitzicht op verbetering, en waren de palliatieve mogelijkheden uitgeput.

De conclusie luidt dat, hoewel het totaal aantal beslissingen rond het levenseinde in de toekomst waarschijnlijk verder zal toenemen, het aantal LHZUV mogelijk zal dalen als gevolg van de toegenomen mogelijkheden voor een openlijke gedachtenwisseling met de patiënt. Desondanks zullen zich altijd omstandigheden blijven voordoen, waarin LHZUV zal moeten worden overwogen.

Hoofdstuk 9 bespreekt de rol van de huisarts bij medische beslissingen rond het levenseinde. 41% van alle sterfgevallen in Nederland vindt thuis plaats. Huisartsen namen minder beslissingen rond het levenseinde dan klinisch specialisten en verpleeghuisartsen (respectievelijk 34%, 40%, en 56% van alle sterfgevallen). De huisarts nam vooral minder vaak een beslissing om een behandeling te staken of niet te beginnen. Daarentegen vonden euthanasie of hulp bij zelfdoding plaats bij 3,2% van alle sterfgevallen in de huisartsenpraktijk, tegen 1,4% in het ziekenhuis. In 54% van de gevallen van intensivering van pijn- en symptoombestrijding of het staken of niet beginnen van levensverlengende therapie had de huisarts de beslissing niet met de patiënt besproken. In de meeste gevallen was de reden gelegen in de wilsonbekwaamheid van de patiënt, in 20% van de gevallen betrof het 'paternalistische' redenen. Oudere huisartsen bespraken dergelijke beslissingen minder vaak met hun patiënten dan jongere. Collega's werden vaker geraadpleegd wanneer de huisarts in een groepspraktijk werkte.

De conclusie is dat verschillen in werksituatie tussen huisartsen en clinici, en verschillen binnen de groep huisartsen gevolgen hebben voor het aantal en het soort beslissingen rond het levenseinde, evenals voor het besluitvormingsproces.

In *hoofdstuk 10* wordt de attitude van de arts met betrekking tot euthanasie vergeleken met het feitelijke gedrag. Van alle artsen gaf 12% te kennen zich geen situatie te kunnen voorstellen waarin ze euthanasie zouden uitvoeren. Van de overigen had 61% ooit euthanasie uitgevoerd. Specialisme (huisarts, internist), geslacht van de arts (vrouw), belang van godsdienst (geen), en het aantal verzoeken van patiënten om euthanasie (een of meer), droegen alle onafhankelijk en significant bij aan de kans dat men het zelf uitvoeren van euthanasie denkbaar acht. Binnen de groep artsen die het uitvoeren denkbaar achtte, was er geen samenhang tussen geslacht en het ooit hebben uitgevoerd van euthanasie. Verschillen tussen specialismen waren hier meer prominent aanwezig, wat een aanwijzing kan zijn dat de kans om ooit euthanasie te hebben uitgevoerd samenhangt met verschillen in patiëntenpopulatie.

Deze resultaten laten zien dat er een verschil is tussen het denkbaar achten van euthanasie en het feitelijk hebben uitgevoerd ervan. Onderzoek dat zich beperkt tot attitudes van artsen met betrekking tot euthanasie is niet voldoende om een indruk te krijgen van de feitelijke toepassing, en omgekeerd.

Hoofdstuk 11 beschrijft de veranderingen in de publieke opinie met betrekking tot euthanasie tussen 1966 en 1991, en veranderingen in de opinies van artsen. De publieke opinie onderging een aanzienlijke verandering tussen 1966 en 1975. Het percentage tegenstanders van euthanasie nam af van 49% tot 15% in 1975, om verder te dalen tot 9% in 1991. Het merendeel van deze verschuiving kwam op rekening van een voorwaardelijke acceptatie van euthanasie. Deze verandering moet geplaatst worden in de veel bredere context van veranderende opvattingen over religie, gezinspatronen, sexualiteit etcetera, welke in die periode in vrijwel de gehele Westerse wereld plaatsvonden. Van de in onderzoek I geïnterviewde artsen gaf 39% aan dat hun opinie over euthanasie in de loop van hun medische praktijk was gewijzigd. 25% zei permissiever te zijn geworden, terwijl 14% restrictiever was geworden.

Een conclusie is dat ervaring uitgesproken opvattingen over euthanasie kennelijk modificeert.

Hoofdstuk 12 behandelt de vraag waarom Nederland zo'n bijzondere positie inneemt in het internationale euthanasiedebat. Een aantal experts uit verschillende landen, die vertrouwd waren met de Nederlandse situatie en afkomstig uit verschillende disciplines, werd gevraagd hierover hun mening op schrift te stellen. Zoals mocht worden verwacht kwam in de antwoorden een groot aantal onderwerpen aan de orde. Hieruit kon een redelijk samenhangend beeld worden samengesteld, ondanks een aantal onvermijdelijke tegenstrijdige en speculatieve elementen. Als belangrijkste kwamen culturele verschillen, verschillen in gezondheidszorgsysteem en verschillen in het rechtsstelsel naar voren.

De resultaten van dit exploratieve onderzoek rechtvaardigen een systematischer en omvangrijker internationaal vergelijkend onderzoek naar de achtergronden van euthanasie.

In het *slothoofdstuk* komt de vraag aan de orde in hoeverre de doelstellingen van dit proefschrift zijn gerealiseerd. De belangrijkste bevindingen worden besproken, evenals de betekenis en de beperkingen van het onderzoek. Er wordt een tentatief oordeel over de medische besluitvorming rond het levenseinde in Nederland gegeven. Verbeteringen in de opleiding van artsen met betrekking tot kennis, attitude en vaardigheden op het gebied van besluitvorming rond het levenseinde worden voorgesteld. Het hoofdstuk eindigt met enkele voorstellen voor verder onderzoek.

Dankwoord

Mijn promotie-onderzoek valt goed in te delen in twee trajecten: de zestien maanden dat ik nauwelijks over promoveren nadacht (ten tijde van het 'Remmelink onderzoek'), en de drie jaar erna, waarin alles in het kader van promoveren stond. Terugdenkend aan het eerste traject voelde het als het rijden in een TGV-trein: snel, geen tijd om stil te staan, voorzien van alle luxe; het tweede meer als het rijden in een stoomtrein: het gaat vooruit, zij het soms hortend en stotend, maar met voldoende stoom wordt het einddoel wel bereikt. Beide trajecten kostten veel energie, maar dankzij steun en begeleiding van vele mensen kijk ik er zeer tevreden op terug.

In het eerste traject werkte ik intensief samen met Paul van der Maas en Hans van Delden. Paul gaf Hans en mij de dagelijkse leiding in handen, en wist ons met een onzichtbare kracht tot daden aan te zetten. Hans leerde mij de beginselen van de ethiek, zo waardevol voor het onderzoek en voor mijzelf. Ondanks het feit dat vele medewerkers van het instituut Maatschappelijke Gezondheidszorg van de Erasmus Universiteit Rotterdam hebben geleden onder de voorrang die de TGV-trein telkens kreeg, bleven zij belangstellend en gaven zij volledige steun. Speciale dank gaat naar het secretariaat - Alice, Monique, Else, Theresa, Aty, Saskia en Ilse - voor het keurig klaren van de immer weer nieuwe spoedklussen, en naar de 'computermannen' - Caspar, Hans en Ton - voor hun wijze raad. Caspar leerde mij om vóór te denken, zodat ik minder hoefde na te denken. Daarnaast wil ik hier ook graag mevrouw Gribling-Laird noemen, die in een aantal hoofdstukken van mijn Engels echt Engels heeft gemaakt.

Omdat mijn proefschrift grotendeels is gebaseerd op het Remmelink onderzoek wil ik hierbij allen die dit onderzoek tot een succes hebben gemaakt, bedanken. Ik denk hierbij in het bijzonder aan de leden van de Commissie Remmelink en de leden van de Subcommissie, de interviewers, en alle betrokkenen van het Centraal Bureau voor de Statistiek. Jan Kardaun en Ko Glerum, mede-auteurs van enkele artikelen, gaven mij veel steun op afstand. Zonder de volledige medewerking van de duizenden artsen die hun kostbare tijd in het onderzoek staken, waren beide trajecten niet uitgereden.

In het tweede traject waren Prof. Borst-Eilers en Prof. de Beaufort bereid om als promotor op te treden. Mevrouw Borst gaf zowel als lid van de Commissie Remmelink als tijdens haar promotorschap immer duidelijke en krachtige adviezen, zonder afbreuk te doen aan eigen creaties. Met Inez samenwerken was behalve heel gezellig ook zeer leerzaam, en voor mij telkens van grote waarde om weer ontspannen verder te gaan.

Door de verandering van functie van mevrouw Borst werd Prof. Gunning-Schepers vlak voor het eindstation gevraagd om het promotorschap over te nemen. Louise was degene die mij adviezen gaf over mijn toekomstige loopbaan reeds voor ik met mijn coschappen begon. Bij het Remmelink onderzoek was zij nauw betrokken geweest als één van de interviewers. Zij vervulde haar taak als promotor met veel enthousiasme en energieke betrokkenheid. Louise en Inez zorgden ervoor dat ik vol vertrouwen mijn werk aan de kleine promotie-commissie ter beoordeling gaf.

Ik wil graag Anky Erlings bedanken voor het feit dat zij mij gedurende het tweede traject de gelegenheid gaf om één dag in de week in haar huisartsenpraktijk waar te nemen. Het wel en wee van haar patiënten vormde een goed tegenwicht tegen de 'papieren' wetenschap. Dankzij deze ervaring besloot ik om te solliciteren voor de opleiding tot huisarts.

Diegenen die het dichtst bij me stonden, hebben het meest van mijn pieken en dalen kunnen genieten. Kees-Jan, jouw levensfilosofie is en blijft belangrijk voor mij: een niet aflatende optimistische kijk is goud waard. Anneke en Marijn, mijn lieve zusjes, wat is het altijd fijn om weer met jullie te zijn, en liefst dan natuurlijk in Maastricht, nog altijd een thuis. Irène en Frans, jullie gaven me al vroeg het gevoel dat ik m'n eigen leven kon en mocht leiden, en dat heeft me altijd enorm gestimuleerd.

Als laatste persoon nogmaals Paul, nu als vriend. Het feit dat onze relatie het tweede traject heeft doorstaan, geeft mij het volste vertrouwen in een prachtige toekomst.

Dit onderzoek werd mogelijk gemaakt door subsidiëring van het Ministerie van Volksgezondheid, Welzijn en Sport, en het Ministerie van Justitie.

Curriculum vitae

Loes Pijnenborg was born on February 2nd, 1965, in Nijmegen, The Netherlands. After completing her secondary education (Gymnasium B) at the Henric van Veldeke college in Maastricht, she started her medical studies in 1983 at the Erasmus University in Rotterdam. During her studies she worked as a student-assistant in the Sophia Childrens' Hospital. She was chairman of the student-association SSR-R, and member of the Council of the Faculty of Medicine and Health Sciences.

During the last year of her study she was invited to participate in the Study on Euthanasia and other Medical Decisions concerning the End of Life, which the Department of Public Health of the Erasmus University performed for the Remmelink Commission. In January 1992 she graduated cum laude, after which she started the further analyses, which constitute the larger part of this thesis.

During this period she worked one day a week as an assistant-general practitioner in a group practice in the centre of Rotterdam. There she resumed her original idea to become a 'real doctor'.

Presently, she is being professionally trained as a general practitioner at the Free University in Amsterdam.