

End-of-life decisions in medicine

Empirical studies on practices and
attitudes in the Netherlands

J.H. Groenewoud

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End-of-life decisions in medicine

Empirical studies on practices and
attitudes in the Netherlands

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opvattingen in Nederland

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Voor de beste mens van de wereld

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Chapters 2-9 are based on the following articles:

2

Groenewoud JH, van der Maas PJ, van der Wal G, Hengeveld MW, Tholen AJ, Schudel WJ, van der Heide A. Physician-assisted death in psychiatric practice in the Netherlands. *N Engl J Med* 1997;336:1795-801.

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A Dutch version was published as:

Groenewoud JH, van der Maas PJ, van der Wal G, Hengeveld MW, Tholen AJ, Schudel WJ, van der Heide A. Hulp bij zelfdoding in de psychiatrie in Nederland. *Ned Tijdschr Geneeskd* 1997;141:2244-8.

3

Groenewoud JH, van der Heide A, Tholen AJ, Schudel WJ, Hengeveld MW, Onwuteaka-Philipsen BD, van der Maas PJ, van der Wal G. Psychiatric consultation with regard to requests for euthanasia or physician-assisted suicide. (submitted)

4

Groenewoud JH, van der Heide A, Schudel WJ, Hengeveld MW, Tholen AJ, van der Wal G, van der Maas PJ. Attitudes and practices of Dutch psychiatrists with regard to physician-assisted death because of a mental disorder. (submitted)

5

Willems DL, Groenewoud JH, van der Wal G. Drugs used in physician-assisted death. *Drugs & Aging* 1999;15:335-40.

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6

Groenewoud JH, Willems DL, van der Heide A, van der Maas PJ, van der Wal G. Use of drugs with a potentially life-shortening effect in Dutch medical practice. (submitted)

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Groenewoud JH, Willems DL, van der Heide A, van der Maas PJ, van der Wal G. Use of drugs with a potentially life-shortening effect in Dutch medical practice. (submitted)

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PART I

Introduction

1

Introduction

1.1 Background

Compared with the situation at the beginning of the last century, the circumstances in which people in the developed countries die have changed considerably. This is the result of a number of medical and societal developments. First, the distribution of causes of death has changed. Infectious diseases, once the most important cause of death, rapidly declined; currently, non-infectious diseases, e.g. cardiovascular disease and cancer are the most frequent causes of death in the industrialised world. Second, the number of treatment alternatives have increased. Medical developments, including advanced medical technologies, today allow physicians to prevent or postpone death in patients who formerly would have died. Whereas a century ago, the physician's role at the end of a person's life was limited, nowadays medical involvement is commonplace; about 70% of deaths in the Netherlands are non-sudden and likely to have been preceded by some kind of end-of-life care. Third, personal autonomy has become more important and there is a growing need to control the moment and the way of dying. All these changes have led to an increased interest in the possibilities and impossibilities of medical care at the end of life. This interest extends to end-of-life decision making, here defined as all medical involvement at the end of life which certainly or probably hastens death.

1.2 Types of end-of-life decisions

There are at least five different end-of-life decisions to be distinguished (Table 1.1), which differ in respect of the following three aspects:

- ♦ the act: the administration of potentially lethal drugs or the withholding or withdrawing of potentially life-prolonging treatment,
- ♦ the involvement of the patient: an end-of-life decision can be made at the explicit request of the patient, i.e., the patient has made a concurrent, explicit and persistent request to hasten death, or not, and
- ♦ the intention with which the end-of-life decision is made: hastening of the patient's death can be the explicit intention of the physician, or hastening of death is foreseen but not explicitly intended.

Euthanasia, physician-assisted suicide and ending of life without the patient's explicit request are also referred to as *physician-assisted death*. These practices have in common the use of potentially life-shortening drugs with the explicit intention to hasten the patient's death.

Table 1.1
Definitions of end-of-life decisions

Euthanasia	the <i>administration</i> of potentially lethal drugs by <i>another person</i> than the patient at the patient's <i>explicit request</i> with the <i>explicit intention</i> to hasten the patient's death
Physician-assisted suicide	the <i>prescription or supply</i> of potentially lethal drugs to be taken by <i>the patient him- or herself</i> at the patient's <i>explicit request</i> with the <i>explicit intention</i> to hasten the patient's death
Ending of life without the patient's explicit request	the <i>administration</i> of potentially lethal drugs by <i>another person</i> than the patient without the patient's <i>explicit request</i> with the <i>explicit intention</i> to hasten the patient's death
Alleviation of pain and symptoms with opioids or comparable drugs in high dosages	the <i>administration</i> of potentially lethal drugs whether or not at the patient's <i>explicit request</i> without the <i>explicit intention</i> to hasten the patient's death
Decisions to forgo treatment (non-treatment decisions)	the <i>withholding or withdrawal</i> of potentially life-prolonging treatment whether or not at the patient's <i>explicit request</i> whether or not with the <i>explicit intention</i> to hasten the patient's death

1.3 Situation in the Netherlands

Legal circumstances

The withholding or withdrawal of treatment at the (competent) patient's explicit request or because of 'medical futility' is generally accepted medical practice, even if the patient's life is shortened as a consequence. Euthanasia, physician-assisted suicide and ending of life without the patient's explicit request are subject to criminal law in almost all countries, except for the state of Oregon in the USA, where assisted suicide to terminally ill patients has been legalised. In the Netherlands, a new bill is pending, but as it now stands euthanasia and physician-assisted suicide are punishable by law. To establish a supervisory mechanism for physician-assisted death, a notification procedure was agreed on in 1990 by the minister of Justice and the Royal Dutch Medical Association.

Notification procedure. The procedure for reporting physician-assisted death was introduced in the Netherlands in 1991 and legally enacted by the Dutch legislature in June 1994.¹ The purposes of the notification procedure are to encourage physicians to disclose cases in which they have assisted in a patient's

death, to promote adherence to the criteria for careful practice, and to ensure that physician-assisted death is reported in a uniform manner throughout the country. According to the procedure, a physician who has assisted in a patient's death does not issue a certificate of natural death but instead informs the coroner that it was a physician-assisted death. The physician is expected to fill in an official checklist with questions about the medical history, the request of the patient, the drugs used to cause death, and the report of the physician who was consulted. The coroner then conducts a post-mortem examination, collects the relevant data, informs the public prosecutor of the death, and submits all the relevant documents. The public prosecutor decides whether to permit burial or cremation, examines the record, and presents a judgement to the prosecutor general. The latter, usually assisted by an advocate general, presents the case, together with his or her own opinion, to the Assembly of Prosecutors General, which has five members. The Assembly provisionally decides whether or not to prosecute. The final decision with regard to prosecution is made by the minister of Justice.

This procedure was revised as of 1 November 1998.² The new procedure requires the coroner to submit, after the post-mortem examination, all the relevant documents to one of five regional multidisciplinary review committees. These committees have 3 members: a lawyer, a physician and an ethicist. The finding of the review committee on whether or not the physician acted with due care is sent to the Public Prosecution Service. The Assembly of Prosecutors General then decides whether or not to institute criminal proceedings. This revised procedure applies to life-ending practices at the patient's explicit request, i.e., euthanasia and physician-assisted suicide; the notification procedure for life-ending practices without the patient's explicit request has not been changed.

Criteria for careful practice. In the Netherlands, any physician who has performed euthanasia or physician-assisted suicide will not be prosecuted if he or she complies with a number of criteria for careful practice, which were formulated by jurisprudence and the medical profession. These criteria are:

- ♦ that the patient's suffering be hopeless and unbearable, according to current medical standards;
- ♦ that the patient's request be well considered and made voluntarily;
- ♦ that at least one other physician be consulted about the attending physician's assessment of the first two criteria;
- ♦ that the euthanasia or physician-assisted suicide be performed in a technically appropriate and professional manner.

Recent developments. In April 2001, an act for termination of life on request and assisted suicide was passed by Dutch parliament.³ This act shall take effect as of a date still to be determined. The grounds on which the termination of life on

request and assisted suicide are permissible remain unchanged under the new regulations.

Table 1.2
Reports and theses on end-of-life decision-making in the Netherlands

Publication	Contents
Nationwide studies (reports)	
1990/1991: Rimmelink study: medical decisions concerning the end of life ^{4,5}	The first complete overview of medical decisions concerning the end of life in a single country.
1995/1996: Evaluation of the notification procedure for physician-assisted death ⁶	Second nationwide study of euthanasia and other medical practices related to the end of life.
Theses	
Euthanasia and physician-assisted suicide by family doctors, by G. van der Wal (1992) ⁷	Frequency of euthanasia and physician-assisted suicide in family practice; characteristics of patients and of family doctors; and methods of ending life.
End-of-life decisions in Dutch medical practice, by L. Pijnenborg (1995) ⁸	Quantification and background characteristics of end-of-life decisions; analysis of the role of the physician in these decisions; and exploration of the socio-historical perspective on euthanasia.
Death on request. Aspects of euthanasia and physician-assisted suicide with special regard to Dutch nursing homes, by M.T. Muller (1996) ⁹	Frequency of euthanasia and physician-assisted suicide in Dutch nursing-homes; patient characteristics; involvement of others in the decision-making; and the adherence to the requirements of careful practice.
Examination and quality assurance of physician-assisted death, by J.M. Cuperus-Bosma (1998) ¹⁰	Practice of late termination of pregnancy and of physician-assisted death; and the possible implementation of regulation, examination and quality assurance in order to ensure prudent and transparent medical practice.
Policies and guidelines on medical decisions concerning the end of life in Dutch health care, by I. Haverkate (1999) ¹¹	Prevalence and content of policies and (written) guidelines on medical decisions concerning the end of life; evaluation of the experiences and compliance of physicians with such guidelines.
Consultation of another physician in cases of euthanasia and physician-assisted suicide, by B.D. Onwuteaka-Philipsen (1999) ¹²	Practice of consultation in cases of euthanasia and physician-assisted suicide in the Netherlands. Evaluation of the project 'Support and Consultation on Euthanasia in Amsterdam' (SCEA) as a method of quality assurance and review.

Empirical research in the Netherlands

In 1990/1991, a nationwide study of euthanasia and other medical practices related to the ending of life was conducted, commissioned by a governmental committee chaired by Professor Jan Rummelink, the attorney general of the Dutch Supreme Court. The results of this study drew much attention in the Netherlands and abroad, particularly because this study offered the first complete overview of the occurrence and types of end-of-life decisions in one country.^{4,5} In 1995/1996 a second nationwide study was conducted, partially identical to the first, in an evaluation of the new notification procedure for physician-assisted death.⁶ This second study was also commissioned by the ministers of Health and Justice. The aim of the replication study was to obtain reliable estimates of the frequency of euthanasia and other medical decisions involving the end of life, to provide insight into the circumstances in which such decisions were made, and to describe any changes compared to 1990. Both studies led to a report and a large number of national and international publications. A number of theses on end-of-life decision-making have been written on the basis of these and other studies. An overview of the reports and theses is presented in Table 1.2.^{4,12} An extensive list of publications is presented in Appendix A.

1.4 Objective of this thesis

Against the background of a gradually increasing body of empirical knowledge on medical end-of-life decisions in the Netherlands, three issues in end-of-life decision-making are addressed in this thesis. One of these issues, namely the role of the psychiatrist in end-of-life decision-making, will be explored for the first time; two other issues, i.e. decisions to forgo potentially life-prolonging treatment and the use of potentially life-shortening drugs, will be examined in greater depth.

1. Psychiatrists' role in end-of-life decision-making

The Rummelink study 1990/1991 provided some evidence of end-of-life decision-making in specific patient categories, such as psychiatric patients, newborns, children and AIDS patients.^{4,5} The numbers of deaths in these patient categories were small and mainly represented in the 5% of deaths that were not covered by the Rummelink study. Nevertheless, studying end-of-life decision-making in these groups is important for the understanding and evaluation of end-of-life practices in patients with specific characteristics and suffering. In a separate survey in 1995/1996, that was part of the second nationwide study, special attention was paid to end-of-life decision-making in Dutch psychiatric practice. In part II of this

thesis the results of this survey will be described. The main questions that were addressed are:

- ♦ what are the experiences of Dutch psychiatrists with patients' requests for euthanasia or physician-assisted suicide?;
- ♦ what is their role as consultant in case of patients' requests for hastening death?;
- ♦ what are their attitudes towards end-of-life practices in patients with a mental disorder?

2. Use of potentially life-shortening drugs at the end of life

Information about the use of potentially life-shortening drugs mainly concentrated on drugs that were used with the explicit intention to hasten death and concerned general practitioners and nursing-home physicians in particular.^{4,5,7,9,13,14} In part III of this thesis, practices that include the administration of potentially life-shortening drugs will be further explored. The main research questions are:

- ♦ what is the frequency of the use of potentially life-shortening drugs, which types of drugs are used, and what is the intention with which these drugs are used in Dutch medical practice?;
- ♦ what are the backgrounds of decisions to administer or prescribe drugs with the intention of alleviating pain and symptoms, while taking into account the possibility or certainty that such drugs may hasten the patient's death?;
- ♦ what are the clinical characteristics of the performance of euthanasia and physician-assisted suicide, i.e. the drugs that are used and how these are administered; and what are the characteristics and frequency of clinical problems with the performance of euthanasia and physician-assisted suicide, such as unintended effects and complications?

3. Decisions to forgo potentially life-prolonging treatment

Non-treatment decisions were the most frequently made end-of-life decisions in both the Rummelink study and the 1995/1996 study. It may be expected that in future such decisions will be even more important. The frequency and background characteristics of non-treatment decisions have already been described in some detail.^{8,15} Part IV of this thesis gives a more recent and comprehensive overview of non-treatment decisions on the ground of the second nationwide study on end-of-life practices in the Netherlands. The research questions are:

- ♦ has the incidence of decisions to withhold or withdraw possibly life-prolonging treatment changed in 1995/1996 compared to 1990/1991?;
- ♦ what types of treatment tend to be forgone?;
- ♦ to what extent are patients and others involved in the decision-making?

1.5 Methods

In order to answer the research questions outlined in the above, data from six different parts of the two nationwide studies were used. The main characteristics of these studies are presented in Table 1.2.

Survey of psychiatrists 1995/1996 (issue 1)

Psychiatrists registered before January 1, 1994, were selected from the register of the Royal Dutch Medical Association. Addresses were organised according to postal code, and every second psychiatrist was included in the sample. Of the 673 selected psychiatrists, 6 did not meet the criteria for selection and were therefore excluded from the study. Of the remaining 667 psychiatrists, 552 returned completed questionnaires (a response rate of 83%), 3 other responses could not be used. Of 112 nonrespondents, 6 had chronic illness or could not be traced, 51 refused to participate, while no reason could be traced for 55 other nonrespondents. All psychiatrists in the sample received a 1-page questionnaire eliciting personal data (age, sex, and domain of practice) and a 20-page questionnaire asking whether they had ever received a request for physician-assisted suicide and if so, how often in 1994 and 1995 and whether they had ever acceded to such a request. Detailed information about the most recent case was requested. In addition, respondents were asked whether they had ever been consulted by other physicians about patients' requests for euthanasia or physician-assisted suicide and if so, how often in 1994 and 1995. Other questions were about the respondents' attitudes towards physician-assisted death and towards consultation and about their opinions on review procedures.

Interview study 1990/1991 and 1995/1996 (issue 2)

In 1990/1991 and in 1995/1996 a stratified random sample of 405 physicians were interviewed. In 1990/1991 the sample included 152 general practitioners, 50 nursing-home physicians, and 203 physicians in five specialties (cardiology, surgery, internal medicine, pulmonology, and neurology); in 1995/1996 these numbers were 124, 74 and 207, respectively. To be selected for the study, the physicians interviewed had to have been practising in their registered specialty for at least two years, and to have worked at the same institution since then. To achieve the desired number of 410 interviews in both cases some 599 physicians were sampled for the studies. In 1990/1991, 138 of 599 physicians did not meet the criteria for selection and 14 others had chronic illnesses or could not be located; 41 (9% of 447 physicians who met the selection criteria) refused to participate. In 1995/1996, 83 physicians did not meet the selection criteria and 21 were chronically ill or could not be located; 50 other physicians (11% of those who met the criteria for selection) refused to participate. In both studies, about 30

experienced physicians conducted the interviews. All the interviewers were trained intensively for the study. The questionnaire used to guide the interview ran to about 120 pages, and the interviews lasted an average of 2½ hours. The respondents were asked to describe in detail the most recent case of euthanasia, physician-assisted suicide or ending of life without the patients' explicit request in which they were the attending physicians. Other questions concerned the most recent cases of alleviation of pain and symptoms with opioids or comparable drugs in large dosages, and decisions to forgo potentially life-prolonging treatment. The questionnaire used in the 1995/1996 study was almost identical to the one used in the 1990/1991 study.

Reported cases study 1995/1996 (issue 2)

From the 741 physicians who reported a total of 804 cases of physician-assisted death between August 1, 1994, and February 1, 1995, a random sample of 175 physicians was drawn, stratified according to judicial multidistrict area and type of practice (general practice, medical specialty, nursing home practice). Of those, 6 could not be traced, 4 had already been included in the random sample for the interview study and 1 was involved in a case that had not yet been closed; 17 other respondents (10%) refused to participate in the study. The remaining 147 physicians were interviewed. They were asked about some background characteristics and about the reported cases of physician-assisted death, the most recent unreported case (if applicable), and their opinions on the notification and review procedures. The interviews were conducted by about 20 experienced physicians, all of whom received training in interviewing. The interviews were based on an extensive, structured questionnaire and lasted an average of 2½ hours.

In addition, 63 of 64 eligible physicians were selected who had been involved in cases of physician-assisted suicide or euthanasia that were discussed in the Assembly of Prosecutors General between January 1, 1991, and July 1, 1995. One physician (2%) declined to be interviewed.

The questionnaires were similar to the ones used in the 1990/1991 and 1995/1996 interview studies.

The death-certificate study 1990/1991 and 1995/1996 (issues 2 and 3)

The causes of deaths for all inhabitants of the Netherlands are reported to Statistics Netherlands. Patients are not mentioned by name on the cause-of-death forms, but the names of the reporting physicians are given. For the 1990/1991 study, all 41,600 death certificates issued from August 1 through December 1, 1990, were examined by two physicians and assigned to one of five strata, denoted 0 through 4. Where the cause of death clearly could not have involved a medical decision about the end of life (for example, a car accident resulting in an instant death), the death was assigned to stratum 0. In the event of a high likelihood of an

end-of-life decision, the death was assigned to stratum 4. The medical officer in charge of the cause-of-death statistics selected a stratified sample that contained half of the cases in stratum 4, 25% of the cases in stratum 3, 12.5% of those in stratum 2, and 8.3% of those in strata 1 and 0 each. For the 1995/1996 study, the same procedure was followed for all 43,000 deaths occurring from August 1 through December 1, 1995. The final sample sizes were 8,500 and 6,600, respectively. Cases in stratum 0 were retained in the sample, but no questionnaires were sent to the physicians, as no further information on whether or not a medical end-of-life decision was involved was needed. Of the 8,000 questionnaires mailed in 1991, 73% were returned. Of the 6,060 questionnaires mailed in 1996, 77% were returned. The study questionnaire contained 24 items. The physicians were asked questions in each case about any end-of-life decisions, the patient's competence and the involvement of the patient or others in the decision-making.

Definitions. In the postal questionnaires that were used for the death-certificate studies, the terms euthanasia and physician-assisted suicide were avoided, because their connotations are too varied. Instead, wording was used that more closely described actual medical practice. The deaths were classified retrospectively in terms of the types of end-of-life decision by considering the respondents' answers to the following questions: (1) What did the physician do (or not do)? (2) What was his or her intention in doing so? (3) Was the physician's decision made at the request of the patient or after discussion with the patient? (4) Was the patient competent (that is, able to assess the situation and make a decision about it adequately)? (see Table 1.1).

Terms such as euthanasia and physician-assisted suicide were used in the interviews, since the interviewer would be able to discuss meanings and obtain more detailed information about the cases described.

Thus, the death certificate and the interview studies were designed to generate complementary information, with the interviews producing more detailed background information and the death-certificate study providing a strong quantitative framework.

Statistics. Statistical reliability of the results was assessed by calculating confidence intervals or P-values from statistical tests, while taking into account the stratification procedure and the nonresponse where this was thought to be relevant. In each chapter of this thesis the statistical methods used will be described in more detail.

Anonymity. A procedure was devised to ensure that the physicians and the deceased persons would remain completely anonymous. Both in 1990 and 1995, all

Dutch physicians received a letter explaining the purpose of the study and how anonymity would be guaranteed. Both studies were supported by the Royal Dutch Medical Association and the Health Care Inspectorate, and financed by the Dutch Ministry of Health, Welfare, and Sports and the Ministry of Justice.

1.6 Contents of this thesis

The role of psychiatrists in end-of-life decision-making will be described in Chapters 2 to 4 (part II). Chapter 2 deals with the experience of Dutch psychiatrists with requests for euthanasia or physician-assisted suicide made by patients under their treatment. Chapter 3 examines psychiatric consultation with regard to patients' requests for euthanasia or assisted suicide in more detail. The frequency with which psychiatrists are asked for consultation with regard to a patient's request for euthanasia or physician-assisted suicide is explored, as well as the content and implications of such consultation. In Chapter 4, the attitudes of Dutch psychiatrists towards physician-assisted death in psychiatric patients are further explored, and related to their specific characteristics.

The use of potentially life-shortening drugs at the end of life is dealt with in Chapters 5 to 8 (part III). In Chapter 5, an overview of the knowledge of potentially life-shortening drugs is given in a review study. Chapter 6 presents an overview of all potentially life-shortening drugs that are used in the broad range of end-of-life decisions in medicine. Chapter 7 describes the use of opioids, which are important drugs in the discussion about the border zones of end-of-life decision-making. Chapter 8 focuses on the drugs that were given with the explicit intention to hasten death in cases of euthanasia and physician-assisted suicide. Not only the types of drugs are described, but also the method of administration and the complications that occur.

The frequency and characteristics of decisions to withhold or withdraw life-prolonging treatment are described in Chapter 9 (part IV).

Finally, in Chapter 10 the most important findings and conclusions are summarised and discussed. This chapter concludes with some recommendations for future research.

References

1. Wet tot wijziging van de Wet op de lijkbezorging. Staatsblad 1993, nr. 643.
2. Eerste kamer, vergaderjaar 2000-2001, 26 691, nr. 137.
3. Wet van 12 april 2001, houdende toetsing van levensbeëindiging op verzoek en hulp bij zelfdoding en wijziging van het Wetboek van Strafrecht en van de Wet op de lijkbezorging (Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding). Review procedures of termination of life on request and assisted suicide and amendment to the Penal Code and the Burial and Cremation Act (Termination of life on request and assisted suicide (review procedures) Act) [in Dutch]. Staatsblad 2001:1-8.
4. Van der Maas PJ, van Delden JJM, Pijnenborg L. Medische beslissingen rond het levenseinde. 's-Gravenhage: Sdu, 1991.
5. Van der Maas PJ, van Delden JJM, Pijnenborg L. Euthanasia and other medical decisions concerning the end of life. *Health Policy* 1992;22:1-262.
6. Van der Wal G, van der Maas PJ. Euthanasie en andere medische beslissingen rond het levenseinde. De praktijk en de meldingsprocedure. Euthanasia and other medical practices involving the end of life. Practice and notification procedure [in Dutch]. Den Haag: Sdu Uitgevers, 1996.
7. Van der Wal G. Euthanasie en hulp bij zelfdoding door huisartsen. Euthanasia and physician-assisted suicide by family doctors [in Dutch]. Rotterdam: WYT Uitgeefgroep, 1992.
8. Pijnenborg L. End-of-life decisions in Dutch medical practice. Thesis. Rotterdam: Erasmus University Rotterdam, 1995.
9. Muller M. Death on request. Aspects of euthanasia and physician-assisted suicide with special regard to Dutch nursing homes. Thesis. Amsterdam: Vrije Universiteit, 1996.
10. Cuperus-Bosma JM. Regulering, toetsing en kwaliteitsbewaking van levensbeëindigend handelen. Examination and quality assurance of physician-assisted death [in Dutch]. Thesis. Amsterdam: Vrije Universiteit, 1998.
11. Haverkate I. Policies and guidelines on medical decisions concerning the end of life in Dutch health care. Thesis. Amsterdam: Vrije Universiteit, 1999.
12. Onwuteaka-Philipsen BD. Consultation of another physician in cases of euthanasia and physician-assisted suicide. Thesis. Amsterdam: Vrije Universiteit, 1999.
13. Van der Wal G, van Eijk JT, Leenen HJ, Spreeuwenberg C. Het gebruik van middelen bij euthanasie en hulp bij zelfdoding in de huisartspraktijk. The use of drugs for euthanasia and assisted suicide in family practice [in Dutch]. *Ned Tijdschr Geneeskd* 1992;136:1299-305.
14. Muller MT, Hertogh CPM, van der Wal G, Ribbe MW. Medisch-technische aspecten van euthanasie en hulp bij zelfdoding in de verpleeghuisgeneeskunde. Medico-technical aspects of euthanasia and physician-assisted suicide in nursing home medicine [in Dutch]. *Vox Hosp* 1992;16:3-7.
15. Pijnenborg L, van der Maas PJ, Kardaun JWPF, Glerum JJ, van Delden JJM, Looman CWN. Withdrawal or withholding of treatment at the end of life. *Arch Intern Med* 1995;155:286-92.

PART **II**

**Psychiatrists' role in
end-of-life practices**

2

Physician-assisted death in psychiatric practice in the Netherlands

Abstract

Background. In 1994 the Dutch Supreme Court ruled that in exceptional cases physician-assisted suicide might be justifiable for patients with unbearable mental suffering but no physical illness. We studied physician-assisted suicide and euthanasia in psychiatric practice in the Netherlands.

Methods. In 1996, we sent questionnaires to 673 Dutch psychiatrists - about half of all such specialists in the country - and received 552 responses from the 667 who met the study criteria (response rate, 83%). We estimated the annual frequencies of requests for physician-assisted suicide by psychiatrists and actual instances of assistance.

Results. Of the respondents, 205 (37%) had at least once received an explicit, persistent request for physician-assisted suicide and 12 had complied. We estimate there are 320 requests a year in psychiatric practice and 2 to 5 assisted suicides. Excluding those who had ever assisted, 345 of the respondents (64%) thought physician-assisted suicide because of a mental disorder could be acceptable, including 241 who said they could conceive of instances in which they themselves would be willing to assist. The most frequent reasons for refusing were the belief that the patient had a treatable mental disorder, opposition to assisted suicide in principle, and doubt that the suffering was unbearable or hopeless. Most, but not all, patients who had been assisted by their psychiatrists in suicide had both a mental disorder and a serious physical illness, often in a terminal phase.

Thirty percent of the respondents had been consulted at least once by a physician in another specialty about a patient's request for assisted death. The annual number of such consultations was estimated at 310, about 3% of the estimated 9700 requests for euthanasia or physician-assisted suicide in medical practice.

Conclusions. Explicit requests for physician-assisted suicide are not uncommon in psychiatric practice in the Netherlands, but these requests are rarely granted. Psychiatric consultation for medical patients who request physician-assisted death is relatively rare.

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Introduction

In the Netherlands, euthanasia and physician-assisted suicide are subject to criminal proposal, although this rarely occurs. When requested by a competent patient suffering unbearably from an irreversible illness, these practices are accepted by the majority of the general public and the medical profession.^{1,2} In 1994 a court ruled against a psychiatrist who had assisted in the suicide of a 50-year-old woman who wished to end her life after having lost her two sons. She had mental suffering but was not terminally ill. Dr. Boudewijn Chabot was found guilty of intentionally assisting another person to commit suicide. However, no punishment or other disciplinary measure was imposed. The Dutch Supreme Court stated that although seven independent medical experts had been consulted on all the relevant aspects of the case, at least one consultant should have seen and examined the patient before giving an opinion. The psychiatrist was convicted because of this inadequate consultation. The Supreme Court, however, also judged that unbearable mental suffering can in exceptional cases justify physician-assisted suicide, even if there is no concurrent medical disease, and that the degree of suffering rather than its cause is decisive.³⁻⁵

Physician-assisted suicide for psychiatric patients is subject to the procedure for reporting physician-assisted death that has been used in the Netherlands since 1991. Our study was part of the evaluation of this procedure, which was commissioned by the ministers of health and justice in 1995.^{1,6} We sought to obtain reliable estimates of the incidences in psychiatric practice of requests for physician-assisted suicide and of compliance with such requests; to describe the characteristics of the patients, physicians and circumstances involved; to explore the role of psychiatrists as consultants to other physicians in euthanasia or physician-assisted suicide; and to explore their opinions about review procedures for physician-assisted death in psychiatric practice.

Methods

Sample. Psychiatrists registered before January 1, 1994, were selected from the register of the Royal Dutch Medical Association, which includes all accredited specialists in the Netherlands. Addresses were organized according to postal code, and every second psychiatrist was included in the sample.

Questionnaire. In March 1996, all 673 psychiatrists in the sample received a 1-page questionnaire eliciting personal data (age, sex, and domain of practice) and a 20-page questionnaire asking whether they had ever received a request for physician-assisted suicide and if so, how often in 1994 and 1995 and whether they

had ever acceded to such a request. Detailed information about the most recent case was requested. Respondents were asked whether they had ever been consulted by other physicians about patients' requests for euthanasia or physician-assisted suicide and if so, how often in 1994 and 1995. There were questions about the respondents' attitudes toward physician-assisted death and toward consultation and about their opinions on review procedures. Each questionnaire and a card with the respondent's name and address were to be returned in separate envelopes after the respondent had marked both questionnaires with a code to enable the researchers to combine the information. Thus, complete anonymity could be guaranteed without precluding the sending of reminders to nonrespondents. Data were collected until July 1996.

Response. Of the 673 psychiatrists selected for the sample, 6 did not meet the criteria for selection and therefore were excluded from the study. Of the remaining 667, 552 returned completed questionnaires (a response rate of 83%, with 3 responses that could not be used). An additional 6 psychiatrists had chronic illnesses or could not be traced. Fifty-one respondents refused to participate, and for 55 other nonrespondents the reason could not be determined. Of the 104 nonrespondents with available data and the 549 respondents, 82 (79%) and 388 (71%), respectively, were male. Nonrespondents were slightly older, with a mean age of 49.7 years (range, 33 to 67), as compared with 47.4 (range, 33 to 77) for respondents. Of the nonrespondents, 31 (28%) provided written or oral information about a number of core issues in the questionnaire. These 31 did not differ markedly from the respondents with respect to their places of work or experience with requests for physician-assisted suicide and consultation.

Statistical analysis. Annual frequencies were estimated by averaging and weighting the number of requests for physician-assisted suicide, of actual instances of assistance, and of consultation in 1994 and 1995. The weighting factor was calculated by dividing the number of psychiatrists in the register by the number of respondents.

Results

Requests for physician-assisted suicide

Of the 552 respondents, 205 (37%) had at least once received an explicit and persistent request for physician-assisted suicide from a patient. Twelve (2%) had at least once assisted in suicide (Table 2.1). Apart from the respondents who had actually assisted in suicide, 345 respondents (64%) thought physician-assisted

suicide for psychiatric patients could be acceptable; of those 241 said they could conceive of a situation in which they would be willing to assist in suicide (Table 2.1). The total incidence of explicit requests for physician-assisted suicide in psychiatric practice was estimated to be about 320 per year. Detailed information was obtained from 202 respondents about their most recent requests: 65 requests were made between 1977 and 1993, and 137 in 1994 or later. Total number vary slightly because of missing data.

Of the 201 requests for which there were data on the sex of the patient, 127 (63%) were made by female patients. The patients' ages ranged from 16 to 80 years (mean 44.9); 124 of the 194 requests (64%) by patients whose ages were known were by patients younger than 50. The predominant psychiatric diagnosis was a mood disorder (Table 2.2); 130 of 202 patients (64%) had personality disorders. Forty-five patients (22%) also had somatic diseases.

At the time of their requests, 114 of the 200 patients on whom such information was available (57%) were in outpatient treatment; half of this group had been hospitalized before, and of those, 40% had been hospitalized involuntarily at least once. The other patients were hospitalized at the time of the request: 63 (32%) in psychiatric hospitals, 13 (6%) in psychiatric wards of general hospitals,

Table 2.1
Psychiatrists' practices and attitudes with respect to physician-assisted suicide because of a mental disorder

Practice or attitude	Ever received a request (N=204)*	Never received a request (N=346)*	Total (N=550)
	number (percent)		
Ever assisted in suicide	12 (6)	0 (0)	12 (2)
Never assisted in suicide but considers physician-assisted suicide acceptable and could conceive of a situation in which he/she would be prepared to participate	101 (50)	140 (40)	241 (44)
Considers physician-assisted suicide acceptable, but could not conceive of a situation in which he/she would be prepared to participate	29 (14)	75 (22)	104 (19)
Considers physician-assisted suicide unacceptable	56 (27)	112 (32)	168 (31)
No opinion	6 (3)	19 (5)	25 (5)

* One respondent in the group did not provide an answer and was therefore excluded from the analysis.

Table 2.2
Psychiatric diagnoses in patients who requested physician-assisted suicide

Diagnosis	No personality disorder (N=72)	Personality disorder (N=130)	Total* (N=202)
	number (percent)		
Mood disorder	40 (56)	64 (48)	103 (51)
Psychosis	19 (26)	10 (8)	29 (14)
Other mental disorder†	13 (18)	10 (8)	24 (12)
No mental disorder†	0 (0)	46 (35)	46 (23)

* Three of 205 respondents did not describe the last time they received a request for physician-assisted suicide and were therefore excluded from the analysis.

† 'Other mental disorder' includes, for example, dissociative and panic disorders. Personality disorders were excluded from the category.

and the remaining 10 (5%) in other institutions, such as nursing homes.

Of the 202 patients, 129 (64%) refused the remaining psychiatric treatment options: medication (63%), psychotherapy (63%), electroconvulsive therapy (20%), and inpatient or day care treatment (16%). According to the respondents, the wish to die was persistent in 135 of the 194 patients (70%), and 172 of 200 (86%) requested assistance in suicide without pressure from others. Pressure from others was mentioned by 28 respondents; for 9 of the 12 patients for whom such information was available, the patients' relatives seemed to have an important role in the request. Sixty-four of 200 patients (32%) were considered competent (that is, able to assess the situation and make a decision about it adequately). The most frequent reasons for requesting assistance in suicide were the absence of any hope of improvement (68%), unbearable mental suffering (58%), being a burden to others (29%), pain or other physical suffering (18%), and the loss of dignity (14%).

Forty-three of the 202 respondents (21%) contemplated granting the patients' requests for physician-assisted suicide. Of those, 40 consulted one or more colleagues each: 30 consulted a psychiatrist working in the same institution, 12 consulted a psychiatrist working in another institution, 16 consulted a general practitioner, and 5 consulted another medical specialist. The main reasons for consultation were to assess whether the phenomena of transference and countertransference (the patient's unconscious feelings and attitudes toward the therapist and vice versa) might have influenced the decision-making process (50%), whether the request was well considered (58%), and whether there were still treatment options (58%).

Four of the 202 most recent requests (2%) resulted in suicides assisted by the responding psychiatrists. In each of 6 other cases (3%), another physician assisted in the suicide; two were general practitioners (information about the specialties of the other four was not available). In 10 cases (5%) the patients died of natural causes, and in 32 cases (16%) the patients ended their lives without assistance from a physician. One hundred twenty-eight patients (63%) were still living: 70 (35%) no longer wished to end their lives, 37 (18%) still persistently asked for assistance in suicide, and in 21 (10%) the requests were less persistent. For 22 patients (11%), the respondents had no follow-up information.

The reasons psychiatrists gave for not assisting in suicide are shown in Table 2.3. The most frequent were the belief that the patient had a treatable mental disorder, opposition in principle to assisting in suicide, and doubt that the patient's suffering was unbearable or hopeless.

Psychiatrists' assistance in suicide

Respondents who had assisted in suicide were asked how often they had done so in 1994 and 1995 and to describe the most recent case. On the basis of the answers to

Table 2.3
Psychiatrists' reasons for not granting requests for physician-assisted suicide*

Reason	Did not consider granting the request (N=159)	Considered granting the request (N=38)†	Total (N=197)‡
		number (percent)	
Mental disorder could be treated	107 (67)	14 (37)	121 (61)
Psychiatrist opposed in principle	59 (37)	3 (8)	62 (31)
Suffering was not unbearable or hopeless	56 (35)	8 (21)	64 (32)
Wish to die was not long-standing	40 (25)	5 (13)	45 (23)
Request was not well considered	40 (25)	5 (13)	45 (23)
Consultant advised against it	-	10 (26)	10 (5)
Respondent had not yet decided	-	5 (13)	5 (3)
Patient no longer wished to die	-	3 (8)	3 (2)
Other reasons§	27 (17)	4 (11)	31 (16)

* More than one answer was possible.

† Data were missing on one respondent who considered acceding to the request; this respondent was excluded from the analysis.

‡ In an additional four cases, the psychiatrist assisted in the patient's suicide.

§ Other reasons included the presence of a treatable physical disorder, the young age of the patient, or the admission of the patient to another hospital.

the first question, physician-assisted suicide in psychiatric practice was estimated to occur two to five times per year in the Netherlands; none of the respondents reported having assisted in suicide more than once during 1994 and 1995. Eleven cases were described (Table 2.4). Most of these patients each had both a mental disorder and a serious physical illness. The most frequently mentioned reasons for assisting in suicide were that the patient's physical suffering was unbearable or hopeless and that all previous treatment had failed.

One psychiatrist assisted a patient by helping him prepare for the suicide; the medication was prescribed by a general practitioner. Eight patients died after taking medication prescribed by respondents; in two other cases (both involving a serious physical disease), psychiatrists administered the drugs. Six patients died at home, two in psychiatric wards, two in medical wards, and one elsewhere. Seven respondents had been present at the suicides. Three respondents had reported the

Table 2.4
Description of 11 patients whose psychiatrists helped them to commit suicide

Patient no.	Sex/Age (yr)	Diagnosis*	
		Psychiatric	Medical
1	F/28	Mood disorder, personality disorder	None
2	F/40	Personality disorder	Whiplash, post-traumatic epilepsy
3	M/60	Mood disorder, personality disorder	Severe respiratory disease
4	M/Unknown	Mood disorder, personality disorder	Respiratory disease, terminal phase
5	F/57	Somatization disorder, personality disorder	Suspected neurologic disease
6	F/47	Mood disorder	Terminal cancer
7	M/34	Organic mental disorder	AIDS
8	F/32	Psychosis	Terminal renal disease
9	F/38	Mood disorder	Terminal cancer
10	M/41	None	AIDS
11	M/~80	None	Neurologic disease, terminal phase

* AIDS denotes acquired immunodeficiency syndrome.

suicides as unnatural deaths. The most important reasons for not reporting a suicide were fear of prosecution (mentioned by four respondents); the belief that it was a private matter between doctor and patient, the wish to protect the patient's relatives from judicial inquiry, a request by relatives to be protected from judicial inquiry (each mentioned twice); the patient's wish, not having fulfilled the requirements necessary to avoid prosecution,⁶ advice from a colleague, a previous unfavorable experience with reporting a death as an unnatural death, and the wish to protect the respondent's relatives from judicial inquiry (each mentioned once).

In another case - that of a woman in her 40s who had a mood disorder for many years but had no somatic disorder - the psychiatrist helped her prepare for the suicide but the patient finally decided against it.

Table 2.4 (continued)

Patient no.	Psychiatric history		Psychiatrists' main reason for assisting
	Duration	Previous inpatient treatment	
1	~3 yr	Yes	Unknown
2	6 mo	No	Failure of all treatment
3	~7 yr	Yes	Unbearable or hopeless mental suffering, prevention of violent suicide
4	3 mo	Yes	Unbearable or hopeless physical suffering
5	3 yr	Yes	Unbearable or hopeless physical suffering, failure of all treatment, prevention of violent suicide
6	~12 mo	No	Unbearable or hopeless physical suffering, failure of all treatment, prevention of further physical and psychological deterioration
7	4 mo	No	Unbearable or hopeless physical suffering, failure of all treatment
8	12 yr	Yes	Unbearable or hopeless physical suffering
9	Unknown	Yes	Unbearable or hopeless physical suffering, unbearable or hopeless mental suffering, failure of all treatment
10	3 mo	No	Unbearable or hopeless physical suffering
11	Unknown	No	Failure of all treatment

Table 2.5
Psychiatric consultations about physician-assisted death

Characteristic	Request granted	Request refused	Follow-up not available
	(N=62)	(N=78)	(N=21)
	number (percent)		
Consulting physician*			
Medical specialist	21 (34)	34 (44)	5 (24)
General practitioner	35 (56)	32 (42)	13 (62)
Other	6 (10)	11 (14)	3 (14)
Patient			
Age†			
Mean ± SD (yr)	59.5±16.1	57.5±17.8	58.8±14.8
Range (yr)	22-89	12-92	35-83
Younger than 50	18 (29)	24 (32)	5 (28)
Female sex‡	34 (56)	42 (55)	12 (63)
Diagnosis§			
Cancer	20 (32)	13 (17)	6 (29)
Neurologic disease	18 (29)	14 (18)	7 (33)
Disease of the respiratory tract	6 (10)	6 (8)	0
AIDS	2 (3)	2 (3)	0
Cardiovascular disease	3 (5)	1 (1)	0
Mental disorder	13 (21)¶	31 (40)**	5 (24)††
Other physical disease	3 (5)	11 (14)	1 (5)
Physical disease, not specified	8 (13)	12 (15)	4 (19)
None	0	2 (3)	1 (5)
Assessment of consultant psychiatrist	yes/no/not assessed (percent)		
Request was well considered	52/3/7 (84/5/11)	32/28/18 (41/36/23)	16/2/3 (76/10/14)
A treatable mental disorder was present	7/37/18 (11/60/29)	24/26/28 (31/33/36)	3/14/4 (14/67/19)
Decision making was influenced by transference or countertransference	12/31/19 (19/50/31)	16/25/37 (21/32/47)	4/8/9 (19/38/43)
All criteria for careful practice had been fulfilled	45/5/12 (73/8/19)	17/28/33 (22/36/42)	10/3/8 (48/14/38)

* Data were missing for one case in the second group.

† Data were missing for three cases in the second group and three cases in the third group.

‡ Data were missing for one case in the first and second groups and for two cases in the third group.

§ Percentages do not add up to 100% because in some cases more than one principal diagnosis was mentioned by the respondent.

¶ Seven of the 13 patients also had a somatic disorder; 2 of them requested physician-assisted suicide because of the mental disorder, 4 because of both the mental and the physical disorder, and 1 for another reason.

** Eleven of the 31 patients also had a physical disorder; these patients' reasons for requesting physician-assisted suicide were the physical disorder in 3, both the mental and the physical disorder in 6, and another reason in 2.

†† Three of the five patients also had a physical disorder; all three patients requested physician-assisted suicide because of the combination of the mental and the physical disorder.

Psychiatrists' role in consultation

Of 549 respondents, 164 (30%) had been asked at least once for consultation by a physician from another specialty about a patient's request for euthanasia or physician-assisted suicide. The annual number of such consultations was estimated to be about 310; 161 of the most recent cases were described (Table 2.5). Of 161 physicians who asked for psychiatric consultation, 80 (50%) were general practitioners, 60 (37%) were clinical specialists, 10 (6%) were nursing home physicians, and 10 (6%) were other medical professionals. The specialty of one physician was unknown. In 112 of 161 consultations (70%) the purpose was to assess whether a treatable mental disorder was present, in 111 cases (69%) it was to assess whether the patient's request was well considered, and in 29 cases (18%) it was to determine whether transference or countertransference was influencing the decision-making process. Fifteen of 161 respondents (9%) did not examine the patients themselves; of the 146 (91%) who did, 80 did so more than once. In 62 of 161 cases (39%), the patients' requests resulted in physician-assisted death, in 78 (48%) it did not, and in 21 (13%) the respondents had no follow-up information. The patients whose requests were finally granted were similar in age and sex to the patients whose requests were not (Table 2.5). Patients whose requests were granted more frequently had cancer or neurologic disease, whereas patients whose requests were not granted more frequently had mental disorders. According to the respondents, among the patients whose requests were granted the request was more often well considered, a treatable mental disorder was more often absent, and the criteria for careful practice were more frequently fulfilled.

Opinions about requirements for careful practice and consultation

Psychiatrists who thought physician-assisted suicide was acceptable for psychiatric patients were asked about the importance they attached to several official and unofficial requirements for careful decision making. A well-considered request was thought to be important or very important by 346 of 355 respondents (97%). Other important considerations were that the requests be voluntary (considered important or very important by 336 of 354, or 95%), that there be no hope of improvement (319 of 350, or 91%), that treatment alternatives be expected to have no or very little effect (321 of 352, or 91%); that mental suffering be unbearable (316 of 354, or 89%), and that the request be written (182 of 349, or 52%).

The respondents who had ever assisted in suicide and those who could conceive of a situation in which they would be prepared to do so were asked how important they considered a number of other aspects of the decision-making process. The

characteristics of the disease were considered to be important or very important by 196 of 216 respondents (91%); the duration and character of previous treatment, by 192 of 217 (88%), the duration and burden of treatment alternatives, by 133 of 216 (62%); the opinion of relatives, by 79 of 217 (36%); the age of the patient, by 65 of 216 (30%), and the threat of a violent suicide, by 71 of 215 (33%).

According to 509 of 532 respondents (96%), one or more psychiatrists should be consulted when physician-assisted suicide because of mental suffering is considered by a physician. When euthanasia or physician-assisted suicide because of physical suffering is considered, 101 of 544 respondents (19%) said psychiatric consultations should always be requested; 422 (78%) thought a psychiatrist should be consulted only if the attending physician judged it necessary. Of 537 respondents, 438 (82%) thought that the psychiatric consultant should always examine the patient. Ninety-three (17%) thought this was necessary in some but not all cases, and 6 (1%) thought it unnecessary.

Discussion

We believe that the information we collected presents a reliable overview of end-of-life decision making in Dutch psychiatric practice. The sample of psychiatrists was large and the response rate was 83%, the questionnaires were filled out carefully, absolute anonymity was guaranteed, and the data could not be used for criminal prosecution.

Explicit and persistent requests for physician-assisted suicide are not uncommon in Dutch psychiatric practice. The annual number of such requests was estimated to be about 320. In the Netherlands (population, about 15 million), the total number of patients receiving mental health care is about 400,000, and the number of psychiatric patients in institutions is about 26,000. In all Dutch medical practice (not just psychiatric), the annual number of explicit requests for euthanasia and physician-assisted suicide was estimated to be 9700, of which 3600 (37%) were acceded to.¹ In psychiatric practice, however, only about 2% of the requests were finally granted. The estimated annual number of suicides in which a psychiatrist assisted was two to five. At least half of these involved a psychiatric patient who also had a serious physical disease, often in a terminal phase. Thus, although nearly two thirds of the Dutch psychiatrists who responded to the survey considered assisted suicide for psychiatric patients acceptable, and a majority of them could conceive of a situation in which they would be prepared to assist, physician-assisted suicide in Dutch psychiatric practice is extremely rare.

Psychiatric patients requesting physician-assisted suicide were relatively young: 64% were under 50, as compared with 16% of all patients requesting euthanasia or physician-assisted suicide.

In its verdict in the Chabot case in 1994, the Supreme Court stated that (1) the absence of a medical illness means that extreme care should be applied in assessing the seriousness of suffering and the prospect for successful treatment; (2) if the patient deliberately refuses a realistic alternative to alleviate suffering, assistance in suicide is not justified; (3) an independent expert must be consulted on all the relevant aspects of the case and must have examined the patient before giving an opinion.^{3,4,5} These statements were in line with earlier standpoints of the Royal Dutch Medical Association⁷ and are reflected in our findings. About two thirds of the patients whose requests for physician-assisted suicide were refused were not considered fully competent by the respondents. The most frequently mentioned reasons for refusing a request were the presence of a treatable mental disorder and the advice of a consultant physician (especially in cases in which the respondent contemplated acceding to the request).

Although the Dutch Supreme Court did not state whether the expert who is consulted has to be a psychiatrist, nearly all the respondents stated that one or more psychiatrists should be consulted when physician-assisted suicide is considered for a psychiatric patient. Only 19% thought that consultation with at least one psychiatrist should be mandatory when euthanasia or physician-assisted suicide is considered because of somatic suffering. Most respondents thought that the attending physician should decide whether such consultation is necessary. This is in line with medical and legal practices in the Netherlands and with the results of a survey among members of the Netherlands Consortium of Consultation-Liaison Psychiatry.⁸ The majority in that survey preferred that the consultation be initiated by the primary care giver and rejected mandatory consultation by a psychiatrist in each case.

Baile et al. argued that comprehensive psychosocial assessment is needed when any request for assistance in dying is evaluated.⁹ Block and Billings stated that most patients, in saying they want to die, are actually asking for assistance in living and delineated the role of psychiatrists in evaluating and managing such requests.¹⁰ Some studies on the psychiatric aspects of terminal somatic illness support this view. Chochinov et al. found that diagnosed depression syndromes were present in 10 of 17 terminally ill patients with a wish to die.¹¹ Emanuel et al.¹² found that patients with cancer who had depression and psychological distress were significantly more likely to have seriously discussed euthanasia, hoarded drugs, or read Derek Humphry's *Final Exit*.¹³ In our study, we found that 30% of the respondents had ever been consulted by a nonpsychiatrist colleague; the annual number of psychiatric consultations requested by nonpsychiatrists because patients had requested euthanasia or physician-assisted suicide was about 310. This represents about 3% of the annual number of explicit requests for euthanasia and physician-assisted suicide in the Netherlands. This finding does not imply that psychiatric and psychosocial aspects were neglected in the other patients. Van der

Wal and Van der Maas found that in 31% of the requests refused by the physician, the reason was that the patient had a depression or another mental disorder, whereas in all instances of euthanasia and physician-assisted suicide the patient was judged to be fully competent.¹⁴ Obviously, the possibility that depression was overlooked or not identified in some patients cannot be excluded.

In Dutch psychiatry, there is a rather liberal attitude toward physician-assisted suicide in psychiatric patients but a very reluctant practice. Consultation of a psychiatrist about requests for euthanasia or physician-assisted suicide because of medical diseases is relatively rare and perhaps should occur more often, although most Dutch psychiatrists think that the primary care giver should decide whether psychiatric consultation is necessary.

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References

1. Van der Maas PJ, van der Wal G, Haverkate I, et al. Euthanasia, physician-assisted suicide, and other medical decisions involving the end of life in the Netherlands, 1990-1995. *N Engl J Med* 1996;335:1699-705.
2. Van der Maas PJ, Pijnenborg L, van Delden JJM. Changes in Dutch opinions on active euthanasia, 1966 through 1991. *JAMA* 1995;273:1411-4.
3. Griffiths J. Assisted suicide in the Netherlands: the Chabot case. *Modern Law Rev* 1995;58:232-48.
4. Gevers S. Physician assisted suicide: new developments in the Netherlands. *Bioethics* 1995;9:309-12.
5. Hoge Raad, 21 juni 1994. Hulp bij zelfdoding psychiatrische patiënt. *Ned Jurisprudentie* 1994;656:3142.
6. Van der Wal G, van der Maas PJ, Bosma JM, et al. Evaluation of the notification procedure for physician-assisted death in the Netherlands. *N Engl J Med* 1996;335:1706-11.
7. Commissie Aanvaardbaarheid Levensbeëindigend Handelen. Discussienota: hulp bij zelfdoding bij psychiatrische patiënten. Utrecht, the Netherlands: Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst, 1993.
8. Huyse FJ, van Tilburg W. Euthanasia policy in the Netherlands: the role of consultation-liaison psychiatrists. *Hosp Community Psychiatry* 1993;44:733-8.
9. Baile WF, DiMaggio JR, Schapira DV, Janofsky JS. The request for assistance in dying. The need for psychiatric consultation. *Cancer* 1993;72:2786-91.
10. Block SD, Billings JA. Patient requests for euthanasia and assisted suicide in terminal illness: the role of the psychiatrist. *Psychosomatics* 1995;36:445-57.
11. Chochinov HMC, Wilson KG, Enns M, et al. Desire for death in the terminally ill. *Am J Psychiatry* 1995;152:1185-91.
12. Emanuel EJ, Fairclough DL, Daniels ER, Clarridge BR. Euthanasia and physician-assisted suicide: attitudes and experiences of oncology patients, oncologists, and the public. *Lancet* 1996;347:1805-10.
13. Humphry D. Final exit: the practicalities of self-deliverance and assisted suicide for

- the dying. Eugene, Oreg.: Hemlock Society, 1991.
14. Van der Wal G, van der Maas PJ. Euthanasie en andere medische beslissingen rond het levenseinde: de praktijk en de meldingsprocedure. Den Haag, the Netherlands: Sdu Uitgevers, 1996.

3

**Psychiatric consultation with
regard to requests for
euthanasia or physician-
assisted suicide**

Abstract

Objective. To describe the practice of psychiatric consultation with regard to explicit requests for euthanasia or physician-assisted suicide in the Netherlands.

Method. Written questionnaires were sent to 673 Dutch psychiatrists, about half of all such specialists in the Netherlands. The response rate was 83%.

Results. Of the respondents, 36% (199 of 549) had at least once been consulted about a patient's request for euthanasia or assisted suicide. The annual number of such psychiatric consultations is estimated to be 400 (about 4% of all requests for physician-assisted death). About one in four consultations is initiated by another psychiatrist. Consultants were mainly asked to assess whether the patient had a treatable mental disorder (66%) or whether the patient's request was well-considered (68%). Assessment of the influence of transference and countertransference was less frequently sought (24%). Of the 221 cases described, 67 (30%) ended in euthanasia or assisted suicide, whereas another 124 (56%) did not. In most, but not all, cases where the patient's request for physician-assisted death was refused, the respondent had judged that this request was not well considered or that a treatable mental disorder was present, or that the decision-making was influenced by transference and countertransference.

Conclusions. Psychiatric consultation for patients requesting euthanasia or physician-assisted suicide in the Netherlands is, as in other countries, rare. The issue of psychiatric consultation with regard to requests for physician-assisted death, particularly in patients with a physical disease, needs to be further addressed.

Introduction

In the Netherlands, euthanasia and physician-assisted suicide are criminal acts by law. However, if a number of defined requirements for careful practice have been fulfilled, the responsible physician will not be prosecuted.¹⁻³ One of these requirements directs that consultation take place with another physician: when considering whether to accede to a patient's request for assisted death, the attending physician should therefore seek the opinion of an independent colleague. This consultant should assess whether the requirements for careful practice have been fulfilled, i.e. whether the patient's request is voluntary, well-considered and persistent, and whether the patient's suffering is unbearable and hopeless. According to the Royal Dutch Medical Association, consultation is essential to a meticulous application of physician-assisted death.⁴

One of the issues under discussion is whether this consultant should be a psychiatrist.⁵⁻¹⁴ The prevalence of mental disorders, especially depression, among terminally ill patients asking for assisted death may warrant such consultation.^{7-9,12,15,16} In the Netherlands, it is recommended that if a patient has requested euthanasia or physician-assisted suicide because of a mental disorder, the consultant be a psychiatrist.^{17,18} In patients who suffer from a physical disorder, the attending physician should consult a psychiatrist if he suspects the patient of being incompetent or suffering from psychiatric (co)morbidity.¹⁸

In 1995, the total number of cases of euthanasia in the Netherlands was about 3,200, or 2.4% of all deaths; the number of physician-assisted suicides was estimated at 400, or 0.2% of all deaths.^{19,20} Consultation with another physician had preceded 63% of all cases of euthanasia or physician-assisted suicide. In 3% of the cases, the consulted physician was a psychiatrist.²¹ In this article we will further explore the frequency, characteristics and implications of psychiatric consultation when euthanasia or physician-assisted suicide is requested by a patient. The data are derived from a nationwide study on physician-assisted death in psychiatric practice in the Netherlands.²²

Method

All records from the Psychiatric Specialists Registration were ordered by postal code, and every second psychiatrist who had been registered before January 1st, 1994, was included in the sample. The final sample consisted of 673 psychiatrists. In March 1996, postal questionnaires were sent out. A written reminder was sent in April 1996. From June 1996 until August 1996, the remaining nonresponding psychiatrists were approached by telephone. The questionnaire consisted of a 1-page questionnaire eliciting personal features of the respondent (age, sex, and

domain of practice) and a 20-page questionnaire with questions about the respondent's experience with and attitudes towards physician-assisted suicide in psychiatric patients. The questionnaire also included questions about whether the respondent had ever been consulted about a patient's request for euthanasia or physician-assisted suicide, and if so, how often in 1994 and 1995. A distinction was made between consultations initiated by psychiatrists and by non-psychiatrists. Detailed information about the most recent consultation, if any, was asked. This included a number of patient characteristics, the aim of the consultation, the evaluation of the patient's request by the respondent, and whether the request had been acceded to or not. In this article the physician who requested psychiatric consultation is referred to as the consultee, and the physician who performed the consultation, i.e. the respondent, as the consultant.

Response. Six psychiatrists were excluded from the study, because they had never practiced as a psychiatrist, or were living abroad. Of the remaining 667 psychiatrists, 555 responded; 552 completed questionnaires could be used (response rate 83%). Fifty-one psychiatrists refused to participate in the study, 6 psychiatrists had a chronic illness or could not be traced, and 55 psychiatrists did not respond for unknown reasons.

Statistical analysis. Differences between subgroups were tested for statistical significance with the Chi-Square test (categorical variables) or the Mann-Whitney U test (continuous variables). A multivariate logistic regression model was used to analyse the relation between the aims of consultation and whether the respondent had examined the patient personally. The significance level was set at $p=0.05$.

Results

Incidence

Of the respondents, 36% (199 of 549) had been consulted at least once about a patient's request for euthanasia or physician-assisted suicide: 25% (139 of 549) had been consulted at least once by a physician from another specialty (a non-psychiatrist), 6% (35 of 549) at least once by a psychiatrist, and 5% (25 of 549) at least once by both. The mean reported annual number of requests for psychiatric consultation in 1994 and 1995 was around 400, of which around 300 requested by non-psychiatrists and about 100 by psychiatrists. We received detailed information about 60 cases in which respondents had been consulted by a psychiatrist, and 161 cases in which respondents had been consulted by a non-psychiatrist. Of the cases described, 79 dated from the period 1974 to 1994, and 142 from 1994 through 1996,

1994 being the year in which the Dutch Supreme Court ruled on the Chabot case that physician-assisted death could be acceptable in cases of extreme mental suffering not accompanied by physical suffering. In 58% (35 of 60) of cases in which the consultee was another psychiatrist, this psychiatrist worked at the same institution as the respondent. Where such consultation had been requested by a non-psychiatrist, 50% (80) of the consultees were general practitioners, 37% (60) were clinical specialists, 6% (10) were nursing-home physicians, 6% (10) were physicians from another medical specialty, and of 1 physician the specialty was unknown.

Patient characteristics

Of cases where a psychiatrist was the consultee, 72% (43 of 60) involved patients requesting assisted death because of a mental disorder, in 12% (7 cases) this request was prompted by a physical disorder and in 10% (6 cases) by both a mental and a physical disorder. In 7% (4 cases) another reason was present. Where a non-psychiatrist was the consultee, these percentages were 16% (25 of 161 cases), 70% (112 cases), 8% (13 cases) and 7% (11 cases), respectively.

Table 3.1 shows the characteristics of patients. Patients who requested physician-assisted death because of a mental disorder were younger (Mann-Whitney U test, $p < 0.001$) and were more often female (Chi-Square test, $p = 0.03$) than patients whose request was motivated by a physical disorder. In all groups, the most frequently reported motives for the patient's request were the patient's hopeless (74% of all cases) or unbearable (58%) suffering. (Fear of) ongoing physical deterioration was more frequently mentioned as a reason to request assistance in dying for patients with a physical disorder than for patients with a mental disorder (56% and 10%, respectively; Chi-Square test, $p < 0.001$). Being a burden to others was mentioned as the motive for the patient's request in 25% of all cases.

Content of the consultation

The aim of the consultation was specified in 219 of all 221 cases. Table 3.2 shows that respondents were most frequently asked to assess whether patients requesting assisted death had a treatable mental disorder (66%) and whether the patient's request was well-considered (68%). No relation was found between these aims of the consultation and the specialty of the consultee (psychiatrist or non-psychiatrist) or whether the patient had asked for assisted death because of a mental or because of a physical disorder. The respondent was more often asked to evaluate transference and countertransference issues in cases where the consultee was a psychiatrist compared to cases where the consultee was a non-psychiatrist (Chi-Square test, $p < 0.001$), and in cases where the patient had requested physician-

assisted death because of a mental disorder compared to cases where a physical disorder was the reason for the patient's request (Chi-Square test, $p=0.01$). The respondent examined the patient in 83% of cases.

The patient was more often examined in cases where the consultee was a non-psychiatrist (Chi-Square test, $p<0.001$) and in cases where the patient requested euthanasia or physician-assisted suicide because of a physical disorder (Chi-Square test, $p<0.001$). Multivariate logistic analysis with the aims of consultation as independent variables, showed that the patient was significantly more often examined if the respondent was asked to evaluate transference and

Table 3.1
Specialty of the consultee and characteristics of patients and their requests for euthanasia or physician-assisted suicide

	Patient requested for physician-assisted death because of			
	Mental disorder (N=68)		Physical disorder (N=119)	
	(N)	(%)	(N)	(%)
Specialty of consultee				
Psychiatrist	43	63	7	6
Non-psychiatrist	25	37	112	94
Patient's age (yr)†				
Mean (range)	47	(27-86)	59	(12-92)
	(N)	(%)	(N)	(%)
0-49	38	56	32	28
50-64	20	29	33	29
65-79	9	13	39	34
≥ 80	1	1	10	9
Female sex‡	47	69	60	52
Specific motives for the patient's request§				
Hopeless suffering	49	73	95	81
Unbearable suffering	47	70	66	56
Being a burden to others	19	28	32	27
(Fear of) ongoing physical deterioration	7	10	66	56
Other motives¶	10	15	7	6

* In 15 other cases the patient requested euthanasia or assisted suicide because of another reason (not because of a mental or physical disorder).

† Data were missing on 5 cases in the second group, and on 1 case in the third group; of all 221 cases, data were missing on 8.

‡ Data were missing on 4 cases in the second group, and on 1 case in the third group; of all 221 cases, data were missing on 5.

countertransference issues than in cases where the evaluation of such issues was not among the aims (Odds Ratio 3.93; 95% CI: 1.79-8.61).

Outcome

Of the cases described, 30% (67) resulted in euthanasia or physician-assisted suicide. In 56% (124), physician-assisted death did not ensue; in 14% (30), no follow-up information was available. Of 67 cases that resulted in euthanasia or physician-assisted suicide, 62 (93%) involved patients of non-psychiatrists. Table

Table 3.1 (continued)

Patient requested for physician-assisted death because	Both mental and physical disorder (N=19)		All cases* (N=221)	
	(N)	(%)	(N)	(%)
Specialty of consultee				
Psychiatrist	6	32	60	27
Non-psychiatrist	13	68	161	73
Patient's age (yr)†				
Mean (range)	60	(35-92)	56	(12-92)
	(N)	(%)	(N)	(%)
0-49	6	33	78	37
50-64	3	17	60	28
65-79	5	28	57	27
≥ 80	4	22	18	8
Female sex‡	13	72	128	59
Specific motives for the patient's request§				
Hopeless suffering	14	74	162	74
Unbearable suffering	10	53	127	58
Being a burden to others	3	16	55	25
(Fear) of ongoing physical deterioration	7	37	81	37
Other motives¶	4	21	33	15

§ More than one answer was possible. Data were missing on 1 case in the first group, and on 1 case in the second group; of all 221 cases, data were missing on 2.

¶ Other motives that were mentioned involved pain or other (psychological or social) circumstances that caused the suffering, no wish for further living or having finished with life.

Table 3.2

Characteristics of the consultation in patients who requested for euthanasia or physician-assisted suicide

Characteristic	Specialty of consultee				Chi-square‡ p
	Psychiatrist (N=60)		Non-psychiatrist (N=161)		
	(N)	(%)	(N)	(%)	
Aim of the consultation§					
To assess whether the patient had a treatable mental disorder	34	59	111	69	0.15
To assess whether the request was well-considered	37	64	112	70	0.42
To assess whether (counter)transference influenced the decision-making	24	41	29	18	<0.001
Other aim¶	14	24	27	17	0.22
Patient was examined	37	62	146	91	<0.001

* In 15 cases the patient requested euthanasia or assisted suicide because of another reason (not because of a mental or physical disorder).

† P-values relate to the comparison of cases in which the consultee was a psychiatrist with cases in which the consultee was a non-psychiatrist.

‡ P-values relate to the comparison of cases in which the patient requested physician-assisted death because of a mental disorder with cases in which the patient requested such because of a physical disorder.

3.3 shows that cases in which the patient requested assisted death because of a physical disorder resulted more often in euthanasia or physician-assisted suicide (45%) than cases in which the patient requested such because of a mental disorder (10%) (Chi-Square test, $p < 0.001$). The frequency in which requests were granted did not differ between sexes (Chi-Square test, $p = 0.45$). Compared with requests that were denied, acceded requests involved patients who were somewhat older (Mann-Whitney U test, $p = 0.07$). In total, 14 patients whose requests were acceded to, had a psychiatric diagnosis: the psychiatric diagnoses were a mood disorder (5 patients), a personality disorder (3 patients) or another or multiple mental disorders (3 patients); in 3 other patients the psychiatric diagnosis had not been specified. To the respondents' knowledge, no requests from patients with a psychotic syndrome had resulted in physician-assisted death.

Table 3.2 (continued)

Characteristic	Reason for the patient's request					All cases* (N=221)	
	Mental disorder (N=68)		Physical disorder (N=119)		Chi-square‡ p		
	(N)	(%)	(N)	(%)		(N)	(%)
Aim of the consultation§							
To assess whether the patient had a treatable mental disorder	41	60	84	71	0.15	145	66
To assess whether the request was well-considered	45	66	78	66	0.93	149	68
To assess whether (counter)transference influenced the decision-making	25	37	23	19	0.01	53	24
Other aim¶	16	24	16	13	0.08	41	19
Patient was examined	48	71	109	92	<0.001	183	83

§ More than one answer was possible. The aim of the consultation was not specified in 2 cases where a psychiatrist was the consultee, and in 2 of all 221 cases.

¶ Other aims of consultation mainly concerned assessment whether taking the patient into custody was indicated, treatment of the patient or giving support to the consultee.

Responding psychiatrists' judgement and implications of the consultation

Table 3.4 shows the psychiatrist's judgement on several aspects of the patient's request for euthanasia or physician-assisted suicide. In the majority (84%) of cases in which the patient's request was acceded to, the request was judged to have been well considered, whereas this was true in 37% of cases in which the patient's request was not acceded to (Chi-Square test, $p < 0.001$). Furthermore, a treatable mental disorder was less often present in cases in which the patient's request was granted compared to cases in which such a request was denied (10% and 49%, respectively; Chi-Square test, $p < 0.001$), transference and countertransference had less frequently influenced the decision-making (19% and 27%, respectively; Chi-Square test, $p = 0.22$), and all criteria for careful practice had more often been fulfilled (73% and 19%, respectively; Chi-Square test, $p < 0.001$). However, in 4% of cases in which the patient's request was acceded to (3 cases), the request was judged not to have been well considered; all three respondents commented in answering this question that they had advised explicitly against euthanasia or

physician-assisted suicide. In 10% (7 cases) the patient's request had been acceded to despite the consultant's judgement that there was a treatable mental disorder. These were mainly older patients who had a serious physical illness as well. In each case the patient had been personally examined by the respondent; 2 respondents advised against euthanasia or physician-assisted suicide, 1 advised that the patient be treated, 1 actually started psychiatric treatment, but unsuccessfully as the patient's physical situation rapidly deteriorated; and 3 other respondents gave no further comments. In another 19% (13 cases) the request was acceded to despite the consultant's judgment that transference and countertransference had influenced the decision-making.

Discussion

We estimate the total number of psychiatric consultations in the Netherlands with regard to a patient's request for euthanasia or physician-assisted suicide at around 400 per year. This is about 4% out of an annual total of 9,700 explicit requests for assistance in dying in the Netherlands.²⁰ In the United States, physicians initially responded to requests of this kind by seeking a psychiatric consultation in 2% of the latest cases in which the request was granted.²³ A study among American oncologists showed that 2 out of 38 patients (5%) who received euthanasia or physician-assisted suicide had been evaluated by a psychiatrist.²⁴ In Oregon, psychiatric or psychological consultation was obtained for 4 of 21 patients who received prescriptions for lethal medications in 1998 under the Death with Dignity Act.²⁵ These data suggest that psychiatric consultation with regard to a patient's request for assisted death is rather uncommon, both in the Netherlands and in the United States of America.

In Oregon, a physician who is considering writing a prescription for lethal medication to a terminally ill patient should refer this patient to a consulting physician for medical confirmation of the diagnosis, and for determining whether the patient is capable and acting voluntarily. Additional consultation by a psychiatrist or psychologist is required if, in the opinion of the attending or the consulting physician, the patient may be suffering from a psychiatric or psychological disorder causing impaired judgment.²⁶ In the Netherlands, consultation with an independent colleague is also required. The Dutch Supreme Court held that the consultant must have personally examined the patient prior to giving his affirmative opinion in cases of euthanasia or assistance in suicide because of mental suffering.²⁷ It is recommended that in such cases this consultant be a psychiatrist.¹⁷

Table 3.3
Patients' and other characteristics in cases that resulted in euthanasia or physician-assisted suicide, and cases that did not (horizontal percentages)

Characteristic	Patient's request was acceded to		Patient's request was not acceded to		Unknown	
	(N)	(%)	(N)	(%)	(N)	(%)
Specialty of consultee						
Psychiatrist (N=60)	5	8	46	77	9	15
Non-psychiatrist (N= 161)	62	39	78	48	21	13
Reason for patient's request						
Mental disorder (N=68)	7	10	54	79	7	10
Physical disorder (N=119)	53	45	49	41	17	14
Both mental and physical disorder (N=19)	4	21	12	63	3	16
Other (N=15)	3	20	9	60	3	20
Patient						
Sex*						
Male (N=88)	29	33	48	55	11	13
Female (N=128)	36	28	75	59	17	13
Psychiatric diagnosis†						
Mood disorder	5 (2)		26 (7)		1 (1)	
Personality disorder	3 (1)		13 (4)		1	
Psychosis	0		8 (1)		3 (1)	
Other / multiple	3 (2)		19 (1)		4 (1)	
Not specified	3 (2)		9 (4)		1	
None	53 (53)		49 (46)		20 (17)	
Physical diagnosis‡						
Cancer	21 (1)		13		6 (1)	
Neurological disorder	17 (1)		18 (10)		7 (1)	
Pulmonary disease	4		5		0	
AIDS	3 (1)		2		1	
Other / multiple	7 (2)		10 (3)		2 (1)	
Physical disease, not specified	8 (2)		15 (4)		4	
None	7 (7)		61 (58)		10 (7)	
Age§ (yrs)	(mean)	(range)	(mean)	(range)	(mean)	(range)
	59.2	22-92	54.1	12-92	53.6	27-83

* In 5 cases, the patient's sex was unknown.

† Between brackets is the number of patients for whom the respondent also reported a (concurrent) physical diagnosis. Of all 99 patients with a psychiatric diagnosis, 68 requested physician-assisted death because of the mental disorder, 3 because of a (concurrent) physical disorder, 19 because of both the mental and a physical disorder, and 9 because of other reasons.

‡ Between brackets is the number of patients for whom the respondent also reported a (concurrent) psychiatric diagnosis. Of all 143 patients with a physical diagnosis, 119 requested physician-assisted death because of the physical disorder, 2 because of the (concurrent) mental disorder, 19 because of both a mental and a physical disorder, and 3 because of other reasons.

§ Data were missing on 1 case in the first group, 3 cases in the second group and 4 cases in the third group.

These judicial requirements are in line with what has shown to be the opinion of Dutch physicians about the need for psychiatric consultation. Some 96% of Dutch psychiatrists think that psychiatric consultation should be obtained when a patient requests assistance in dying because of mental suffering. If a physical disorder is the sole reason for the patient's request, 19% of Dutch psychiatrists believe that psychiatric consultation should always be sought, whereas 78% believe that this should be optional.²² Of Dutch non-psychiatrists, 7% think that psychiatric consultation should be mandatory in patients requesting euthanasia.¹⁹ Some 60% of a random selection of physicians in Washington State (strongly) agreed with the statement that psychiatric consultation should be obtained to rule out treatable

Table 3.4
The responding psychiatrist's judgement of specific aspects

Judgement	Patient's request was acceded to (N=67)		Patient's request was not acceded to (N=124)		Total (N=221)	
	(N)	(%)	(N)	(%)	(N)	(%)
Patient's request was well-considered						
Yes	56	84	46	37	121	55
No	3	4	50	40	58	26
Not assessed	8	12	28	23	42	19
Patient had treatable mental disorder						
Yes	7	10	61	49	75	34
No	41	61	32	26	89	40
Not assessed	19	28	31	25	57	26
(Counter)transference influenced the decision-making						
Yes	13	19	34	27	55	25
No	34	51	40	32	84	38
Not assessed	20	30	50	40	82	37
All criteria for careful practice had been fulfilled*						
Yes	49	73	23	19	86	39
No	5	7	45	36	55	25
Not assessed	13	19	56	45	80	36

* The criteria for careful practice are: 1. the request for euthanasia or assisted suicide must be voluntary; 2. the request must be well-considered; 3. the patient's desire to die must be a lasting one; 4. the patient must experience his suffering as unbearable and hopeless; 5. the doctor concerned must consult a colleague.¹

psychiatric illness that may be underlying a patient's request to end his or her life.²⁸ However, 32% of Oregon psychiatrists who favored implementation of Oregon's Death with Dignity Act would refuse to perform a psychiatric evaluation of a patient's request for physician-assisted suicide, mainly because they considered such evaluation to fall outside their area of expertise.²⁹

Apparently, the issue of whether psychiatric consultation should be optional or mandatory for requests for physician-assisted death made by patients with a physical disease remains controversial. The risk of the attending physician misjudging the patient's competence or of disturbing emotions arising in the physician-patient relationship argue in favour of mandatory psychiatric consultation. However, the risk of unnecessary stigmatization ('psychiatrization') of human and medical-ethical decisions, the lack of empirical knowledge about the extent to which mental or emotional disorders play a role in patients' requests for assistance in dying, and practical limitations are all counter-arguments to mandatory psychiatric consultation.⁶ In our study, one respondent actually started psychiatric treatment, that was, however, unsuccessfully as the patient's physical situation rapidly deteriorated. This illustrates that in some cases the length of time that a psychiatrist needs for an adequate psychiatric evaluation may conflict with the patient's debility and remaining life expectancy.²⁹

The guidelines issued by the Dutch Association for Psychiatry in 1998 for the careful evaluation of requests for physician-assisted suicide state that the psychiatrist consulted should offer a second opinion on the psychiatric diagnosis, evaluate whether the request made by the patient is informed and voluntary, evaluate whether the patient is suffering irremediable and unbearable and assess the persistence of the request next to forming a judgement on transference and countertransference issues.¹⁸ Most of these aspects are mentioned by other authors as well.^{9,12} In our study, which deals with cases that occurred before 1998, psychiatrists were most frequently asked to assess whether the patient had a treatable mental disorder and whether the request was well-considered. Another study among Dutch psychiatrists in consultation-liaison services mentioned the assessment of the patients' judgement as most important reason for consultation.³⁰ Non-psychiatrists who were consulted about a patient's request for physician-assisted death, were less frequently asked to assess whether the patient's request was well-considered (in 33% of cases versus 68% for psychiatrist consultants in our study).²¹

According to the Royal Dutch Medical Association, a physician is not obliged to follow the consultant's opinion; the physician retains his or her own professional responsibility and should report his considerations with respect to the patient's request as comprehensively as possible.⁴ However, in the event of disagreement between the attending physician and the consultant, a second consultant should always be asked.¹⁸ We found that in most cases there was concordance between the

respondent's assessment and the final outcome of the patient's request. However, in some cases the patient's request was acceded to despite the respondent's judgment that the patient's request had not been well considered or that the patient had a treatable mental disorder. In particular, determination by the psychiatrist of the presence of transference and countertransference seemed to be of little consequence to the decision-making on whether the request for physician-assisted death would be acceded to.

Further debate on and research into the circumstances that may require psychiatric consultation, the potential of psychiatrists in exploring the patient's request for assistance in dying, and the implications of the psychiatrist's judgement of the patient's competence, the presence of a mental disorder and other aspects assessed, are needed. In addition, the prevalence of mental disorders among patients asking for assisted death and other factors that may influence the patient's competence should be further studied.

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References

1. Griffiths J, Bood A, Weyers H. Euthanasia and law in the Netherlands. Amsterdam University Press, 1998.
2. Gevers S. Euthanasia: law and practice in the Netherlands. *Br Med Bull* 1996;52:326-33.
3. Legemaate J. Legal aspects of euthanasia and assisted suicide in the Netherlands, 1973-1994. *Camb Q of Health Ethics* 1995;4:112-21.
4. Royal Dutch Medical Association. Vision on euthanasia, in Euthanasia in the Netherlands. Utrecht, Royal Dutch Medical Association, 1996, pp 24-56.
5. Muskin PR. The request to die. Role for a psychodynamic perspective on physician-assisted suicide. *JAMA* 1998;279(4):323-8.
6. Hengeveld MW, Klijn FAM, Casteelen G. Actieve levensbeëindiging in het ziekenhuis: de rol van de consultatieve psychiater. Active euthanasia in the hospital: the role of the consultant psychiatrist [in Dutch]. *Ned Tijdschr Geneesk* 1996;140:1709-12.
7. Breitbart W, Rosenfeld BD, Passik SD. Interest in physician-assisted suicide among ambulatory HIV-infected patients. *Am J Psychiatry* 1996;153:238-42.
8. Emanuel E, Fairclough DL, Daniels ER, Clarridge BR. Euthanasia and physician-assisted suicide: attitudes and experiences of oncology patients, oncologists, and the public. *Lancet* 1996;347:1805-10.
9. Block SD, Billings JA. Patient requests for euthanasia and assisted suicide in terminal illness. The role of the psychiatrist. *Psychosomatics* 1995;36:445-7.
10. Conwell Y. Physician-assisted suicide: a mental health perspective. *Suicide and Life-Threatening Behavior* 1994;24:326-33.

11. Block SD, Billings JA. Patient requests to hasten death. Evaluation and management in terminal care. *Arch Intern Med* 1994;154:2039-47.
12. Baile WF, DiMaggio JR, Schapira DV, Janofsky JS. The request for assistance in dying. The need for psychiatric consultation. *Cancer* 1993;72:2786-91.
13. Benrubi GI. Euthanasia - The need for procedural safeguards. *N Engl J Med* 1992;326:197-9.
14. Quill TE, Cassel CK, Meier DE. Care of the hopelessly ill. Proposed clinical criteria for physician-assisted suicide. *N Engl J Med* 1992;327:1380-4.
15. Back AL, Wallace JI, Starks HE, Pearlman RA. Physician-assisted suicide and euthanasia in Washington State. Patient requests and physician responses. *JAMA* 1996;275(12):919-25.
16. Chochinov HM, Wilson KG, Enns M, Mowchun N, Lander S, Levitt M, Clinch JJ. Desire for death in the terminally ill. *Am J Psychiatry* 1995;152:1185-91.
17. Commissie Aanvaardbaarheid Levensbeëindigend handelen. Medisch handelen rond het levenseinde bij wilsonbekwame patiënten. Medical practices concerning the end of life of incompetent patients [in Dutch]. Houten/Diegem, Bohn Stafleu Van Loghum, 1997.
18. Dutch Association for Psychiatry. Hulp bij zelfdoding door patiënten met een psychiatrische stoornis; richtlijnen voor de psychiater. Assisted suicide by patients with a mental disorder; guidelines for the psychiatrist [in Dutch]. Utrecht, 1998.
19. Van der Wal G, van der Maas PJ. Euthanasie en andere medische beslissingen rond het levenseinde. Euthanasia and other medical decisions concerning the end of life [in Dutch]. 's-Gravenhage, Sdu Uitgevers, 1996.
20. Van der Maas PJ, van der Wal G, Haverkate I, de Graaff CLM, Kester JGC, Onwuteaka-Philipsen BD, van der Heide A, Bosma JM, Willems DL. Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in the Netherlands, 1990-1995. *N Engl J Med* 1996;335:1699-1705.
21. Onwuteaka-Philipsen BD, van der Wal G, Kostense PJ, van der Maas PJ. Consultation with another physician on euthanasia and assisted suicide in the Netherlands. *Soc Sci Med* 2000;51:429-38.
22. Groenewoud JH, van der Maas PJ, van der Wal G, Hengeveld MW, Tholen AJ, Schudel WJ, van der Heide A. Physician-assisted death in psychiatric practice in the Netherlands. *N Engl J Med* 1997;336:1795-1801.
23. Meier DE, Emmons CA, Wallenstein S, Quill T, Morrison RS, Cassel CK. A national survey of physician-assisted suicide and euthanasia in the United States. *N Engl J Med* 1998;338:1193-1201.
24. Emanuel EJ, Daniels ER, Fairclough DL, Clarridge BR. The practice of euthanasia and physician-assisted suicide in the United States: adherence to proposed safeguards and effects on physicians. *JAMA* 1998;280:507-13.
25. Chin AE, Hedberg K, Higginson GK, Fleming DW. Legalized physician-assisted suicide in Oregon - the first year's experience. *N Engl J Med* 1999;340:577-83.
26. Oregon revised Statute 127.800-127.897 (The Oregon Death with Dignity Act).
27. Griffiths J. Assisted suicide in the Netherlands: the Chabot case. *Modern Law Review* 1995;58:232-48.
28. Cohen JS, Fihn SD, Boyko EJ, Jonsen AR, Wood RW. Attitudes toward assisted suicide and euthanasia among physicians in Washington State. *N Engl J Med* 1994;331:89-94.
29. Ganzini L, Fenn DS, Lee MA, Heintz RT, Bloom JD. Attitudes of Oregon psychiatrists toward physician-assisted suicide. *Am J Psychiatry* 1996;153:1469-75.
30. Huyse FJ, van Tilburg W. Euthanasia policy in the Netherlands: the role of consultation-liaison psychiatrists. *Hosp Community Psychiatry* 1993; 44:733-8.

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**Attitudes and practices of
Dutch psychiatrists with
regard to physician-assisted
death because of a mental
disorder**

Abstract

Background. The debate about physician-assisted suicide focuses on terminally ill patients. In the Netherlands, in exceptional cases physician-assisted death because of non-physical suffering may be acceptable. We studied the attitudes of Dutch psychiatrists towards such practice.

Methods. In 1996, we sent questionnaires to half of all Dutch psychiatrists. Questions were about their attitudes, and about whether they ever received a patient's request for physician-assisted death. 552 psychiatrists responded (response rate 83%).

Results. Of Dutch psychiatrists, 65% thought that assistance with suicide because of a mental disorder could be acceptable; 31% considered such assistance unacceptable, and 5% had no opinion. Of psychiatrists, 31% had over the years become more permissive towards assistance with suicide, 21% had become more restrictive, and 49% had not changed attitudes. No relation was found between the psychiatrists' judgement of the patient's request and their attitudes, but a significant relation with the main psychiatric diagnosis was found. For refusing patients' requests, psychiatrists who considered physician-assisted death unacceptable most frequently mentioned reasons of principle (73%), the presence of a treatable mental disorder (51%), or doubt about the patient's suffering (42%). Psychiatrists who considered such assistance acceptable less frequently mentioned doubt about the patient's suffering (28%; $p=0.07$), and more frequently that the patient had a treatable mental disorder (68%; $p=0.04$).

Discussion. Dutch psychiatrists have a rather liberal attitude towards physician-assisted death because of mental suffering, showing some trend towards an increased acceptance. However, their judgements of individual patients' requests provide evidence of a careful practice.

Introduction

Several empirical studies have addressed the attitudes of physicians towards euthanasia and physician-assisted suicide. Some studies specifically explored the attitudes of psychiatrists towards physician-assisted death.¹⁻⁶ Most studies addressed euthanasia or physician-assisted suicide in terminally ill patients, or in patients who suffer physically without being terminally ill. Psychosocial or psychiatric aspects are rarely addressed. In a previous study, we reported on the attitudes of Dutch psychiatrists towards assistance with suicide in patients who request such because of a mental disorder. We found that about two thirds of Dutch psychiatrists considered such assistance acceptable.⁷ In the present article, we will explore a number of background characteristics of Dutch psychiatrists in relation to their opinions about physician-assisted suicide because of a mental disorder, and how these opinions affect their decisions regarding requests for physician-assisted suicide made by patients with a mental disorder.

Methods

Sample. In 1996, we sent written questionnaires to 673 psychiatrists in the Netherlands. These psychiatrists were sampled from the Specialists Registry of the Royal Dutch Medical Association, which contains the names and addresses of all specialists. All registered psychiatrists were ordered by postal code, and every second psychiatrist was included in the sample.

Questionnaire. The questionnaire consisted of two parts. A 1-page questionnaire contained questions about a number of background characteristics of the respondent: gender, age (5 categories), year of registration (5 categories), domain of practice (5 categories) and the province where the respondent worked. In a 20-page questionnaire the respondents were, amongst others, asked whether they had ever received an explicit request for physician-assisted suicide from a patient in therapy. If so, more detailed questions were asked about the most recent request they acceded to, and about the most recent request they refused.

Response. Of the sampled psychiatrists, 6 did not meet the criteria for selection and therefore were excluded from the study. Of the remaining 667, 555 returned completed questionnaires (a response rate of 83%, excluding 3 responses that could not be used). An additional 6 psychiatrists had chronic illnesses or could not be traced. Fifty-one psychiatrists refused to participate, and for 55 other nonrespondents the reason could not be determined. Of the 104 nonrespondents with available data and the 549 respondents, 82 (79%) and 388 (71%) were male.

Nonrespondents were slightly older, with a mean age of 49.7 years (range, 33 to 67), as compared with 47.4 (range, 33 to 77) for respondents. Of the nonrespondents, 31 (28%) provided written or oral information about a number of core issues in the questionnaire. These 31 did not differ markedly from the respondents with respect to their places of work or experience with requests for physician-assisted suicide and consultation.

Statistical analysis. Differences between subgroups were tested for statistical significance with the Chi-Square test or the Fisher's Exact test. A multivariate logistic regression model was used to analyse the relation between physicians' or patients' background characteristics and the physicians' attitudes, and the physicians' judgement of the patient's request. The significance level was set at $p=0.05$.

Results

Psychiatrists' characteristics

The characteristics of the 552 respondents are presented in Table 4.1. Of respondents, 71% were male. Almost half were 45 years or younger, and 41% were between 46 and 55 years. Eighty-five percent had been registered as a psychiatrist for 5 years or more. Of the respondents, 44% were working in more than one type of practice (mean: 1.5 types of practice). Thirty-seven percent had ever received a request for physician-assisted death by a patient in therapy; of those, 62% had received at least one request within the last 2 years.

Attitudes towards assistance with suicide because of a mental disorder

Of the respondents, 357 (65%) considered assistance with suicide because of a mental disorder acceptable; of those, 253 (71%) could conceive of a situation in which they themselves would assist (46% of all respondents). Assistance with suicide because of a mental disorder could never be acceptable according to 168 respondents (31%), and 25 respondents (5%) had no opinion (data were missing on two respondents; these were excluded from the analysis). Table 4.2 presents the respondents' attitudes in relation to a number of background characteristics. No significant relation was found between the attitudes and the respondents' sex or age, or their year of registration (not in Table; Chi-Square Test, $p=0.17$). Psychiatrists working in a psychiatric hospital more frequently considered

physician-assisted suicide because of a mental disorder unacceptable than psychiatrists who did not work in a psychiatric hospital (35% and 28%, respectively), and less frequently could conceive of a situation in which they themselves would provide assistance with suicide (39% and 50%, respectively). The attitudes were also significantly related to psychiatrists' experience with patients' requests for assistance with suicide ($p=0.005$), but not to the total number of

Table 4.1
Characteristics of respondents

	No.	%
Sex*		
Male	388	71
Female	161	29
Age (years) *		
≤45	271	49
46-55	223	41
≥56	55	10
Year of registration*		
≤1980	198	36
1981-1990	270	49
≥1991	81	15
Domain of practice†		
Private practice	209	38
Institution for outpatient and ambulatory psychiatric care	206	38
Psychiatric ward of a general (or academic) hospital	111	20
Psychiatric hospital	198	36
Elsewhere‡	98	18
Experience with requests		
Never received any request	347	63
Ever received any request	205	37
No. of requests received in the past two years‡		
0	78	38
1	58	28
2	38	19
≥3	30	15

* Data on the respondent's sex, age and year of registration were missing for 3 respondents. Of the respondents, 1% were younger than 36, 3% were 66 years or older (percentages not in Table).

† Data on the working place of the respondent were missing for 4 respondents. Respondents could have more than one working place.

‡ Data on the number of requests were missing for 1 respondent who had ever received any request.

§ Respondents were not asked to specify this.

requests that the respondent had received in the past two years ($p=0.43$) (not in Table).

Multivariate regression analysis with the respondents' sex, age and year of registration, the different types of practice and their experience as independent variables, showed that the chance of being able to conceive of a situation in which they themselves would assist was significantly related to the respondents' age ($p=0.04$) and experience ($p<0.001$). Compared to psychiatrists aged 56 and older, psychiatrists in the youngest age category more frequently could conceive of such a situation (Odds Ratio 1.64; 95% CI, 0.75-3.58), and those in the middle age category less frequently (Odds Ratio 0.86; 95% CI, 0.45-1.65). For psychiatrists who had at least once received a patient's request the Odds Ratio was 1.91 (95% CI, 1.32-2.77) compared with those who never had. Multivariate regression analysis, using the same independent variables, showed no significant relations for the chance that psychiatrists thought that assisted suicide because of a mental disorder could be acceptable (whether or not they could conceive of a situation in which they themselves would assist).

Among the reasons respondents gave for considering assisted suicide because of a mental disorder unacceptable were their professional attitude (86%), fear of error of judgement (45%), and religion or philosophy of life (41%). These were the reasons for being unable to conceive of a situation in which they themselves would assist in 54%, 28% and 17%, respectively; other frequently mentioned reasons for this were fear of prosecution or sentencing (25%) and the policy of the institution (21%).

Changing attitudes

Table 4.3 shows how the respondents' attitudes towards assisted suicide because of a mental disorder had changed during their years of practice. Of all respondents, 49% had not changed opinions, 31% had become more permissive, and 21% had become more restrictive. A change in attitude was not significantly related to the respondent's sex or age, nor to the year of registration ($p=0.08$), but a significant relation was found with the respondent's previous experience with patients' requests for physician-assisted suicide ($p<0.001$): of respondents who had ever received a request, attitudes had changed more often, mostly in a more permissive direction. There was no significant relation with the number of requests received ($p=0.93$).

Table 4.2

Attitude* towards physician-assisted suicide because of a mental disorder, according to the characteristics of the respondents (horizontal percentages)

	Acceptable		Not acceptable	No opinion	P value†
	Can conceive of a situation to give such assistance him- or herself	Cannot conceive of a situation to give such assistance him- or herself			
	%	%	%	%	
Sex‡					0.31
Male (N=388)	47	19	31	3	
Female (N=161)	44	19	29	7	
Age (years)‡					0.12
≤45 (N=271)	49	21	26	5	
46-55 (N=223)	42	18	36	3	
≥56 (N=55)	46	11	35	7	
Type of practice§					
Private practice (N=209)	48	18	30	3	0.73
Institution for outpatient and ambulatory psychiatric care (N=206)	48	20	27	4	0.45
Psychiatric ward of a general (or academic) hospital (N=111)	50	19	28	2	0.43
Psychiatric hospital (N=198)	39	18	35	7	0.04
Elsewhere (N=98)	49	15	32	3	0.73
Experience with requests					0.005
Never received any request (N=347)	40	21	33	6	
Ever received any request (N=205)	55	14	27	3	
All (N=552)	46	19	31	5	

* For 2 respondents data on the respondent's attitude were missing; these cases were excluded from the analysis.

† P-value for Fisher's Exact Test.

‡ Data on the respondent's sex and age were missing for 3 respondents.

§ Data on the working place of the respondent were missing for 4 respondents. Respondents could have more than one working place.

We also found a relation with the respondent's current attitude: those who considered physician-assisted suicide because of a mental disorder unacceptable were less likely to have changed their attitudes, and if so, in a more restrictive way than those who considered such assistance acceptable. These associations remained significant in multivariate regression analysis correcting for the respondent's sex, age, year of registration and domain of practice. The Odds Ratio for a change in attitude was 1.78 (95% CI, 1.20-2.66) for respondents who had ever received a request compared to respondents who had never received a request. The Odds Ratio was 6.15 (95% CI, 3.87-9.76) for respondents who could conceive of a situation in which they themselves would assist, and 3.23 (95% CI, 1.88-5.55) for respondents who could not conceive of such a situation, compared to respondents

Table 4.3
Changes in attitudes towards physician-assisted death because of a mental disorder*
(horizontal percentages)

	Less acceptable	No change	More acceptable	P value†
Sex‡				0.92
Male (N=388)	21	49	30	
Female (N=161)	20	48	32	
Age (years)‡				0.34
≤45 (N=271)	22	46	32	
46-55 (N=223)	22	48	30	
≥56 (N=55)	11	60	28	
Experience with requests				<0.001
Never received any request (N=347)	18	55	27	
Ever received any request (N=205)	25	38	37	
Current attitude§				<0.001
Can conceive of a situation to give such assistance him- or herself (N=250)	18	32	50	
Cannot conceive of a situation to give such assistance him- or herself (N=102)	18	48	35	
Not acceptable (N=168)	26	72	2	
All (N=552*)	21	49	31	

* Data on the respondent's change in attitude were missing for 4 respondents; these cases were excluded from the analysis.

† P-value for Fisher's Exact Test.

‡ Data on the respondent's sex and age were missing for 3 respondents.

§ Twenty-five other respondents had no opinion; for 2 respondents information about their current attitude was missing.

Table 4.4
Motives for a change in attitudes towards physician-assisted death because of a mental disorder*

Less acceptable (motivated by 39 respondents)
Prognostic uncertainty ('recovery can never be excluded' / 'course of mental disorder often is unpredictable') (8)
Diagnostic uncertainty (with regard to the mental disorder or the meaning of the request for assisted death) (7)
Undermining therapy ('request may disappear when seriously considered') (5)
Unwanted / unnecessary medicalisation ('no right for physician-assisted suicide' / 'patient autonomy' / 'alternative suicide methods') (5)
Chabot Case† (4)
Slippery slope argument (4)
Knowledge (treatment / diagnostic) (3)
Other reasons (9)
More acceptable (motivated by 25‡ respondents)
Notion (by experience) that suffering because of a mental disorder can be hopeless or unbearable (9)
No longer taboo, recent societal or professional debate (6)
Experience with (violent) suicides (4)
Experience (not specified) (3)
Other reasons (3)

* Between brackets are the numbers of respondents who mentioned the motive.

† The Chabot Case is the case of a psychiatrist who assisted the suicide by a 50-years old woman who suffered unbearably and hopelessly after having lost her two sons, which came before the Dutch Supreme Court in 1994.

‡ Of the 25 respondents, 5 emphasised that they would accept assistance with suicide because of a mental disorder only in exceptional cases.

who considered physician-assisted suicide because of a mental disorder unacceptable.

Table 4.4 presents an overview of the respondents' motives for a change in attitude towards physician-assisted death because of a mental disorder. The most frequently mentioned motives for having become more restrictive were the prognostic or diagnostic uncertainty of the mental disorder or the meaning of the request. Some respondents thought that accepting assisted-suicide in psychiatric patients would undermine therapy. The most frequently mentioned reasons for a more permissive attitude were the personal experience that suffering accompanying a mental disorder could indeed be hopeless or unbearable. Others had become more permissive after the recent societal and professional debate about the issue.

Attitude and practice

Of 205 respondents who had at least once received a request for assistance with suicide from a patient, 198 described the most recent request that they had refused. The assessment of these patients' requests was compared between respondents who considered assisted suicide because of a mental disorder acceptable and respondents who considered such unacceptable. The patients' requests were made voluntarily and independently according to 87% and 85% of the respondents, respectively (Fisher's Exact Test; $p=0.82$). The patient was considered competent by 83% and 81%, respectively ($p=1.0$), and the wish to die was persistent according to 69% and 68%, respectively ($p=1.0$). Multivariate regression analysis correcting for the patients' age and sex, the main psychiatric diagnosis, the presence of a personality disorder and the presence of a concomitant

Table 4.5
Reasons for not acceding to the most recent request for assisted suicide made by a patient in therapy (vertical percentages)*

	Acceptable			P value
	Can conceive of a situation to give such assistance him- or herself (N=109)	Cannot conceive of a situation to give such assistance him- or herself (N=28)	Not acceptable (N=55)	
Considered acceding to the most recent request	29	7	9	0.002
Reasons for not acceding to the most recent request†				
Request was not well-considered	26	18	18	0.42
Wish to die was not persistent	23	18	25	0.74
A treatable mental disorder was present	65	79	51	0.04
Suffering was not unbearable or hopeless	25	39	42	0.07
Reasons of principle	8	43	73	<0.001
Discussion / consultation with others	8	4	2	0.21
Patient no longer wished to die	2	0	2	0.77
Other reasons	16	7	9	0.31

* Of 198 psychiatrists who described the most recent request that they refused, 6 had no opinion about physician-assisted suicide because of a mental disorder.

† More than one answer was possible.

physical disease, showed no significant association between the respondents' judgements on the patient's request and the respondents' attitudes; the respondents' judgements, however, were significantly related to the psychiatric diagnosis.

Table 4.5 shows the respondents' reasons for refusing the patients' requests. Compared to respondents who considered assisted suicide because of a mental disorder unacceptable, respondents who considered such assistance acceptable more frequently mentioned the presence of a treatable mental disorder (51% and 68%, respectively; Chi-Square Test, $p=0.04$). Respondents who considered assisted suicide because of a mental disorder unacceptable more frequently mentioned that the suffering was not unbearable or hopeless, but the difference did not reach statistical significance (42% versus 28%; Chi-Square Test, $p=0.07$).

Of the respondents who considered assistance with suicide because of a mental disorder unacceptable, 96% fully supported their decision of having refused the patient's request, compared with 92% of respondents who considered such assistance acceptable (Chi-Square Test, $p=0.3$). Of the respondents in the first group, no one had doubts or regrets about the decision; of respondents who considered assisted suicide because of a mental disorder acceptable, 7% had doubts about having refused the request, and 1% had regrets.

Discussion

In the present study, psychiatrists' attitudes towards physician-assisted death because of a mental disorder were further explored. To our knowledge, this study was the first empirical study of attitudes towards physician-assisted death because of a mental disorder. Many other studies primarily focussed on physicians' and public attitudes towards euthanasia and physician-assisted suicide in physically ill patients in the terminal stage of their disease. If psychological or psychiatric aspects are addressed, these are often used to illustrate the relevance of a concomitant mental disorder, in particular depression, for the patient's request or the patient's competence.

In a previous publication, we reported that about two thirds of psychiatrists in the Netherlands considered physician-assisted death because of a mental disorder acceptable. In spite of this rather liberal attitude, there was a very reluctant practice. Out of an annual total of 320 explicit requests for physician-assisted death that Dutch psychiatrists receive, about 2 to 5 are acceded to, often involving patients with a serious physical illness as well.⁷ Of Dutch non-psychiatric physicians, 46% thought that physician-assisted suicide for patients with a mental disorder in exceptional cases could be acceptable.⁸ According to Dutch jurisprudence, physician-assisted death because of mental suffering may, in

exceptional cases, be acceptable. In the case of a psychiatrist who assisted the suicide by a 50-years old woman suffering unbearably and hopelessly after having lost her two sons, the Dutch Supreme Court stated in 1994 that the origin of suffering, be it physical or mental, does not detract from the extent to which a patient suffers.^{9,10} But jurisprudence and the medical profession require extra carefulness if a physician considers to assist such a patient with suicide.¹¹

One of the few other studies of attitudes towards assisted death because of non-physical suffering is a study among 148 American consultation-liaison psychiatrists, who were offered six vignettes. This study showed that the acceptance of assisted death practices was greater for medical illnesses than for unremitting pain or severe psychiatric illness.⁵ A study among 355 American oncologists also showed that euthanasia and physician-assisted suicide were thought to be most acceptable for a patient with terminal cancer and unremitting pain, and least acceptable for the pain-free patient with terminal cancer who viewed life as meaningless.¹²

In the present study, psychiatrists who opposed to physician-assisted death because of a mental disorder mainly did so because of their professional attitude, (fear of) error of judgement and religious feelings or philosophy of life. The same reasons were, to a lesser extent, mentioned by psychiatrists who could not conceive of a situation in which they themselves would assist, but nevertheless considered physician-assisted suicide because of a mental disorder acceptable. For the last-mentioned, practical circumstances, including fear of prosecution or sentencing, the policy institution, or the juvenile age of their patients, were other important motives for their reluctance to give the assistance themselves.

We also found that Dutch psychiatrists' attitudes towards assistance with suicide because of a mental disorder have changed over the years, showing some trend towards a growing acceptance. It would be interesting to know what the trend will have been in the years after the study, and whether this will have had implications for the practice of assisted suicide because of a mental disorder.

Physicians' attitudes about euthanasia – in terminally ill patients – have found to be related to demographic and professional characteristics.¹³ In the present study, we found a significant relation between psychiatrists' attitudes towards assisted suicide because of mental suffering and their experience with patients' requests for physician-assisted death. In general, psychiatrists who ever faced a patient's request for physician-assisted death more frequently considered assistance with suicide because of a mental disorder acceptable. However, the motives for having changed opinions, as reported by the psychiatrists, show that experience may change psychiatrists' attitudes in opposite directions. Some psychiatrists had become more permissive over the years, because they realised that the suffering accompanying a mental disorder could indeed be hopeless or unbearable. Experience with (violent) suicides by patients was another important

reason for having become more permissive. Other psychiatrists, however, had become more restrictive on the ground of their experience: they mentioned the unpredictability of the course of a mental disorder, sometimes resulting in an unexpected improvement in the patient's circumstances. Psychiatrists' attitudes were, in multiple logistic regression analysis, also related with their age: psychiatrists in the middle age category less frequently considered physician-assisted death because of a mental disorder acceptable than older or younger psychiatrists. A hypothesis is that younger psychiatrists more frequently consider the patient's suffering unacceptable, whereas older psychiatrists more frequently empathise with dying.

We found that psychiatrists' attitudes did not influence their judgement of the patients' requests or competence. This judgement was related to the patient's diagnosis. However, the reasons for refusing the patients' requests differed with attitudes. Psychiatrists who thought that physician-assisted suicide because of a mental disorder could be acceptable more frequently mentioned the presence of a treatable mental disorder as the reason for having refused the request than psychiatrists who opposed to such assistance; they, in turn, more frequently mentioned that the patient's suffering, in their opinion, was not unbearable or hopeless. Psychiatrists who consider assisted death because of mental suffering acceptable, may be more understanding towards the patient's suffering, and thus more frequently mentioned other reasons for their refusal of the patient's request.

This study gives insight into Dutch psychiatrists' attitudes towards physician-assisted death because of a mental disorder, and into their considerations about this issue. These considerations are illustrative of the arguments that are put forward in favour and against physician-assisted death in psychiatric patients. Studies on attitudes towards assisted death because of a mental disorder should be extended to the public, and to other medical specialties, in particular family practitioners, who also have psychiatric patients among their patients. The area of physician-assisted death because of a mental disorder needs further discussion and study, in order to increase knowledge of prognostic and diagnostic aspects of mental suffering, and to develop guidelines for physicians who are confronted with patients' requests for physician-assisted suicide because of mental suffering.

References

1. Cohen JS, Fihn SD, Boyko EJ, Jonsen AR, Wood RW. Attitudes toward assisted suicide and euthanasia among physicians in Washington State. *N Engl J Med* 1994;331(2):89-94.
2. Ganzini L, Fenn DS, Lee MA, Heintz RT, Bloom JD. Attitudes of Oregon psychiatrists toward physician-assisted suicide. *Am J Psychiatry* 1996;153(11):1469-75.
3. Berger D, Fukunishi I, O'Dowd MA, Hosaka T, Kuboki T, Ishikawa Y. A comparison of Japanese and American psychiatrists' attitudes towards patients wishing to die in the general hospital. *Psychother Psychosom* 1997;66(6):319-28.

4. Forde R, Aasland OG, Falkum E. The ethics of euthanasia - attitudes and practice among Norwegian physicians. *Soc Sci Med* 1997;45:887-92.
5. Roberts LW, Muskin PR, Warner TD, McCarty T, Roberts BB, Fidler DC. Attitudes of consultation-liaison psychiatrists toward physician-assisted death practices. *Psychosomatics* 1997;38:459-71.
6. Shah N, Warner J, Blizard B, King M. National survey of UK psychiatrists' attitudes to euthanasia. *Lancet* 1998;352:1360.
7. Groenewoud JH, van der Maas PJ, van der Wal G, et al. Physician-assisted death in psychiatric practice in the Netherlands. *N Engl J Med* 1997;336:1795-801.
8. Van der Wal G, van der Maas PJ. Euthanasie en andere medische beslissingen rond het levenseinde. Euthanasia and other medical decisions concerning the end of life [in Dutch]. 's-Gravenhage: Sdu Uitgevers, 1996.
9. Nr. 656. Hulp bij zelfdoding psychiatrische patiënt. Assisted suicide by psychiatric patient [in Dutch]. *Nederlandse Jurisprudentie*. 1994.
10. Griffiths J. Assisted suicide in the Netherlands: the Chabot case. *Modern Law Review* 1995;58:232-48.
11. Dutch Association for Psychiatry. Hulp bij zelfdoding door patiënten met een psychiatrische stoornis; richtlijnen voor de psychiater. Assisted suicide by patients with a mental disorder; guidelines for the psychiatrist [in Dutch]. Utrecht: Dutch Association for Psychiatry, 1998.
12. Emanuel EJ, Fairclough DL, Daniels ER, Clarridge BR. Euthanasia and physician-assisted suicide: attitudes and experiences of oncology patients, oncologists, and the public. *Lancet* 1996;347(9018):1805-10.
13. Chochinov HM, Wilson KG. The euthanasia debate: attitudes, practices and psychiatric considerations. *Can J Psychiatry* 1995;40(10):593-602.

PART **III**

Potentially life-shortening
drugs used at the end of life;
physicians' practices

5

Drugs used in physician- assisted death

Abstract

Epidemiological studies, case reports, and recommendations concerning the drugs used in physician-assisted death are reviewed in this paper. Using a MEDLINE and Cancerlit search, we found a total of 20 relevant publications. Recent research, mainly from the Netherlands, has shown that high doses of barbiturates are usually effective for physician-assisted suicide, whereas a combination of a barbiturate and a derivative of curare are effective for euthanasia. Opioids are less reliable drugs for physician-assisted death because of the unpredictable duration of the dying process even after high doses. The same applies to benzodiazepines. The most frequent undesired effect is an unexpectedly long dying process due to impaired uptake of the drugs. Although the evidence base is incomplete, the Dutch recommendations issued in 1994 and renewed in 1998 do not seem inappropriate.

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Introduction

Euthanasia and physician-assisted suicide have been a topic of heated political and ethical debate for over 2 decades. Whereas initial publications described single cases of physician-assisted death,^{1,2} since 1990 empirical research has been done involving not only attitudes and opinions of physicians and the prevalence of physician-assisted death,³⁻⁶ but also the practical aspects of providing assistance in dying.⁷ A recent American study indicates that physicians are often uncertain about the drugs they would use if they consented to assist a patient in dying.⁸ In this article, we present an overview of the literature on technical aspects: drugs used, their effectiveness and the occurrence of undesired effects. We will not go into the ethical pros and cons of physician-assisted death.

The term physician-assisted death covers euthanasia (defined as: the administration of drugs with the explicit intention of ending the patient's life, at the patient's explicit request), physician-assisted suicide (defined as: the prescription or supplying of drugs with the explicit intention of enabling the patient to end his or her life), and ending of life without an explicit request of the patient (LAWER; defined as: the administration of drugs with the explicit intention of ending the patient's life without a concurrent, explicit request by the patient). Although there are important moral, legal and psychological differences between these categories of physician-assisted death, they have the intention to end the life of a patient in common – for our purpose, we will take them together. The term physician-assisted death does not cover decisions to withhold or withdraw treatment, nor the increase of opioid doses for symptom management without the intention to shorten life. However, it does cover the use of opioids with the explicit intention to shorten life.

Methods

We performed a literature search in MEDLINE and Cancerlit 1996 to 1999, using the following search terms (textword mode): euthanasia, physician-assisted suicide, drugs, insulin, opioids, potassium chloride, curare, propofol, ketamine. Through citation-tracking, we searched for more publications, such as books. We included all epidemiological studies about technical aspects of physician-assisted death. For some specific drugs, however, only case reports could be found. Finally, we included published recommendations for physician aid in dying, provided they concerned terminally ill patients. We excluded both animal studies, because extrapolation to severely ill patients is very difficult, and the large number of recommendations on how to commit suicide.

Because of the scarcity and heterogeneity of the retrieved studies, we could not systematically review the studies and give a comparative quality assessment.

Results

We found a total of 20 publications satisfying our inclusion criteria: 7 epidemiological studies reporting the drugs used in physician-assisted death and their effects^{3,5,9-15} (the results of 1 study were published in a paper and 2 books), 9 case reports,¹⁶⁻²⁴ and 4 publications discussing a set of recommendations.^{13,25-27}

Drugs used in physician-assisted death

Table 5.1 presents an overview of the types of drugs used in physician-assisted death in the epidemiological studies and case reports. It shows that almost all quantitative data came from Dutch studies.

A 1992 nationwide study by one of the authors (G. van der Wal) on drugs used by Dutch general practitioners in euthanasia and physician-assisted suicide showed that more than 40 different drugs were used.⁹ In 30% of patients a single drug was used, most frequently a barbiturate or an opioid. In 57%, a combination of 2 drugs was given, most often a benzodiazepine or a barbiturate with a neuromuscular relaxant (curare derivative). In this study, 75% of the drugs were given parenterally, 21% orally, and 3% rectally.

A 1995 nationwide study on physician-assisted death among all medical specialties in the Netherlands has shown that only morphine was used in 25% of the euthanasia and 64% of cases of LAWER.³ Neuromuscular relaxants were used in 46 and 18%, respectively. Benzodiazepines, and also barbiturates, were most often given in combination with another drug (usually a neuromuscular relaxant): in 100 and 86% of the cases, respectively.¹⁴ Insulin, potassium chloride, or propofol were used much less often than morphine, neuromuscular relaxants, benzodiazepines or barbiturates (each drug less than 5%).

Compared with a similar study in 1991, in the 1995 study there was an increase in the use of short-acting barbiturates and neuromuscular relaxants, and a decrease in the use of opioids or other drugs in cases with an explicit request.⁵

In a study among nursing home physicians, barbiturates and neuromuscular relaxants formed 32% and 29% of the drugs used in euthanasia, respectively.¹¹

The first study on the practice of physician-assisted suicide involving patients from Oregon (n=15), reported the use of 9g of pentobarbital or secobarbital in all patients but one.¹² An earlier observational study from Seattle reported similar data.¹⁶

A study on euthanasia and physician-assisted suicide in patients with AIDS in Amsterdam showed that benzodiazepines and barbiturates were used together as the only drugs in 38% of cases, and together with a neuromuscular relaxant or opioids in 50 and 9% of cases, respectively.¹⁰

Effects of drugs in physician-assisted death

In the 1995 Dutch study, 85% of the patients died within 1 hour of the beginning of euthanasia or physician-assisted suicide, and 96% died within 1 day. Ninety percent of the physicians were satisfied about the dying process.¹⁴ In a study evaluating the implementation of a protocol for pharmacists and physicians, death

Table 5.1
Reviewed epidemiological studies and case reports concerning drugs used in physician-assisted death

First author	Design	Subject	Study population
Epidemiological studies			
Chin et al. ¹²	Case-control	Frequency of PAS	21 patients
Onwuteaka-Philipsen et al. ¹³	Survey	Effects of a protocol	28 pharmacists, 177 general practitioners
van der Maas / van der Wal ^{3,14,15}	Randomised stratified survey	Frequency and type of PAD	4405 patients
Laane ¹⁰	Survey	Frequency of euthanasia and PAS	204 patients
van der Wal et al. ⁹	Survey	Frequency and type of PAD	388 family physicians
Muller et al. ¹¹	Survey	Frequency and type of PAD	69 nursing home physicians
van der Maas et al. ⁵	Survey	Frequency and type of PAD	5197 patients
Case reports			
Preston & Mero ¹⁶	Patient series	Characteristics of PAS	24 patients
Jamison ²⁴	Patient series	Complications of PAD	140 caregivers
Cooper ¹⁸	Case	Insulin	1 patient
Chao et al. ¹⁹	Case	Propofol	1 patient
Kaminer & Robbins ²¹	Patient series	Insulin	2 patients
Arem & Zoghbi ²⁰	Patient series	Insulin	8 patients
Stapczynski & Haskell ¹⁷	Patient series	Insulin	15 patients
Wetli & Davis ²³	Case	Potassium	1 patient
Martin et al. ²²	Patient series	Insulin	4 patients

(PAD = Physician-assisted death; PAS = physician-assisted suicide)

occurred on average 5 minutes after an intravenous injection, and 21 minutes after oral administration.¹³ In the 1999 Oregon study, the median time between taking the medication and death was 26 minutes (15 minutes to 11.5 hours).¹²

Table 5.2 presents the most frequently mentioned drugs from the epidemiological studies and the case reports, and the available data on their lethal effects. The lethality of opioids is due to the depression of the respiratory centre, which occurs almost exclusively in opioid-naïve patients.²⁸ Whether opioids really have the effect of hastening death in patients who have used them for some time remains controversial.

Depolarising or nondepolarising neuromuscular blocking agents such as tubocurarine and pancuronium bromide cause a general paralysis by competing with acetylcholine on the neuromuscular junction. The respiratory muscles are the last to be paralysed. With a sufficient dosage the lethal effect is certain.

Short-acting barbiturates, if they are given orally in high doses such as pentobarbital 9g, cause a comatose state, followed by a decrease of cardiac output and finally a respiratory arrest.²⁹

Benzodiazepines are sometimes used orally for the induction of a coma, although there is considerable uncertainty about the doses needed and the duration of the ensuing comatose state. Benzodiazepines play an important role in terminal sedation defined as sedating a patient to unconsciousness by the continuous administration of either benzodiazepines or barbiturates. There is no standard dosage – the necessary dosage is reached when the patient becomes unconscious. It may take days or even weeks for death to occur.^{30,31}

The most frequently mentioned problem in the different studies was that death occurred either not at all, or later or sooner than expected.^{13,24,32} In the 1992 general practitioners study, this happened most frequently when opioids or brallobarbitol combinations were used.⁹

In physician-assisted suicide, the dying process sometimes take more than 24 hours, probably as a consequence of an affected absorption due to the underlying disease or chronic drug therapy; for example, previous use of opioids may cause slow bowel emptying.³³ There are indications that low protein diet and hypothermia may decrease the absorption and pharmacological activity of drugs.³⁴⁻³⁶ Also, barbiturates may accelerate their own metabolism by induction of liver enzymes.³⁹ On the other hand, studies in acutely critically ill patients have shown that the metabolism and clearance of sedatives and opioids are either unaffected or impaired in situations of liver and/or renal failure, the latter resulting in higher toxicity.³⁷ Infrequent problems included vomiting, myoclonus and cyanosis (1 to 3%),^{9,11,13,32}

Tricyclic antidepressants are sometimes advised as suicide drugs.²⁶ Although they may be lethal in a high dosage, they often lead to seizures, which makes them unsuitable for physician-assisted suicide.³⁸

Table 5.2
Frequency of use and effectiveness of drugs used in different types of physician-assisted death (PAD)

Drugs	Euthanasia ^{3,10,15}		PAS ^{3,10,12,15,16}
	Frequency (%)	Effectiveness	Frequency (%)
Opioids only	17-25	Variable duration ^{3,10}	
Oral barbiturates only			>80
Barbiturates/benzodiazepines + neuromuscular relaxant ³	31-50	Mostly < 1h	
Benzodiazepines only			< 12
Insulin	< 5	Very variable, adverse effects ¹⁷	
Potassium chloride	< 5	Very variable, adverse effects ²³	
Propofol	< 5	Unclear ¹⁹	

(LAWER = ending of life without explicit request of the patient; PAS = physician-assisted suicide)

Table 5.2 (continued)

Drugs	PAS ^{3,10,12,15,16}	LAWER ³	
	Effectiveness	Frequency (%)	Effectiveness
Opioids only		64	Variable duration
Oral barbiturates only	Mostly < 1h, but variable ^{3,12}		
Barbiturates/benzodiazepines + neuromuscular relaxant ³		18	Mostly < 1h
Benzodiazepines only	Very variable ²⁴		
Insulin		< 5	Very variable, adverse effects
Potassium chloride		< 5	Very variable, adverse effects
Propofol		< 5	Unclear

Data about lethal doses of insulin, potassium chloride and propofol in humans are scarce, and come from case reports and studies of suicide attempts.³³ From the literature on insulin overdosage, it appears that the onset and duration of hypoglycaemia is largely unpredictable,^{17,18,21} and that the lethal effect is uncertain: 1 study reported on 8 patients who took large overdoses, 4 of whom had not used insulin before and none of whom died.²⁰ In terminally ill patients, the uncertain lethal effect may be due to the slow release of insulin from a

subcutaneous injection site;²² no research has been conducted into the lethal effect of intravenous insulin.

Lethal potassium chloride overdose is due to cardiac effects (arrhythmias) and ascending paralysis. As with insulin, the time between administration and death, and the occurrence of death, are uncertain.^{23,39}

Propofol and other anaesthetic agents, such as ketamine, are rarely reported as euthanising drugs. Literature on these drugs is restricted to case reports. A recent case report describes suicide by an injection of propofol 1600mg, being about 15 times the dose used in anaesthesia.¹⁹

Guidelines and recommendations

Recommendations for physicians and pharmacists have been issued by the Royal Dutch Pharmaceutical Association (KNMP) in 1987⁴⁰ and revised in 1994. The 1994 revision was not based on systematic evidence, but on physicians' experiences that were gathered from returned questionnaires which were enclosed in the recommendations.²⁵ The recommendations have been restated without modification on the basis of the same type of data in 1998.⁴¹

For physician-assisted suicide, the recommendations advise 9g of either pentobarbital or secobarbital in a 100ml solution. Other barbiturates and mixtures, for example with brallobarbital, are discouraged. It is advised that anti-emetics (for instance, metoclopramide 20mg every 8 hours) be started 24 hours before taking the barbiturate. Even so, the dying process may take between 1 and 24 hours. Because this may cause serious uncertainty and fear for family members, the recommendations stipulate that patient and family should be informed about this. The physician should remain in the vicinity of patient and family in case unexpected or terrifying effects occur, and should be prepared to end life by an injection if suicide fails.

For parenteral euthanasia, the KNMP recommends the administration of thiopental sodium 20mg/kg in 10ml of saline solution intravenously to induce a coma, followed by 20mg of pancuronium bromide or vecuronium bromide, also intravenously. If an intravenous route cannot be found, an intramuscular injection of pancuronium 40mg is advised (intramuscular administration of barbiturates is not mentioned).

As rectal euthanasia is much less certain and more cumbersome, the recommendations state it should only be considered in situations where no other possibility is left. For those patients, the advice is to give 3 suppositories containing thiopental sodium 1g every hour.

The KNMP considers opioids and benzodiazepines to be unsuitable as single drugs for physician-assisted death.

A study describing the implementation of a protocol for euthanatics showed that both pharmacists and general practitioners had a positive attitude towards standardisation of the drugs used in physician-assisted death, and that 59% of the general practitioners actually used a standard package as defined in the protocol.¹³

Apart from these official recommendations, several guides have been published for terminally ill who want to terminate their life,^{26,27} of which Final exit²⁶ is the most renowned. These guides, which have little or no evidence base, mention a vast array of life-ending drugs, from carbon monoxide to tricyclic antidepressants to benzodiazepines. Case descriptions of failing attempts at assisted suicide with the help of Final exit-recipes describe the often traumatizing situations (e.g. putting a plastic bag over the head) for family members.²⁴

Discussion

Compared with the enormous quantity of papers about the ethical, societal, and legal aspects of physician-assisted death, publications discussing the drugs used are scarce; this lack of data has also been noticed by others.^{7,16} Moreover, the quality of the publications we found was quite variable. Both these aspects can be explained by the legal situation in most countries, which preclude the collection of reliable data on practices that are not allowed. That is the reason why many of the reviewed papers come from the Netherlands. As a consequence, the recommendations we reviewed are based on rather scanty, but growing evidence.

However, some of the drugs seem inappropriate even on the anecdotal evidence available: for example, insulin, propofol and tricyclic antidepressants.

The role of opioids in physician-assisted death is far from clarified. Although it is doubtful whether opioids have a life-shortening effect in patients who already use them for symptom management, morphine is the most frequently used life-ending drug in the Netherlands. Apparently, physicians have reasons to use morphine for this purpose (e.g. availability, invisibility, continuity) against the strong discouragement which is part of the recommendations we reviewed.

Conclusions

It has been argued that the ethical discussion has focused too exclusively on the question of the allowability of help in dying, to the neglect of the obligation to perform physician-assisted death, if at all, in a humane way.⁴² This requires that the drug(s) used should certainly be lethal and be able to be given in small quantities, and that death should be mild and the dying process not protracted. Effects such as myoclonus and prolonged breathing abnormalities should be avoided.

Taking into account the fact that in many countries physician-assisted death is practiced, whether that is accepted or not, more research into the technical aspects is needed. However, experience with the recommendations of the Royal Dutch Pharmaceutical Association, which advise the same drugs as those used in the first reported cases of physician-assisted suicide in Oregon, has not shown major problems.

References

1. Quill TE. Death and dignity. A case of individualized decision making. *N Engl J Med* 1991;324:691-4.
2. Anonymous. A piece of my mind; it's over, Debbie. *JAMA* 1988;259:272.
3. Van der Maas PJ, van der Wal G, Haverkate I, et al. Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in the Netherlands, 1990-1995. *N Engl J Med* 1996;335:1699-705.
4. Van der Wal G, van der Maas PJ, Bosma JM, et al. Evaluation of the notification procedure for physician-assisted death in the Netherlands. *N Engl J Med* 1996;335:1706-11.
5. Van der Maas PJ, van Delden JJ, Pijnenborg L, et al. Euthanasia and other medical decisions concerning the end of life. *Lancet* 1991;338:669-74.
6. Emanuel EJ, Fairclough DL, Daniels ER, et al. Euthanasia and physician-assisted suicide: attitudes and experiences of oncology patients, oncologists, and the public. *Lancet* 1996;347:1805-10.
7. Drickamer MA, Lee MA, Ganzini L. Practical issues in physician-assisted suicide. *Ann Intern Med* 1997;126:146-51.
8. Lee MA, Nelson HD, Tilden VP, et al. Legalizing assisted suicide: views of physicians in Oregon. *N Engl J Med* 1996;334:310-5.
9. Van der Wal G, van Eijk JT, Leenen HJ, et al. The use of drugs for euthanasia and assisted suicide in family practice [in Dutch]. *Ned Tijdschr Geneesk* 1992;1299:305.
10. Laane HM. Euthanasia, assisted suicide and AIDS. *AIDS Care* 1995;7:S163-7.
11. Muller MT, Hertogh C, van der Wal G, et al. Medico-technical aspects of euthanasia and assisted suicide in nursing home medicine [in Dutch]. *Vox Hospitii* 1992;163-7.
12. Chin A, Hedberg K, Higginson G, et al. Legalized physician-assisted suicide in Oregon: the first year's experience. *N Engl J Med* 1999;340:577-81.
13. Onwuteaka-Philipsen BD, Muller MT, van der Wal G. Euthanatics: implementation of a protocol to standardise euthanatics among pharmacists and GPs. *Patient Educ Couns* 1997;31:131-7.
14. Statistics Netherlands. The end of life in medical practice (1995, 1990) [in Dutch]. Den Haag: Centraal Bureau voor de Statistiek, 1996.
15. Van der Wal G, van der Maas PJ. Euthanasia and other medical decisions concerning the end of life: practice and notification procedure [in Dutch]. Den Haag: Sdu, 1996.
16. Preston T, Mero R. Observations concerning terminally ill patients who choose suicide. *J Pharm Care Pain Sympt Control* 1996;4:183-92.
17. Stapczynski JS, Haskell RJ. Duration of hypoglycemia and need for intravenous glucose following intentional overdoses of insulin. *Ann Emerg Med* 1984;13:505-11.
18. Cooper A. Attempted suicide using insulin by a non diabetic. *Can J Psych* 1994;29:103-7.
19. Chao T, Lo D, Chui P, et al. The first fatal propofol poisoning in Singapore. *Forensic Sci Int* 1994;66:1-7.
20. Arem R, Zoghbi W. Insulin overdose in eight patients: insulin pharmacokinetics and review of the literature. *Medicine* 1985;64:323-32.

21. Kaminer Y, Robbins DR. Attempted suicide by insulin overdose in insulin-dependent diabetic adolescents. *Pediatrics* 1988;81:526-8.
22. Martin FI, Hansen N, Warne GL. Attempted suicide by insulin overdose in insulin-requiring diabetics. *Med J Aust* 1977;1:58-60.
23. Wetli CV, Davis JH. Fatal hyperkalemia from accidental overdose of potassium chloride. *JAMA* 1978;240:1339.
24. Jamison S. When drugs fail: assisted deaths and not-so-lethal drugs. In: Battin M, Lipman A, editors. *Drug use in assisted suicide and euthanasia*. New York: Haworth Press, 1996:223-45.
25. Admiraal PV. Administration of euthanasia-inducing agents [in Dutch]. *Ned Tijdschr Geneesk* 1995;139:265-8.
26. Humphrey D. Final exit: the practicalities of self-deliverance and assisted suicide for the dying. Eugene (OR): Hemlock Society, 1991.
27. Smith C, Docker C. *Departing drugs. An international guidebook to self-deliverance*. Edinburgh: 1993.
28. Inturissi C, Hanks G. Opioid analgesic therapy. In: Doyle D, Hanks G, MacDonald N, editors. *Oxford textbook of palliative medicine*. 2nd ed. Oxford: Oxford University Press, 1998:166-82.
29. Sumner DJ, Kalk J, Whiting B. Metabolism of barbiturate after overdosage. *BMJ* 1975;1:335.
30. Quill TE, Lo B, Brock DW. Palliative options of last resort: a comparison of voluntarily stopping eating and drinking, terminal sedation, physician-assisted suicide, and voluntary active euthanasia. *JAMA* 1997;278:2099-104.
31. Rousseau P. Terminal sedation in the care of dying patients. *Arch Intern Med* 1996;156:1785-6.
32. Onwuteaka-Philipsen BD, Muller MT, van der Wal G, et al. Active voluntary euthanasia or physician-assisted suicide? *J Am Geriatr Soc* 1997;45:1208-13.
33. Crouch B. Toxicological issues with drugs used to end life. In: Battin M, Lipman A, editors. *Drug use in assisted suicide and euthanasia*. New York: Haworth Press, 1996:211-23.
34. Park GR, Miller E. What changes drug metabolism in critically ill patients – III? Effect of pre-existing disease on the metabolism of midazolam. *Anaesthesia* 1996;51:431-4.
35. Jung D, Prasad PP. Influence of nutritional status on the pharmacokinetics and pharmacodynamics of pentobarbital. *Drug Metab Dispos* 1989;17:365-8.
36. Stavchansky S, Tung IL. Effects of hypothermia on drug absorption. *Pharm Res* 1987;4:248-50.
37. Penfold N, Park G. Effects of organ failure and therapy on drug metabolism. *Curr Opin Anaesth* 1990;3:154-71.
38. Power BM, Hackett LP, Dusci LJ, et al. Antidepressant toxicity and the need for identification and concentration monitoring in overdose. *Clin Pharmacokinet* 1995;29:154-71.
39. Saxena K. Clinical features and management of poisoning due to potassium chloride. *Med Toxicol Adverse Drug Exp* 1989;4:429-43.
40. Koninklijke Nederlandse Maatschappij ter Bevordering der Pharmacie (KNMP). Technical report concerning euthanatics [in Dutch]. Den Haag: KNMP, 1987.
41. Wetenschappelijk Instituut voor Apothekers. *Advices for the application of euthanatics* [in Dutch]. *Medisch Contact* 1998;53:1366-8.
42. Kimsma GK. Clinical ethics in assisting euthanasia: avoiding malpractice in drug application. *J Med Phil* 1992;17:439-43.

6

Use of drugs with a potentially life-shortening effect in Dutch medical practice

Abstract

Purposes. To describe the use of potentially life-shortening drugs at the end of life.

Procedures. Questionnaires were mailed to the physicians attending 6,060 deaths that were identified from death certificates.

Findings. In 29% of all deaths in the Netherlands, and 42% of non-sudden deaths, physicians used drugs while taking into account a potentially life-shortening effect. In 37% of non-sudden deaths these drugs were given without explicitly intending to hasten the patient's death; opioids were used in 86% of these cases. In 5% of non-sudden deaths the drugs were given with the explicit intention of hastening death; in these cases, neuromuscular relaxants were the most frequently used drugs (50%) for euthanasia, barbiturates (91%) for physician-assisted suicide, and opioids (81%) for cases of intentionally hastening death without the patient's explicit request.

Conclusions. Potentially life-shortening drugs are commonly used. The distinction between explicit ending of the patient's life and alleviating pain and symptoms while only taking into account the possible shortening of life is often related to the type of drug and dosage.

Introduction

Medical decisions that may shorten a patient's life are often made in medical practice. Mostly these end-of-life decisions concern the withholding or withdrawal of life-prolonging treatment, or the alleviation of pain and symptoms with opioids or comparable drugs in such doses that the patient's life might be shortened. Decisions to use drugs with the explicit intention of ending the life of a patient who is suffering unbearably and hopelessly, as in euthanasia or physician-assisted suicide, are relatively rare.¹⁻⁴

Whereas the management of pain and symptoms with opioids or comparable drugs while taking into account that the patient's life may be shortened as a result, is a rather widely accepted practice, the use of lethal medications with the explicit intention of hastening death is subject to criminal law all over the world, except for the state of Oregon, USA, where physician-assisted suicide in 1997 became legal for terminally ill patients. Nevertheless, euthanasia and physician-assisted suicide occur in other countries as well.^{2,4,5-10}

To control the use of lethal medications with the explicit intention of hastening death in the Netherlands, official requirements have been developed. In this country, current legislation protects physicians who perform euthanasia or assist in a patient's suicide from criminal prosecution if they comply with a number of criteria for careful practice, which have been formulated by the courts and the medical profession.¹¹ One of the criteria concerns the clinical performance of physician-assisted death. To support physicians in choosing adequate drugs for physician-assisted death, since 1987 guidelines have been available.^{12,13} For euthanasia, these guidelines recommend a barbiturate to induce coma, followed by a neuromuscular relaxant to cause death, and for assisted suicide a high dosage of barbiturate for oral administration.¹³

In 1995/96, we performed a study on the incidence of euthanasia and other medical decisions concerning the end of life in the Netherlands.^{2,14} This paper describes the frequency with which physicians decided to administer drugs while taking into account or intending that this would shorten the patient's life, and the types and dosages of drugs involved.

Methods

Design. All 43,002 deaths reported to Statistics Netherlands from August 1 through November 30, 1995, were divided into 5 strata by two physicians. Deaths were assigned to stratum 0 when a medical decision concerning the end of life could be ruled out (e.g. car accident resulting in sudden death); stratum 4 contained the deaths in which the chance of such a decision was deemed high. A sample was

taken from each stratum: 1/12 from strata 0 and 1, 1/8 from stratum 2, 1/4 from stratum 3, and 1/2 from stratum 4. Deaths from stratum 0 (n=542) were retained in the sample, but no questionnaires were sent to the physicians involved. Physicians responsible for deaths in strata 1 to 4 received a questionnaire containing 24 questions about the case. They were asked whether a decision to withhold or withdraw life-prolonging treatment, or to administer or prescribe potentially life-shortening drugs had preceded death. We distinguished three intentions: taking into account the probability or certainty that death would occur, partly intending to hasten death, and explicitly intending to hasten death (Table 6.1). The decision with the most explicit intention to shorten life was defined as the most important end-of-life decision, while the administration of drugs was considered to be more decisive than the withholding or withdrawal of treatment in case of equal intentions. For the most important medical decision concerning the end of life, questions were asked about the estimated shortening of life and about the decision-making, including the patient's competence and the involvement of the patient, the patient's relatives or other caregivers. If the physician reported to have administered or prescribed drugs, questions were asked about the type of drug, the way of administration, and dosages. A total of 6,060 questionnaires were sent out, of which 4,678 were returned (response rate 77%). Nearly all questionnaires were completed carefully. The results of this study are based on 5,146 death cases.

Definitions. We distinguished cases in which drugs were used with the explicit intention of ending the patient's life from cases where potentially life-shortening drugs were used without such intention. Cases where drugs were used explicitly intending to end the patient's life were classified as euthanasia if the physician administered the drugs to the patient at the patient's explicit request; as

Table 6.1
Questions about the use of drugs with a potentially life-shortening effect (standard questionnaire, death certificate study 1995/1996)

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1. Did you or a colleague take one or more of the following acts (or ensure that one of them was taken), taking into account the probability or certainty that this act would hasten the end of the patient's life: a. withhold treatment? b. withdraw treatment? c. intensify the alleviation of pain and symptoms by using morphine or a comparable drug?
 2. Was hastening the end of life partly the intention of the act indicated in question 1c?
 3. Was death caused by one or more of the following acts, taken by you or a colleague with the explicit intention of hastening the end of life? a. withhold treatment? b. withdraw treatment?
 4. Was death caused by the use of a drug prescribed, supplied, or administered by you or a colleague with the explicit intention of hastening the end of life?
-

physician-assisted suicide if the patient took the drugs him- or herself; and as the ending of life without an explicit request if the physician administered the drugs without a concurrent, explicit request by the patient. In about half of the cases in the last group, the decision was discussed with the patient earlier in the illness or had the patient expressed a wish for hastening death if suffering would become unbearable, in the other cases the patient was incompetent but evidently suffering greatly.² Cases where drugs were used without the explicit intention of hastening death consisted of the alleviation of pain and symptoms with opioids or other drugs while taking into account the probability or certainty that death would be hastened or only partly intending death to be hastened. The alleviation of pain and symptoms with the partial intention of hastening death (the respondent answered question 2 in the affirmative, but answered question 4 negatively, see Table 6.1) refers to situations where the patient's death was not the physician's primary intention, although it was not unwelcome as a secondary effect.

Statistical analysis. In order to calculate representative percentages for all deaths in 1995, a weighting procedure was applied to correct for sampling fractions and nonresponse for each combination of age and sex of the patient, the cause of death and the place of death. Statistical testing of differences between percentages was done with the Fisher's Exact Test. For multivariate analyses we used a logistic regression model. Two-sided P values of less than 0.05 were considered to indicate statistical significance. Percentages of missing data on the returned surveys are mentioned where applicable. We were unable to further explore these missing data because of the strict anonymity of the survey.

Results

Incidence

Preceding 29% of all deaths, and 42% of all non-sudden deaths in the Netherlands, the attending physician decided to use drugs at least taking into account the probability or certainty that these drugs might hasten death. Such drugs were used without the explicit intention of hastening death in 37% of non-sudden deaths and with the explicit intention of hastening death in 5%. Table 6.2 shows that in non-sudden deaths potentially life-shortening drugs were more often used in younger than in older age groups and in patients dying from cancer and congenital or perinatally acquired diseases compared to other causes of death. These were also the groups where drugs were most frequently used with the explicit intention of ending the patient's life. No differences between male and female patients were found.

Table 6.2

Use of potentially life-shortening drugs with or without the explicit intention of ending the patient's life (weighted percentages; raw numbers between brackets*)

	Proportion non-sudden deaths	Non-sudden deaths			Total
		No drugs were used considering a potentially life-shortening effect	Drugs were used		
			Without explicit intention of ending the patient's life†	With explicit intention of ending the patient's life‡	
Patient's age					
0-49 yrs (n=661)	49 (459)	47 (206)	43 (187)	10 (66)	100
50-64 yr (n=652)	65 (505)	47 (194)	43 (223)	10 (88)	100
65-79 yrs (n=1792)	68 (1374)	56 (696)	38 (546)	5 (132)	100
80+ (n=2041)	74 (1641)	63 (996)	35 (585)	2 (60)	100
Patient's sex					
Male (n=2611)	64 (1931)	57 (995)	38 (763)	5 (173)	100
Female (n=2535)	73 (2048)	58 (1097)	37 (778)	5 (173)	100
Cause of death					
Cancer (n=2119)	92 (1990)	44 (841)	47 (893)	9 (256)	100
Cardiovascular disease (n=910)	39 (351)	69 (235)	30 (111)	1 (5)	100
Neurological disease (n=466)	79 (384)	71 (263)	26 (103)	3 (18)	100
Pulmonary disease (n=306)	81 (251)	64 (161)	35 (82)	2 (8)	100
Mental disorder (n=251)	85 (225)	61 (138)	38 (84)	1 (3)	100
Congenital or perinatally acquired disease (n=251)	82 (211)	53 (112)	35 (74)	12 (25)	100
Disease of digestive tract (n=162)	81 (133)	64 (82)	34 (45)	2 (6)	100
Other diseases (n=681)	59 (434)	63 (260)	33 (149)	3 (25)	100
Physician's specialty§					
General practitioner (n=2493)	60 (1838)	57 (923)	35 (671)	8 (244)	100
Clinical specialist (n=1560)	73 (1222)	61 (677)	35 (456)	4 (89)	100
Nursing-home physician (n=929)	88 (845)	55 (454)	44 (379)	1 (12)	100
All deaths 1995 (N=5146)	69 (3979)	58 (2092)	37 (1541)	5 (346)	100

* Due to the weighting procedure, percentages cannot be directly calculated from the raw numbers.

† Alleviation of pain and symptoms by using morphine or a comparable drug, taking into account the probability or certainty that death would occur or partly with the intention of ending the patient's life.

‡ Euthanasia, physician-assisted suicide, or ending of life without the patient's explicit request.

§ From the other 164 physicians, 158 had another speciality, and from 6 physicians we had no information about their speciality.

General practitioners and clinical specialists more often administered drugs with the explicit intention of hastening death, whereas nursing-home physicians relatively frequently used drugs without the explicit intention of hastening death. In a multivariate logistic regression analysis that adjusted for the patient's age and sex and the cause of death, the association between the physician's specialty and the intention remained significant in non-sudden deaths: the Odds ratio was 5.3 (95% CI for OR: 2.6-10.8) for general practitioners compared to nursing home physicians, and 2.9 (95% CI: 1.4-6.1) for clinical specialists compared to nursing home physicians.

Drugs used

Of the cases in which death was preceded by the use of drugs with a potentially life-shortening effect, 66% involved only one drug and in 23% two drugs were used (in 11% the number and type of drugs were not specified). Table 6.3 presents the types of drugs that were used.

In 86% of cases where drugs were used without the explicit intention of hastening death, opioids were given (almost exclusively morphine): in 74% of these cases opioids were the only type of drugs, in 7% they were used in combination with benzodiazepines. Neuromuscular relaxants and barbiturates were rarely used in these cases. There was no significant difference between the three medical specialties in the types of drugs used without the explicit intention of hastening death (Fisher's Exact Test).

When drugs were given with the explicit intention to hasten death, neuromuscular relaxants were administered in 40%, always preceded by another drug (to induce coma): a barbiturate in 25%, a benzodiazepine in 12%, an opioid in 3% and another drug in 1%. In 13% barbiturates were given, sometimes in combination with opioids. In 44% opioids were used, single (33%) or in combination with benzodiazepines (6%) or another type of drug (4%) (neuromuscular relaxants or barbiturates excluded).

In cases of euthanasia, a neuromuscular relaxant was the drug used most frequently. The neuromuscular relaxant was pancuronium in 27% of euthanasia cases, alcuronium in 10%, vecuronium in 4%, and a non-specified curare derivative in 7%. The medical specialties used different types of drugs for euthanasia: general practitioners used neuromuscular relaxants in 60% and opioids in 28%, whereas clinical specialists used these drugs in 25% and 58% of euthanasia cases, respectively. In cases of physician-assisted suicide, barbiturates were the most frequently used drugs (91%). In cases of ending life without the patient's explicit request opioids were the drugs used most frequently (81%). General practitioners almost exclusively (98%) used opioids in these cases (single or in combination with

Table 6.3

Classification of drugs according to the intention with which they were used in end-of-life decision-making (weighted percentages; raw numbers between brackets*)

	Drugs were used					
	Without the explicit intention of ending the patient's life		With the explicit intention of ending the patient's life			
			Euthanasia		Physician-assisted suicide	
Neuromuscular relaxants (any combination)	0.1	(9)	50	(160)	3	(1)
+ barbiturates	0	(2)	30	(106)	3	(1†)
+ other	0.1	(7)	20	(54)	-	
Barbiturates (any combination, but no neuromuscular relaxants)	0.2	(7)	11	(29)	91	(23)
Barbiturates only	0	(1)	7	(16)	54	(13)
+ opioids	0.2	(5)	4	(10)	28	(8)
+ other	0.1	(1)	1	(3)	10	(2)
Opioids (any combination, but no neuromuscular relaxants or barbiturates)	86	(1298)	37	(61)	-	
Opioids only	74	(1109)	27	(43)	-	
+ benzodiazepines	7	(118)	6	(11)	-	
+ other‡	4	(71)	4	(7)	-	
Other§	1	(23)	0.3	(1)	-	
Not specified	13	(204)	2	(6)	6	(1)
Total	100	(1541)	100	(257)	100	(25)

* Due to the weighting procedure, percentages cannot be directly calculated from the raw numbers.

† One respondent mentioned having used a barbiturate (thiopental) with a neuromuscular relaxant (vecuronium), while both drugs were said to have been taken orally by the patient.

another type of drug, but no neuromuscular relaxants or barbiturates), whereas clinical specialists mentioned having used opioids in 67% and neuromuscular relaxants in 32% of the cases.

Way of administration

When drugs were administered without the explicit intention of ending the patient's life, at least one of the drugs was administered parenterally in 64% of cases, and drugs were administered exclusively orally or rectally in 20%

Table 6.3 (continued)

	Drugs were used					
	With the explicit intention of ending the patient's life				All cases in which drugs were used 1995	
	Without the patient's explicit request		Total			
Neuromuscular relaxants (any combination)	18	(12)	40	(173)	5	(182)
+ barbiturates	11	(3)	25	(110)	3	(112)
+ other	7	(9)	16	(63)	2	(70)
Barbiturates (any combination, but no neuromuscular relaxants)	1	(2)	13	(54)	2	(61)
Barbiturates only	-		8	(29)	1	(30)
+ opioids	1	(2)	4	(20)	1	(25)
+ other	-		1	(5)	0	(6)
Opioids (any combination, but no neuromuscular relaxants or barbiturates)	81	(49)	44	(110)	81	(1408)
Opioids only	64	(35)	33	(78)	70	(1187)
+ benzodiazepines	9	(10)	6	(21)	7	(139)
+ other‡	8	(4)	4	(11)	4	(82)
Other§	0.3	(1)	0.4	(2)	1	(25)
Not specified	-		2	(7)	11	(211)
Total	100	(64)	100	(346)	100	(1887)

‡ Of the other type of drugs that were given together with an opioid without the explicit intention of ending the patient's life, levomepromazine, atropine, oxygen and haloperidol were the most important. In cases of intentionally ending the patient's life levomepromazine also was an important drug that was given in combination with an opioid; insulin and potassium chloride were both mentioned, too.

§ This category mainly comprised benzodiazepines; two respondents mentioned having administered potassium chloride after a benzodiazepine, both cases of intentionally ending the patient's life.

(information on the way of administration was insufficient for 16% of the cases). Medical specialties differed in their method of administration: general practitioners administered drugs orally or rectally in 40% and parenterally in 38% (data were missing in 22%). For clinical specialists these percentages were 5% and 82%, respectively (data missing in 13%), for nursing-home physicians 14% and 74%, respectively (data missing in 12%). In multivariate logistic regression analysis, corrected for the patient's age, sex, cause of death and competency, the chance of the drug(s) being administered parenterally was significantly related to physician's specialty ($P < 0.001$).

In physician-assisted suicide drugs were mainly taken orally (86%); in another 5% the drugs were administered rectally, and from 9% information about the method of administration was missing. In euthanasia cases and in cases of ending of life without the patient's explicit request, parenteral administration was the option most commonly chosen, namely in 88% and 82% of the cases, respectively.

Table 6.4
Dosages of the most important potentially life-shortening drugs (unweighted results)
(patients younger than 20 years excluded)

	Number of cases for which information about both way of administration and dosage was available	Drug given with the explicit intention of ending the patient's life	Way of administration	Median dosage (mgs)	Range* (mgs)
Cumulative 24 hrs dose before death of					
Morphine†	801	No	Orally/parenterally	30‡	5-240‡
Morphine†	51	Yes	Orally/parenterally	60‡	10-540‡
Nicomorphine†	23	No	Orally/parenterally	20‡	5-120‡
One single or considerably increased dosage of					
Morphine†	103	No	Orally/parenterally	15‡	1-108‡
Morphine†	17	Yes	Orally/parenterally	40‡	10-100‡
Pancuronium§	53	Yes	Parenterally	18	3-34
Vecuronium§	11	Yes	Parenterally	16	10-100
Alcuronium§	9	Yes	Parenterally	45	20-50
Thiopental¶¶	11	Yes	Parenterally	1000	4-4000
Pentobarbital¶¶	6	Yes	Orally	9000	6000-9000
Secobarbital¶¶	5	Yes	Orally/rectally	6000	1000-9000

* 2.5th and 97.5th percentiles.

† Given as the only potentially life-shortening drug.

‡ Dosages of opioids were calculated in parenteral equivalents; in order to do so oral or rectal dosages were halved.¹⁸

§ Given as second drug in any combination.

¶¶ Given as the only or the second drug, but not in combination with neuromuscular relaxants.

Table 6.5
Time interval* between administration of the only or last drug and death (unweighted results)

	Median (minutes)	Range† (minutes)	Number of cases for which data were available
The (last) drug was a(n)			
Neuromuscular relaxant (any combination)	5	0 - 33	107
Barbiturate (any combination, but no neuromuscular relaxants)	15	2 - 600	33
Opioid (not in combination with any other type of drugs)	120	1 - 2060	239
Benzodiazepine (in combination with an opioid)	120	0 - 2880	27
Drugs were used			
Without the explicit intention of ending the patient's life	135	0 - 2039	258
With the explicit intention of ending the patient's life	10	0 - 423	182

* The time interval was only asked in cases in which the drug was administered in a single dose, or in which the dosage had been increased.

† 2.5th and 97.5th percentiles. In some cases the time interval between administration of the (last) drug and death was 0; those cases were included in the analysis.

Dosages

Twenty-one percent of respondents who specified the first type of drug, and 39% of those who specified a second drug, did not provide information on the dosages of the drugs given in the last 24 hours before death. For the other cases, we explored both cumulative doses in the last 24 hours before death, and, in cases where the drug had been given in one single dose or had been considerably increased shortly before death, the final dosages for the most frequently used drugs (Table 6.4). Cases of patients under the age of 20 were excluded in order to compare adult dosages only.

When morphine was the only drug with a potentially life-shortening effect used, the median cumulative 24 hours dose was 30 mgs (5-240 mgs) if given without the explicit intention of hastening death, and 60 mgs (range: 10-540 mgs) in cases where the explicit intention was to hasten death. When morphine was given in a single or in a considerably increased dosage, the median dosage was also higher in cases where hastening death was explicitly intended than in cases without such explicit intention.

Single or final doses of neuromuscular relaxants varied between 3-34 mgs pancuronium, 10-100 mgs vecuronium, or 20-50 mgs alcuronium. If pentobarbital was the only or the last drug given (not in combination with a neuromuscular relaxant), the final dose was 6000-9000 mgs. The dose of thiopental showed a much wider range (4-4000 mgs).

Time interval between administration of the (last) drug and death

Table 6.5 shows that the median time-interval between administration of the last drug and death was 10 minutes when the explicit intention was to hasten death (range: 0-423 minutes, or 0-7 hours), and 135 minutes when this was not the case (range: 0-2039 minutes, or 0-14 days). The time-interval was shortest when neuromuscular relaxants were used (0-33 minutes). When barbiturates (single or in combination with another type of drug, but no neuromuscular relaxants) were used, time until death could be up to 10 hours. For opioids (single or in combination with another type of drug, but no neuromuscular relaxants or barbiturates) intervals ranged from 0 minutes to 2 days.

Discussion

Our study shows that 29% of all deaths in the Netherlands were preceded by a decision to use drugs while at least taking into account a potentially life-shortening effect; 42% of all non-sudden deaths were preceded by such decision. Whereas the use of drugs that may hasten the end of the patient's life is frequently being discussed in the medical literature, empirical data on the frequency and characteristics of the use of potentially life-shortening drugs are scarce. Studies have mainly concentrated on the attitudes of physicians towards euthanasia or physician assistance in suicide.²⁻⁴⁻¹⁰ In a previous publication on end-of-life decision making in the Netherlands, we showed that a decision to alleviate pain and symptoms with opioids in such doses that the patient's life might have been shortened had been the most important end-of-life decision in 19% of all deaths, whereas drugs were administered with the explicit intention of ending the patient's life in 3.4%.³ In Australia, comparable figures were 31% and 5.3%, respectively, and in Flanders, Belgium, 18.5% en 4.4%, respectively.^{3,4} Thus, potentially life-shortening drugs are more commonly used, mostly to alleviate pain and symptoms, but in fewer cases also to end the patient's life.

In this paper, we aimed to give a more detailed description of the use of potentially life-shortening drugs in Dutch medical practice. By distinguishing

whether or not potentially life-shortening drugs were given with the explicit intention to hasten death, we tried to provide a more nuanced insight into the different practices that are involved. The intention with which the drugs were applied was to a certain extent reflected in the (combination of) drug(s) that were used and their dosages. When the physician intended to alleviate pain and symptoms without the explicit intention to hasten the patient's death, opioids were the drugs predominantly used. In cases where there was an explicit intention to hasten death, neuromuscular relaxants and barbiturates were frequently used. In particular, neuromuscular relaxants were the most frequently used drugs in euthanasia, and barbiturates in cases of physician-assisted suicide. In cases of intentionally ending a patient's life without the patient's explicit request, opioids were used most frequently.

We also found a certain degree of overlap in types of drugs between cases in which the explicit intention was to hasten death, and cases without such an explicit intention. This overlap particularly involves opioids. Although the median dosage was larger and the median time interval between the administration and death was somewhat shorter when opioids were given with the explicit intention of hastening death, the ranges of the dosages and of the time-intervals showed a considerable degree of overlap between the different types of cases. Differences in the intention with which potentially life-shortening drugs are administered are thus not always reflected in different clinical practices. Obviously, our data did not enable us to determine whether any specific dosage of morphine actually hastened the patient's death, but many clinicians may overestimate the life-shortening effect of opioids. As a consequence, in many cases where the physicians in our study took into account the probability or certainty that death would occur, in fact the patient's life may not have been shortened at all.

The use of neuromuscular relaxants in euthanasia and of barbiturates in physician-assisted suicide concurs with the guidelines as issued by the Royal Dutch Association for the Advancement of Pharmacy. In these guidelines, the use of morphine and other opioids for euthanasia or physician-assisted suicide is discouraged.^{13,15} The lethal effects of opioids are uncertain, especially in patients taking opioids on a chronic basis for treatment of pain: they develop tolerance to the respiratory depression, and, therefore, to the lethal effects of opioids.¹⁶ Nevertheless, opioids (single or together with another type of drug, but no neuromuscular relaxants or barbiturates) were used in 37% of the euthanasia cases in our study.

We found a difference in the method of administration of drugs between the medical specialties: compared to clinical specialists and nursing-home physicians, general practitioners administered drugs orally or rectally more frequently. Neither patients' nor decision-making characteristics could explain this difference in administration method. Practical circumstances may at least partially explain

the difference: parenteral administration, either by intravenous injection or by drip, may be less commonly applied at home. Moreover, clinical symptoms, the patient's (physical) condition and the preferences of physician or patient may play a role as well.¹⁷

Our article is limited to drugs that the physician used while at least taking into account the probability or certainty that the patient's death may be hastened. It does not provide detailed information about all kinds of drug therapy that patients with a terminal disease receive. The use of opioids and other drugs for analgesic purposes only is beyond the focus of our study. Moreover, the use of lethal drugs, such as neuromuscular relaxants, does not exclude the use of adequate analgesia.

It is remarkable that so little representative information has been published about the use and clinical aspects of potentially life-shortening drugs, such as dosages, methods of administration, time intervals between administration and death, and complications. Due to an increasing demand for high quality medical support of terminally ill people, end-of-life care has become a more prominent issue in medical professional training and major investments to improve palliative care are being made, in the Netherlands as well as in other countries. In order to determine whether high quality end-of-life care might reduce the frequency of euthanasia requests or the use of potentially life-shortening drugs, much more high quality research of clinical, epidemiological and ethical issues in this area is needed.

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References

1. Maas PJ van der, Delden JJM van, Pijnenborg L, Looman CWN. Euthanasia and other medical decisions concerning the end of life. *Lancet* 1991;338:669-74.
2. Maas PJ van der, Wal G van der, Haverkate I, et al. Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in the Netherlands. *N Engl J Med* 1996;335:1699-1705.
3. Deliens L, Mortier F, Bilsen J, et al. End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey. *Lancet* 2000;356:1806-11.
4. Kuhse H, Singer P, Baume P, Clark M, Rickard M. End-of-life decisions in Australian medical practice. *Medical Journal of Australia* 1997;166:191-6.
5. Stevens CA, Hassan R. Management of death, dying and euthanasia: attitudes and practices of medical practitioners in South Australia. *J Med Ethics* 1994;20:41-6.
6. Ward BJ, Tate PA. Attitudes among NHS doctors to requests for euthanasia. *BMJ* 1994;308:1332-4.
7. Black AL, Wallace JI, Starks HE, Pearlman RA. Physician-assisted suicide and euthanasia in Washington State: patient requests and physician responses. *JAMA* 1996;275:919-25.

8. Emanuel EJ, Fairclough DL, Daniels ER, Clarridge BR. Euthanasia and physician-assisted suicide: attitudes and experiences of oncology patients, oncologists and the public. *Lancet* 1996;347:1805-10.
9. Folker AP, Holtug N, Jensen AB, Kappel K, Nielsen JK, Norup M. Experiences and attitudes towards end-of-life decisions amongst Danish physicians. *Bioethics* 1996;10:233-49.
10. Lee MA, Nelson HD, Tilden VP, Ganzini L, Schmidt TA, Tolle SW. Legalizing assisted suicide: views of physicians in Oregon. *N Engl J Med* 1996;334:310-5.
11. Gevers S. Euthanasia: law and practice in the Netherlands. *Br Med Bull* 1996;52:326-33.
12. Royal Dutch Association for the Advancement of Pharmacy (KNMP). [Use and preparation of euthanazing drugs] [in Dutch] *Toepassing en bereiding van euthanatica*. 's-Gravenhage: KNMP, 1994.
13. Royal Dutch Association for the Advancement of Pharmacy (KNMP). [Use and preparation of euthanazing drugs] [in Dutch] *Toepassing en bereiding van euthanatica*. 's-Gravenhage: KNMP, 1998.
14. Wal G van der, Maas PJ van der, Bosma JM, et al. Evaluation of the notification procedure for physician-assisted death in the Netherlands. *N Engl J Med* 1996;335:1706-11.
15. Admiraal PV. [Administration of euthanasia-inducing agents] [in Dutch] *Toepassing van euthanatica*. *Ned Tijdschr Geneesk* 1995;139:265-8.
16. Winger G, Hofmann FG, Woods JH. A handbook on drug and alcohol abuse. The biomedical aspects. New York/Oxford: Oxford University Press, 1992.
17. Onwuteaka-Philipsen BD, Muller MT, Wal G van der, van Eijk JTM, Ribbe MW. Active voluntary euthanasia or physician-assisted suicide? *J Am Geriatr Soc* 1997;45:1208-13.
18. Doyle D, Hanks GWC, MacDonald N. *Oxford Textbook of Palliative Medicine*. Oxford/New York/Tokyo: Oxford University Press, 1998.

7

**Giving opioids with a
potentially life-shortening
effect: experiences and
perceptions of Dutch
physicians**

Abstract

In the care of patients with a terminal disease, physicians sometimes prescribe opioids in dosages that, in their view, could shorten life even if unintentionally. Empirical information on the experiences and perceptions of such actions is lacking. In a nationwide survey with written questionnaires and face-to-face interviews, we investigated the frequency, intentions, and other circumstances of such decisions made by Dutch physicians.

In 17% of the deaths, physicians had given dosages of opioids they regarded as possibly life-shortening. Physicians estimated the amount of time by which life had been shortened as less than 24 hours in the majority of cases. In most cases, the dosages of opioids used were less than 100 mg in the last 24 hours before the patient's death.

We conclude that physicians often take a life-shortening effect of opioids into account without explicitly intending it. Physicians may attribute stronger lethal effects to opioids than is warranted.

Introduction

Palliative care for patients in the terminal stage of their disease often involves giving opioids in dosages that physicians, patients and family members may rightly or wrongly associate with shortening life. The rule or doctrine of the double effect states that life-shortening by opioids is permissible if foreseen but unintended.¹ The double effect rule has recently been subject to renewed debate.¹⁻⁵ However, in an extensive literature search we found only one publication reporting empirical data.⁶

This paper presents data about situations where physicians thought that the use of opioids had possibly hastened the death of their patient from a nationwide Dutch study on medical decisions concerning the end of life, that was conducted in 1995/1996.^{7,8} We focus on frequencies, intentions and dosages.

Methods

The study consisted of two main parts: a death-certificate study to provide reliable quantitative information, and an interview study to provide more in-depth case-related information.

1. Death-certificate study 1995/1996

Questionnaires were sent to the physicians who had attended to the deaths in a stratified random sample that was drawn from all 43,000 deaths occurring in the Netherlands from August 1 through December 1, 1995. For this purpose all cause-of-death forms were assigned on clinical grounds to one of five strata with an increasing probability that a medical decision concerning the end of life could have been made. A procedure was devised to ensure that both the physician and the deceased person would remain completely anonymous. Of the 6,060 questionnaires mailed, 77% were returned.

The questionnaire contained 24 questions about medical decisions concerning the end of life, patients' and decision-making characteristics, and drug dosages. Three questions concerned opioids and their (presumed) life-shortening effect (see Table 7.1).

2. Interview study

We interviewed a stratified random sample of 405 physicians, which included 124 general practitioners, 74 nursing-home physicians, and 207 physicians in five specialties (cardiology, surgery, internal medicine, pulmonology, and neurology). Such physicians attend 87% of all deaths in the Netherlands occurring in hospitals, and almost all deaths occurring elsewhere. In total, some 559 physicians were

Table 7.1
Relevant questions asked in the death-certificate study 1995/1996

-
4. Did you or a colleague take one or more of the following acts (or ensure that one of them was taken), taking into account the probability or certainty that this act would hasten the end of the patient's life:
 - 4a. withholding of treatment*?
 - 4b. withdrawing of treatment*?
 - 4c. intensifying the alleviation of pain and/or other symptoms using morphine or a comparable drug?

* In this study, 'treatment' includes tube feeding.

5. Was hastening the end of life partly the intention of the action indicated in 4c?
-

7. Was death caused by the use of a drug* prescribed, supplied or administered by you or a colleague with the explicit intention of hastening the end of life (or of enabling the patient to end his or her own life)?

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

sampled. Eighty-three did not meet the criteria for selection, and 21 were ill or could not be located; 50 other physicians (11% of those who met the selection criteria) refused to participate.

The interviews were conducted from November 1995 through February 1996 by about 30 experienced physicians who were trained intensively for this purpose. Apart from questions about opinions and attitudes, detailed questions were asked about the most recent case in which the physician had made any medical decision that he or she thought could have hastened the patient's death.

For this article, we selected cases in which physicians reported having given opioids in dosages that might, in their view, have shortened the patient's life. We excluded cases in which death had been the consequence of either withholding or withdrawing a treatment or in which opioids were given in combination with certainly lethal drugs, such as neuromuscular relaxants. Dosages of opioids were converted into milligrams of oral morphine using an equianalgesic table.⁹

Statistics. To extrapolate the findings to all deaths in the Netherlands, we calculated weights based on the stratification procedures. Interview data were corrected for the 13% of in-hospital deaths that were attended by clinicians from other specialties than the five sampled. Univariate and multivariate logistic regression analyses were performed to calculate Odds Ratios (OR) and their 95% confidence intervals (95% CI). P-values less than 0.05 were considered to indicate statistical significance.

Results

The death-certificate study showed that preceding 17% of all deaths, physicians had given dosages of opioids which they considered to be (possibly) life-shortening. Physicians only took into account the possibility of shortening life in 13%; life-shortening was partly intended in 3%, and explicitly in 1% of all deaths.

Table 7.2 shows that, whatever the intention, decisions to give opioids which in the perception of the physician possibly hastened the patient's death concerned cancer patients in more than half of the cases. Multivariate logistic regression analysis relating the physician's intention to the patient's age and diagnosis, and to the physician's specialty, showed no statistically significant relationship between intention and diagnosis ($p=0.20$) or age ($p=0.99$). However, an explicit intention was significantly related to the physician's specialty: compared to clinical specialists, nursing-home physicians administered opioids less frequently with the explicit intention of shortening life (43% and 10%, respectively) (OR 0.24; 95% CI, 0.10-0.57).

Table 7.2 also shows that discussion of the decision with colleagues, family and nursing staff occurred most often in cases where death was explicitly intended.

The decision to use opioids in a possibly life-shortening dosage had been discussed with the patient in 45% of all cases, and in 78% if life-shortening was explicitly intended. If life-shortening was partly intended, discussion had taken place with 54% of the patients, and if life-shortening had only been taken into account with 40%.

The lower part of the table shows that of the patients with whom starting or increasing opioids had not been discussed, 18% were fully competent. This proportion was 20% if the physician had only taken into account the shortening of life, and 4% if life-shortening had been explicitly intended. The most frequently mentioned reasons for not discussing the decision with the patient were that the patient was unconscious (35%), or had dementia (28%), or that the physician thought that the decision was clearly in the patient's best interests (22%). The latter reason was mentioned as the sole reason in 7% of all cases in which the decision had not been discussed with the patient.

Data about the amount of time by which physicians estimated that life had been shortened are not in the table. Physicians estimated that the shortening of life had been 'probably none' in 48% of all cases (but almost never if life-shortening had been their explicit intention), less than 24 hours in 72% of all cases, and less than 1 week in 94%.

Table 7.2

Giving opioids with a perceived possible effect of shortening life, according to the physician's intention. Death certificate study 1995/1996. Weighted percentages.

	Shortening life			Total (n=1,028)	p-value
	only taken into account (n=765)	partly intended (n=169)	explicitly intended (n=94)		
Diagnosis					<0.001
Cancer	52	64	71	55	
Circulatory disease	12	15	3	11	
Respiratory disease	8	4	6	7	
Neurological disease	8	6	7	7	
Infections (a.o. AIDS)	1	3	-	1	
Other	20	8	13	18	
Age of patient, y					0.159
20-49	6	8	9	7	
50-64	15	21	22	16	
65-79	38	37	38	38	
≥80	41	34	32	39	
Discussed with*					
One or more colleagues	34	36	59	36	<0.001
Nursing staff	32	35	54	35	<0.001
Family	54	66	74	57	<0.001
Other	2	3	-	2	0.38
No one	20	15	6	19	0.003
Discussed with patient†					<0.001
Shortly before giving opioids	18	21	30	20	
Some time before	21	33	48	25	
No	60	46	22	55	
Decision not discussed with the patient	(n=427)	(n=71)	(n=20)	(n=518)	
Patient was competent at the time of giving opioids					0.72
Yes	20	7	4	18	
Not fully	19	20	22	20	
No	61	72	72	63	
Reason for not discussing decision with patient*					
Patient unconscious	31	58	50	35	<0.001
Dementia	29	17	33	28	0.08
Clearly the best for patient	22	19	33	22	0.44
Would do more harm than good	7	7	6	7	0.98
Mental disorder	3	4	11	4	0.19
Mentally handicapped	1	-	-	0	0.82
Other reasons	23	11	11	21	0.04

* More than one answer could be given.

† Data about discussion with the patient were missing in 38 cases (4%).

Univariate logistic regression showed that an explicit intention involved an estimated shortening of life by more than 1 day more often than cases in which life-shortening had only been taken into account (OR 6.0; 95%CI 3.7-9.8).

In 95% of the cases, opioids were the only drug given; in another 2%, benzodiazepines were the other drug. In the remaining 3%, various secondary drugs were used. Opioid dosages in the last 24 hours before the patient's death varied between 0.83 and 8,000 mg as an equivalent of oral morphine (24% missing data on dosages or method of administration; dosages not convertible into oral morphine in 1%).

Table 7.3 shows that the reported dosages of opioids were under 100 mg in 68%, under 200 mg in 89%, and 200 mg or more in 11%. When the dosage was 50 mg or less, shortening life had only been taken into account in 86%, whereas it had been the explicit intention in 2%; when the dosage had been over 500 mg, these proportions were 43% and 33%, respectively.

For the lowest dosages (50 mg or less), physicians estimated that the life-shortening had been 'probably none' or less than 24 hours in 83%, and between 1 and 7 days in 13%. When the dosage was over 500 mg, these proportions were 9% and 73%, respectively. A univariate logistic regression analysis with the dosage as independent variable confirmed that an estimated life-shortening by more than 1 day was more likely when dosages of over 500 mg were given, compared to dosages of 50 mg or less (OR 20.3; 95% CI: 6.6-62.1).

Table 7.3
Dosages of opioids given in the last 24 hrs preceding the patient's death (calculated as mg of oral morphine*), according to the physician's intention and the estimated shortening of life. Death-certificate study 1995/1996. Weighted percentages.

Dosage †	N (%)	Intention			Estimated shortening of life			
		only taken into account	partial intention	explicit intention	probably none	<24 hours	1-7 days	>7 days
0-50	306 (39)	86	12	2	62	21	13	4
51-100	252 (29)	79	14	7	43	32	22	4
101-200	174 (21)	66	24	10	39	27	27	7
201-500	70 (8)	60	21	19	24	31	34	10
>501	24 (3)	43	24	33	9	9	73	9

* Parenteral opioids are considered twice as strong as oral opioids.²¹ To calculate equivalent dosages from other opioids to morphine, an equianalgesic table has been used.¹⁰

† Data on dosages or method of administration missing for 196 cases (24%); they could not be calculated as equivalent of morphine in 6 cases (1%).

Table 7.4

Other aspects of giving opioids with the possible effect of shortening life. Interview study 1995/1996. Weighted percentages.

	Only taken into account (n=117)	Partly intended (n=130)	Explicitly intended (n=73)	Total (n=320)
Patient treated with opioids before giving opioids in a possibly life-shortening dosage	82	89	73	80
Physician would act in a similar way with a similar patient	95	93	92	93
Action improved quality of dying process				
Considerably	68	63	64	67
Somewhat	28	31	27	28
Not	4	6	8	5

The interview study provided information about previous opioid use and about the physicians' motives and attitudes. Table 7.4 shows that of the patients who had received opioid dosages that possibly shortened their lives, 80% had been using opioids in advance. Of the 20% opioid-naïve patients, 42% received 50 mg of opioids or less in the 24 hours preceding death, 24% received 51-100 mg, 30% 101-200 mg, and 4% 201-500 mg (not shown in table).

In response to the question what they meant by 'partly intending to hasten the end of life', 15% of the physicians indicated that the intention to hasten death had been equally important as any other intentions, usually the alleviation of pain. In 48%, life-shortening had been a less important, secondary intention. In the remaining 37% of cases, physicians indicated that life-shortening was rather hoped for than intended, or, on second thoughts, not intended at all. The majority of the physicians said that they would act in a similar way with a similar patient in similar circumstances (93%).

Discussion

Dutch physicians gave opioids thinking that this could hasten death in about one sixth of all deaths. Comparable figures were found in the 1990 Rimmelinck study and in a recent Belgian study.^{10,11} In approximately one fifth of the cases, hastening death was partially or explicitly intended, which practice does not conform to the rule of double effect. In an American study of hospitalised pancreatic cancer patients, this percentage was considerably higher: out of 118 comatose patients, 54

(46%) were given narcotics (three of them in combination with major sedatives) in the last 4 hours of their lives, which, according to the authors, has a 'recognised life shortening potential'.⁶

The diagnoses of patients receiving opioids with a possible life-shortening effect differ from those in euthanasia: 55% had cancer, compared with 80% in cases of euthanasia.⁷

An important question is whether physicians are right in attributing a life-shortening effect to the opioids they gave. Opioids can be taken in large dosages for long periods,^{10,12} and it is unclear whether an increase in opioid dosage really hastens death (and if so, how strong an increase). The physicians in our study seemed to be aware of this, since the estimated life-shortening (none or less than 1 day in 72% of cases) was relatively small. In addition, any life-shortening effect of opioids is more likely to be overestimated than underestimated, because physicians are inaccurate in predicting the survival of terminally ill patients, with a tendency to overestimate this.^{15,16}

The reported opioid dosages generally were not high (less than 100 mg for 70% of the patients in the death-certificate study), especially considering that the majority of the patients were already using opioids. This could be indicative of physicians overrating the lethal effect of opioids and lacking knowledge about opioids, which needs to be addressed in their professional education.¹⁷⁻²⁰

The relationship between the physician's experience with prescribing opioids and his or her assessment of the potentially lethal effect of opioids is unclear. Do well-educated physicians or physicians with extensive experience with prescribing opioids less frequently think that an increased dosage of opioids is lethal than less educated and less experienced physicians? Surprisingly, data from Flanders point in the opposite direction: palliative care physicians more often increased opioid dosages supposing that this might shorten the patient's life than other physicians did.¹¹

The more explicit the intention to shorten life, the more likely it was that the physician had discussed the decision with the patient. Occasionally, however, an explicit intention was not discussed with a competent patient. A few physicians mentioned that they felt this was 'clearly in the patient's best interests' as the sole reason for not discussing their decision. Decisions to give opioids with an alleged possible life-shortening effect often involved incompetent patients. Discussion with colleagues occurred in less than half of the cases, even if life-shortening was explicitly intended. This shows that decision-making in this area should be improved, both in order to prevent the unjustified attribution of any lethal effect to opioids, and to increase transparency for the patient and others involved.

Our data indicate a number of additional shortcomings of the double effect rule. First, physicians' intentions are more differentiated than 'intended' or

'unintended' for which the double effect rule allows. There are at least the three categories of intention that we distinguished.

Second, the ethical focus has been almost exclusively on allowability, neglecting the quality of 'double effect' actions. As a consequence, questions such as whether physicians should discuss possible life-shortening effects (if any) with patients and families, and whether living wills or advance directives are of significance to actions with a double effect remain unanswered. In addition, safeguards which are needed to prevent both abuse and unjustified attributions of lethality are not addressed by the double effect rule.

Third, in addition to the physicians' intentions, their motives for giving possibly or presumably lethal dosages of opioids (e.g., unbearable suffering, respect for autonomy) are important aspects, that are not accounted for in the double effect literature.

The most important problem with the double effect rule, however, is over-estimation of the lethal effects of opioids. Various authors have pointed out that intention is a vague and malleable concept. Our study indicates that this may be as true for prediction.^{1,3}

A limitation of our study is that the data were derived retrospectively from the self-reports by physicians. Moreover, there were 24% missing data on dosages. It is unclear whether this has biased our results, but if so, it is likely that physicians tend to forget the lower dosages; on the other hand, we cannot exclude the possibility that some physicians selectively forget about higher dosages.

It is unclear to what extent the prevalence and circumstances of these decisions are dependent on cultural, religious and legal circumstances. In countries where termination of a human life is forbidden under all circumstances, physicians might be inclined to increase dosages of opioids, taking into account or even intending to shorten life. However, the data from Flanders, Belgium, showed similar percentages as the Dutch studies.¹¹ It would also be important to relate the decision-making to national regulations concerning the prescription of opioids, and to the views and attitudes of physicians and lay people with regard to these drugs.

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References

1. Quill TE, Dresser R, Brock DW. The rule of double effect - a critique of its role in end-of-life decision making. *N Engl J Med* 1997;337(24):1768-71.
2. Cavanaugh TA. The ethics of death-hastening or death-causing palliative analgesic administration to the terminally ill. *J Pain Symptom Manage* 1996;12:248-54.

3. Sulmasy DP. The use and abuse of the principle of double effect. *Clin Pulm Med* 1996;3:86-90.
4. Marquis DB. Four versions of double effect. *J Med Phil* 1991;16:515-44.
5. Gillon R. Foreseeing is not necessarily the same as intending. *BMJ* 1999;318:1431-2.
6. Brown NK, Thompson DJ, Prentice RL. Nontreatment and aggressive narcotic therapy among hospitalized pancreatic cancer patients. *J Am Geriatr Soc* 1998;46:839-48.
7. Van der Maas PJ, van der Wal G, Haverkate I, et al. Euthanasia, physician-assisted suicide, and other medical decisions concerning the end of life in the Netherlands, 1990-1995. *N Engl J Med* 1996;335:1699-705.
8. Van der Wal G, van der Maas PJ, Bosma J, et al. Evaluation of the notification procedure for physician-assisted death in the Netherlands. *N Engl J Med* 1996;335:1706-11.
9. Hanks G, Cherny N. Opioid analgesic therapy. In: Doyle D, Hanks GWC, MacDonald N (eds). *Oxford Textbook of Palliative Medicine*. 2nd edition. Oxford/New York/Tokyo: Oxford University Press, 1998:331-55.
10. Van der Maas PJ, van Delden JJ, Pijnenborg L, Looman CW. Euthanasia and other medical decisions concerning the end of life. *Lancet* 1991;338:669-74.
11. Deliens L, Mortier F, Bilsen J, Cosyns M, Vander Stichele R, Vanoverloop J, Ingels K. End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey. *Lancet*. 2000;356:1806-11.
12. WHO. Looking forward to cancer pain relief for all. International consensus on the management of cancer pain. Oxford: CBC, 1997.
13. Wall PD. The generation of yet another myth on the use of narcotics. *Pain* 1997;73:121-2.
14. Manfredi PL, Morrison RS, Meier DE. The rule of double effect [letter]. *N Engl J Med* 1998;338:1390.
15. Christakis NA. *Death foretold. Prophecy and prognosis in medical care*. Chicago/London: Chicago University Press, 1999.
16. Muers MF, Shevlin P, Brown J. Prognosis in lung cancer: physicians' opinions compared with outcome and a predictive model. *Thorax* 1996;51:894-902.
17. Foley KM. Misconceptions and controversies regarding the use of opioids in cancer pain. *Anticancer Drugs* 1995;6 Suppl 3:4-13.
18. Larue F, Colleau SM, Fontaine A, Brasseur L. Oncologists and primary care physicians' attitudes toward pain control and morphine prescribing in France. *Cancer*. 1995;76:2375-82.
19. Sapir R, Catane R, Strauss-Liviatan N, Cherny NI. Cancer pain: knowledge and attitudes of physicians in Israel. *J Pain Symptom Manage*. 1999;17:266-76.
20. Hill CS. The barriers to adequate pain management with opioid analgesics. *Semin Oncol* 1993;20(2 Suppl 1):1-5.

8

Clinical problems with the performance of euthanasia and physician-assisted suicide in the Netherlands

Abstract

Background and Methods. The characteristics and frequency of clinical problems with the performance of euthanasia and physician-assisted suicide are uncertain. We analyzed data from two studies of euthanasia and physician-assisted suicide in the Netherlands (one conducted in 1990 and 1991 and the other in 1995 and 1996), with a total of 649 cases. We categorized clinical problems as technical problems, such as difficulty inserting an intravenous line; complications, such as myoclonus or vomiting; or problems with completion, such as a longer-than-expected interval between the administration of medications and death.

Results. In 114 cases, the physician's intention was to provide assistance with suicide, and in 535, the intention was to perform euthanasia. Problems of any type were more frequent in cases of assisted suicide than in cases of euthanasia. Complications occurred in 7% of cases of assisted suicide, and problems with completion (a longer-than-expected time to death, failure to induce coma, or induction of coma followed by awakening of the patient) occurred in 16% of the cases; complications and problems with completion occurred in 3% and 6% of cases of euthanasia, respectively. The physician decided to administer a lethal medication in 21 of the cases of assisted suicide (18%), which thus became cases of euthanasia. The reasons for this decision included problems with completion (in 12 cases) and the inability of the patient to take all the medications (in 5).

Conclusions. There may be clinical problems with the performance of euthanasia and physician-assisted suicide. In the Netherlands, physicians who intend to provide assistance with suicide sometimes end up administering a lethal medication themselves because of the patient's inability to take the medication or because of problems with the completion of the physician-assisted suicide.

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Introduction

Although euthanasia and physician-assisted suicide are illegal in most countries, they are performed in several parts of the world.¹⁻⁹ Oregon has made physician-assisted suicide legal under specified conditions.¹⁰ In the Netherlands, a physician who performs euthanasia or provides assistance with suicide will not be prosecuted if the act has been carried out under strict conditions, which have been formulated by the courts and the medical profession.¹¹ One of these conditions is that euthanasia or assistance with suicide must be carried out in a professionally responsible way. In 1987, the Royal Dutch Association of Pharmacy issued guidelines on the use and preparation of drugs for euthanasia. The guidelines were revised on the basis of doctors' experiences in 1994 and 1998.^{12,13}

The incidence of physician-assisted suicide and euthanasia and attitudes toward these practices have been studied extensively, but the few reports on the clinical aspects of these practices are based on limited data or small numbers of cases.¹⁴⁻¹⁸ We performed a study to determine whether there are problems with the clinical aspects of euthanasia and physician-assisted suicide as reported by the physicians involved, including complications and problems with completion, such as a prolonged interval between the administration of medications and the patient's death.

Methods

Study design. In 1990 and 1991 and in 1995 and 1996, we performed two studies of euthanasia, physician-assisted suicide, and other medical practices involving the end of life in the Netherlands. Detailed information about the design of these studies has been reported elsewhere.^{1,19,20} In three parts of the studies, detailed information on the clinical aspects of euthanasia and physician-assisted suicide was collected.

In 1990 and 1991, we interviewed a stratified random sample of 405 physicians that included 152 general practitioners, 50 nursing-home physicians, and 203 physicians in the specialties of cardiology, surgery, internal medicine, pulmonology, and neurology. Nine percent of eligible physicians declined to take part in the study. The interviews were based on an extensive questionnaire and lasted an average of 2.5 hours. Respondents were asked whether they had ever performed euthanasia or provided assistance with suicide. If the answer was yes, more detailed questions were asked about the most recent case. Some of the questions were about technical problems, complications, and the length of the interval between the administration of medications and death.

In 1995 and 1996, we replicated the earlier interview study. We interviewed a randomized stratified sample of 405 physicians, including 124 general practitioners, 74 nursing-home physicians, and 207 physicians in the specialties noted above. Eleven percent of eligible physicians declined to take part in the study. The questionnaire was virtually identical to the one used in the 1990-1991 study.

In 1995 and 1996, we also interviewed a random sample of 147 physicians who had reported a case of physician-assisted suicide or euthanasia for judicial review by the public prosecutor between August 1, 1994, and February 1, 1995. Ten percent of eligible physicians declined to be interviewed. We asked the physicians questions about the reported case and the most recent unreported case (if any). In addition, we interviewed 63 of 64 eligible physicians who had been involved in cases of physician-assisted suicide or euthanasia discussed in the Assembly of Prosecutors General between January 1, 1991, and July 1, 1995. One physician declined to be interviewed. The questionnaire was similar to the one used in the 1990-1991 and 1995-1996 interview studies.

The protocol for the studies was reviewed and approved by a special committee of the Dutch Ministry of Health, Welfare, and Sports and the Dutch Ministry of Justice. It was also approved by the Royal Dutch Medical Association.

To obtain data from a sufficiently large number of cases, we combined all cases of euthanasia and physician-assisted suicide for which information on clinical problems was available. There were 649 such cases: 185 from the 1990-1991 interview study, 194 from the 1995-1996 interview study, and 250 from the 1995-1996 reported-cases study. These cases were divided into two groups according to whether the physician's intention had been to provide assistance with suicide or to perform euthanasia. Cases in which all the lethal drugs were administered by the patient were assigned to the assisted-suicide group; as were cases in which the last drug was administered by another person, although the intention had been that the patient would administer all the drugs. Cases in which someone other than the patient administered at least one of the lethal drugs at the patient's explicit request were assigned to the euthanasia group.

The data we used did not represent a random sample of cases, since we combined cases from different (stratified) samples and asked physicians about only the most recent case. We performed three analyses to assess the degree to which our data were representative of all cases of euthanasia or assisted suicide in the Netherlands. We compared the prevalence of technical problems, complications, and problems with completion between samples and according to the type of practice. We also analyzed the probability of a problem according to the number of cases of physician-assisted suicide or euthanasia that physicians had been involved in during the two years before the interview. Finally, we repeated all our analyses with only the data from the 1990-1991 interview study and the 1995-1996

interview study, which were both based on representative samples. The prevalence of technical problems, complications, and problems with completion was virtually identical for all samples and for all types of practice, and the likelihood of a problem was not related to the physician's prior experience with physician-assisted suicide or euthanasia. Therefore, we report the results for the overall samples.

We categorized clinical problems as technical problems, such as difficulty inserting an intravenous line; complications, such as spasm, myoclonus, nausea, or vomiting; and problems with completion, such as a longer-than-expected time to death or failure to induce coma. If more than one type of drug was administered, the combination of drugs was classified according to the drug with the greatest potential for causing death. Neuromuscular relaxants and potassium chloride were considered to have the greatest lethal potential, followed by barbiturates, and then opioids. Thus, for example, if a barbiturate and a neuromuscular relaxant had been administered, the medication was classified as a neuromuscular relaxant, and if a barbiturate and an opioid had been administered, the medication was classified as a barbiturate.

Statistical analysis. The chi-square test was used for comparisons of categorical variables. Two-sided P values of less than 0.05 were considered to indicate statistical significance. All statistical analyses were performed with SPSS software for Windows, version 7.5 (SPSS, Chicago).

Results

The characteristics of the 649 cases of euthanasia and assisted suicide are shown in Table 8.1. Fifty-five percent of the patients were men, and the mean age was 63.9 years (range, 21 to 96). Seventy-five percent of the patients had cancer. In 535 cases (82%), the physician intended to perform euthanasia, and in 114 cases (18%), the intention was to provide assistance with suicide.

Medications

In 367 of the 535 cases in which euthanasia was intended (69%), a neuromuscular relaxant was given (Table 8.2), in most cases after the administration of a barbiturate to induce coma. In 10% of the euthanasia cases, a barbiturate was the only or the most potent lethal drug administered; in 13%, an opioid was the only or the most potent lethal drug administered. Potassium chloride was administered in 2% of the euthanasia cases. In 485 cases of euthanasia (91%), a physician administered all or some of the medications. In 29 cases (5%), a physician did not administer any of the drugs: a nurse administered the drugs in 23 cases, and

Table 8.1
Characteristics of the cases of euthanasia and physician-assisted suicide

Characteristic	1990-1991 Interview study (N=185)	1995-1996 Interview study (N=194)	1995-1996 Reported- cases study (N=270)	Total (N=649)
Patients				
Men (%)*	51	59	54	55
Age (yr)†				
Mean ± SD	62.3 ± 14.4	62.6 ± 13.8	65.9 ± 14.9	63.9 ± 14.5
Range	23-91	25-91	21-96	21-96
Diagnosis of cancer (%)‡	78	82	68	75
Type of physician (%)				
General practitioner	51	52	60	55
Clinical specialist	46	40	34	39
Nursing-home physician	3	8	6	6
Intended intervention (%)				
Euthanasia	86	79	83	82
Physician-assisted suicide	14	21	17	18
Year of death (%)§				
1987 or earlier	38	13	8	18
1988-1994	62	54	60	59
1995 or later	-	34	33	23

* Data were missing for one case in the 1995-1996 interview study and three cases in the reported-cases study.

† Data were missing for three cases in the 1995-1996 interview study and three cases in the reported-cases study.

‡ Data were missing for four cases in the 1995-1996 interview study and three cases in the reported-cases study.

§ Data were missing for four cases in the 1995-1996 interview study and 12 cases in the reported-cases study. Because of rounding, percentages do not all total 100.

another person (generally a family member) did so in 6 cases. In 384 cases of euthanasia (72%), the physician who completed the interview was present continuously from the time the first drug was administered until the patient's death. In 10 cases (2%), the respondent was not present at all; instead, a colleague or a nurse administered the medication.

In the group of 114 cases in which the intention was to provide assistance with suicide, a barbiturate was used in 81 cases (71%); in 9 cases (8%), an opioid was used. In 14% of the cases, a neuromuscular relaxant was administered after a barbiturate. In 85 cases (75%), the patient took the drug (or drugs) without help. In

5 cases, the physician or a relative helped the patient take an oral drug; in 19 other cases, the physician administered a second or third drug parenterally because of complications or a perceived lack of effect of the first drug. The physician who completed the interview was continuously present in 52% of cases of physician-assisted suicide ($P < 0.001$ for the comparison with cases of euthanasia).

Table 8.2
Medication use during euthanasia and physician-assisted suicide and presence or absence of the physician who was interviewed

Variable	Euthanasia intended (N=535)	Assisted suicide intended (N=114)
	no. of cases (%)	
Medications*		
Neuromuscular relaxant†	367 (69)	16 (14)
Potassium chloride	10 (2)	-
Barbiturate	56 (10)	81 (71)
Opioid	70 (13)	9 (8)
Other drugs or drug combinations	19 (4)‡	3 (3)§
Unknown	13 (2)	5 (4)
Person who administered drugs		
Physician¶	485 (91)	21 (18)
Nurse¶	23 (4)	-
Person other than physician or nurse¶	6 (1)	3 (3)
Patient only	-	85 (75)
Unknown	21 (4)	5 (4)
Presence or absence of physician		
Continuously present	384 (72)	59 (52)
Present at intervals	61 (11)	18 (16)
Present after being called	39 (7)	20 (18)
Absent	10 (2)	11 (10)
Unknown	41 (8)	6 (5)

* For a description of how medications were classified, see the Methods section.

† In seven cases, potassium chloride was also administered.

‡ In eight cases, insulin was administered.

§ Insulin was administered with a barbiturate in one case, orphenadrine was administered in one case, and an unspecified combination of drugs was administered in one case.

¶ The patient may also have administered one or more drugs.

Table 8.3
Clinical problems associated with euthanasia and physician-assisted suicide*

Variable	No. of cases	Technical problems†		P value
		no./total no.	(%)	
Intended intervention				0.03
Euthanasia	535	24/529	(5)	
Assisted suicide	114	11/112	(10)	
Type of physician				<0.001
General practitioner	356	28/353	(8)	
Clinical specialist	256	4/253	(2)	
Nursing-home physician	37	3/35	(9)	
Type of drug initially administered‡				
Barbiturate	320	21/317	(7)	
Opioid	142	10/141	(7)	
Other	171	3/169	(2)	
Route of administration of initial drug**				0.003
Oral or rectal	116	14/115	(12)	
Parenteral	327	14/325	(4)	
All cases	649	35/641	(5)	

* In 10 cases, more than one type of problem occurred.

† Data were not available for eight cases.

‡ Data were not available for six cases.

§ Data were not available for 11 cases.

Clinical problems

Table 8.3 shows the frequency of the clinical problems that occurred. Technical problems occurred in 35 cases (5%), complications in 24 cases (4%), and problems with completion in 44 cases (7%). In 10 cases, more than one type of problem occurred. Assisted suicide was more frequently associated with each type of problem than was euthanasia ($P=0.03$, $P=0.03$, and $P=0.001$, respectively). General practitioners and nursing-home physicians were more likely than specialists to report technical problems ($P<0.001$) and problems with completion ($P=0.04$). Oral or rectal administration of medications was more likely than parenteral administration to be associated with technical problems ($P=0.003$) and problems with completion ($P<0.001$).

Specific information about the reported problems is provided in Table 8.4. The most common technical problems were difficulty finding a vein in which to inject the drug and difficulty administering an oral medication. The most frequently

Table 8.3 (continued)

Variable	Complications‡ no/total no. (%)	P value	Problems with completion§ no/total no. (%)	P value
Intended intervention		0.03		0.001
Euthanasia	16/532 (3)		28/528 (6)	
Assisted suicide	8/111 (7)		16/110 (16)	
Type of physician				0.04
General practitioner	15/354 (4)		30/351 (9)	
Clinical specialist	6/253 (2)		11/252 (4)	
Nursing-home physician	3/36 (8)		3/35 (11)	
Type of drug initially administered¶				
Barbiturate	11/317 (3)		19/315 (7)	
Opioid	8/141 (6)		15/140 (11)	
Other	5/171 (3)		10/169 (7)	
Route of administration of initial drug**				<0.001
Oral or rectal	8/113 (7)		15/113 (13)	
Parenteral	12/326 (4)		11/324 (3)	
All cases	24/643 (4)		44/638 (7)	

¶ The type of drug was not specified in 16 cases.

** In the 1990-1991 interview study, the route of administration was not determined; the 185 cases in that study were therefore excluded from this analysis. In addition, data were not available for 21 cases in the other two studies; these cases have also been excluded from the analysis.

mentioned complications were spasm or myoclonus and nausea or vomiting. The most common problems with completion were a longer-than-expected interval between the administration of medications and death and failure to induce a comatose state. Table 8.5 shows the intervals between the administration of the medication (or the first medication, if there was more than one) and the patient's death, as well as the physician's assessment whether the interval was shorter than expected, longer than expect, or as expected.

Intervention of physician in cases of assisted suicide

In 21 of the cases in which the intention had been to provide assistance with suicide, the physician administered the lethal drug. In 12 of these cases, a problem with completion was mentioned as the reason for the physician's intervention: the interval between the administration of medication and the occurrence of coma or

Table 8.4
Specific technical problems, complications, and problems with completion

Specific problem	Euthanasia intended (N=535)	Assisted suicide intended (N=114)
	no. of cases	
Technical problems		
Difficulty finding vein in which to inject drug	10*	1†
Problem with the intravenous catheter	4	-
Difficulty administering oral drug	4	7
Other‡	3	3
Not specified	3	-
Complications§		
Spasm or myoclonus	6	1
Cyanosis	4	1
Nausea or vomiting	2	4
Other¶	7¶	4**
Not specified	1	-
Problems with completion		
Time to death was longer than expected or patient did not become comatose	23	14
Patient awoke from coma	5	2

* In one case, intravenous injection was difficult because of lymphedema. In two other cases, the physician finally administered the drug intramuscularly.

† Fluid injected into a vein flowed back out of the vein at the injection site.

‡ Other problems included inappropriate equipment and drugs that were unpleasant to swallow or that irritated the throat.

§ In six cases, two complications were reported.

¶ In one case, the patient's eyes remained open, and in another case, the patient sat up. Other complications included tachycardia, excessive production of mucus, hiccups, perspiration, and extreme gasping.

** Other complications were a feeling of drunkenness in one case and extreme gasping in three cases.

death was too long (in 9 cases), the patient did not become comatose after taking the first drug (in 1), or the patient awoke from coma (in 2). In five other cases, the physician intervened because the patient had difficulty taking all the oral medication; for example, one patient vomited after taking the first medication, and one patient fell asleep before taking all the medication. In four cases, no specific reason for the physician's intervention was given.

Discussion

We found that there were sometimes clinical problems with the performance of physician-assisted suicide and euthanasia. The problems reported by physicians frequently concerned a longer-than-expected interval between the administration of the lethal drug (or the first drug, if more than one was administered) and the patient's death. In general, problems were more frequently reported in cases of assisted suicide than in cases of euthanasia. The responsible physician decided to administer the lethal medication in 21 of 114 cases in which the original intention had been only to provide assistance with suicide. In most of these cases, the patient did not die as soon as expected or awoke from coma, and the physician felt compelled to administer a lethal injection because of the anticipated failure of the assisted suicide. In some cases, the physician administered a lethal injection because the patient had difficulty swallowing the oral medication, vomited after swallowing it, or became unconscious before swallowing all of it.

Two limitations of our study should be considered. First, we included all cases of euthanasia and physician-assisted suicide for which we had clinical information.

Table 8.5
Interval from the administration of the first drug to death and the physician's assessment of the interval

Physician's assesment	No. of cases (%)	Interval*	
		Median	Range
		min	
Euthanasia intended*			
All cases†	535	10	0.5 min - 7 days
As expected	449 (84)	10	0.5 min - 4 days
Shorter than expected	18 (3)	5	0.5 min - 12 hr
Longer than expected	51 (10)	180	5 min - 7 days
Physician-assisted suicide intended‡			
All cases	114	30	1 min - 14 days
As expected	67 (59)	30	2 min - 14 days
Shorter than expected	13 (11)	8	1 min - 2 hr
Longer than expected	22 (19)	180	45 min - 7 days

* Data on the actual interval between the administration of the first drug and death were not available for 33 cases in which euthanasia was intended and for 9 in which assisted suicide was intended.

† In 10 cases, the interval differed from the expected interval but was not specified as shorter or longer; in seven cases, the physician's assessment of the interval was not available.

‡ In five cases, the interval differed from the expected interval but was not specified as shorter or longer; in seven cases, the physician's assessment of the interval was not available.

These cases may not be representative of all cases of euthanasia and assisted suicide in the Netherlands. We performed several analyses to check for differences between samples or strata, which did not yield any significant differences. Second, the information was provided by the responsible physician in each case, who may have underestimated the number or seriousness of problems.

In two other Dutch studies of the clinical aspects of euthanasia and physician-assisted suicide, general practitioners and nursing-home physicians reported problems in 12% and 7% of cases, respectively.^{14,15} In a study of physician-assisted suicide in the United States, Emanuel et al. reported that assisted suicide failed in 3 of 20 cases described by American oncologists.¹⁶ In a study in Washington State, no unsuccessful attempts at physician-assisted suicide were reported.¹⁷ In 15 cases of physician-assisted suicide in Oregon, no complications, such as vomiting or seizures, occurred.¹⁸

Information on problems with the performance of euthanasia or physician-assisted suicide is relevant to the debate about whether to legalize these practices, for several reasons. First, such information may be helpful in cases in which the distinction between physician-assisted suicide and euthanasia is unclear. We found that in most cases in which assistance with suicide had been intended, the physician's role was confined to prescribing or supplying the drugs to be used. In 21% of the cases, however, the physician or another person helped the patient take one or more of the drugs. It is not clear at what point a physician's assistance with suicide becomes euthanasia. For example, how should cases be classified in which the physician pours an oral medication into the patient's mouth because the patient is unable to administer it? A judicial distinction between physician-assisted suicide and euthanasia may be complicated by such practical issues.²¹

Second, if physician-assisted suicide is legalized but euthanasia is not, some competent patients may not be able to end their own lives for purely physical reasons, as in the case of patients with neurologic illnesses who have problems with swallowing or using their hands and patients who are physically too weak to take all the oral medication themselves. One study found that general practitioners and nursing-home physicians preferred euthanasia to assisted suicide because of limitations imposed by the patient's condition in 48% of 155 cases of euthanasia and in 78% of 50 cases, respectively.²²

Third, a physician who decides to assist with a patient's death should have adequate knowledge of the technical performance of euthanasia and physician-assisted suicide. In the Netherlands, one of the requirements for prudent practice concerns care in choosing doses and administering medications.²³ The Royal Dutch Association of Pharmacy recognized in the 1980s that physicians and pharmacists should have at their disposal reliable information on the technical performance of euthanasia, and the association regularly updates its guidelines on the use and preparation of relevant drugs.^{12,13} Studies in the United States and in the

Netherlands have shown that many physicians lack knowledge about the use of lethal drugs and that recommendations about which drugs to use are not always followed.^{2,13,16-18,24,25}

Finally, the responsible physician's presence must be considered. According to the Royal Dutch Medical Association, the physician should be present when euthanasia or physician-assisted suicide is carried out. A physician who decides not to be present (e.g., at the patient's request) should make arrangements to be available if the prescribed drugs fail to have the intended effect.²⁶ About two thirds of both general practitioners and nursing-home physicians in the Netherlands endorse the statement that a physician who provides assistance with suicide should be prepared to administer a lethal drug if the suicide attempt fails.²⁷ To be available under such circumstances, the physician must have previously informed the patient and the patient's relatives about what to expect during the actual performance of physician-assisted suicide, including possible complications and the expected interval between the administration of the medication and death.

Decisions about physician-assisted suicide and euthanasia are difficult and emotional for all persons involved. Unexpected events can be traumatic. Professional training, empirical research, and an open debate on the practical aspects of physician-assisted suicide and euthanasia may contribute to the prevention of complications and other clinical problems.

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References

1. Van der Maas PJ, van der Wal G, Haverkate I, et al. Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in the Netherlands. *N Engl J Med* 1996;335:1699-1705.
2. Meier DE, Emmons CA, Wallenstein S, Quill T, Morrison RS, Cassel CK. A national survey of physician-assisted suicide and euthanasia in the United States. *N Engl J Med* 1998;338:1193-1201.
3. Kuhse H, Singer P, Baume P, Clark M, Rickard M. End-of-life decisions in Australian medical practice. *Med J Aust* 1997;166:191-6.
4. Matzo ML, Emanuel EJ. Oncology nurses' practices of assisted suicide and patient-requested euthanasia. *Oncol Nurs Forum* 1997;24:1725-32.
5. Emanuel EJ, Fairclough DL, Daniels ER, Clarridge BR. Euthanasia and physician-assisted suicide: attitudes and experiences of oncology patients, oncologists and the public. *Lancet* 1996;347:1805-10.

6. Asch DA. The role of critical care nurses in euthanasia and assisted suicide. *New Engl J Med* 1996;334:1374-9.
7. Doukas DJ, Waterhouse D, Gorenflo DW, Seid J. Attitudes and behaviors on physician-assisted death: a study of Michigan oncologists. *J Clin Oncol* 1995;13:1055-61.
8. Baume P, O'Malley E. Euthanasia: attitudes and practices of medical practitioners. *Med J Aust* 1994;161:137,140,142-4.
9. Fried TR, Stein MD, O'Sullivan PS, Brock DW, Novack DH. Limits of patient autonomy: physician attitudes and practices regarding life-sustaining treatments and euthanasia. *Arch Intern Med* 1993;153:722-8.
10. Oregon revised Statute 127.800-127.897 (The Oregon Death with Dignity Act) (1994).
11. Gevers S. Euthanasia: law and practice in the Netherlands. *Br Med Bull* 1996;52:326-33.
12. Toepassing en bereiding van euthanatica. 's-Gravenhage, the Netherlands: Koninklijke Nederlandse Maatschappij ter bevordering der Pharmacie.1994.
13. Wetenschappelijk Instituut Nederlandse Apothekers. Euthanaticarapport herzien. Adviezen voor de toepassing van euthanatica. *Medisch Contact* 1998;53:1366-7.
14. Van der Wal G, van Eijk JTM, Leenen HJJ, Spreeuwenberg C. Het gebruik van middelen bij euthanasie en hulp bij zelfdoding in de huisartspraktijk. *Ned Tijdschr Geneesk* 1992;136:1299-1305.
15. Muller MT, Hertogh CPM, van der Wal G, Ribbe MW. Medisch-technische aspecten van euthanasie en hulp bij zelfdoding in de verpleeghuisgeneeskunde. *Vox Hosp* 1992;16:3-7.
16. Emanuel EJ, Daniels ER, Fairclough DL, Clarridge BR. The practice of euthanasia and physician-assisted suicide in the United States: adherence to proposed safeguards and effects on physicians. *JAMA* 1998;280:507-13.
17. Back AL, Wallace JL, Starks HE, Pearlman RA. Physician-assisted suicide and euthanasia in Washington State: patient requests and physician responses. *JAMA* 1996;275:919-25.
18. Chin AE, Hedberg K, Higginson GK, Fleming DW. Legalized physician-assisted suicide in Oregon - the first year's experience. *N Engl J Med* 1999;340:577-83.
19. Van der Maas PJ, van Delden JJM, Pijnenborg L, Looman CWN. Euthanasia and other medical decisions concerning the end of life. *Lancet* 1991;338:669-74.
20. Van der Wal G, van der Maas PJ, Bosma JM, et al. Evaluation of the notification procedure for physician-assisted death in the Netherlands. *N Engl J Med* 1996;335:1706-11.
21. Woolfrey J. What happens now? Oregon and physician-assisted suicide. *Hastings Cent Rep* 1998;28:9-17.
22. Onwuteaka-Philipsen BD, Muller MT, van der Wal G, van Eijk JT, Ribbe MW. Active voluntary euthanasia or physician-assisted suicide? *J Am Geriatr Soc* 1997;45:1208-13.
23. Legemaate J. Legal aspects of euthanasia and assisted suicide in the Netherlands. 1973-1994. *Camb Q Healthcare Ethics* 1995;4:112-21.
24. Drickamer MA, Lee MA, Ganzini L. Practical issues in physician-assisted suicide. *Ann Intern Med* 1997;126:146-51.
25. Lee MA, Nelson HD, Tilden VP, Ganzini L, Schmidt TA, Tolle SW. Legalizing assisted suicide - views of physicians in Oregon. *N Engl J Med* 1996;334:310-5.
26. Royal Dutch Medical Association. Vision on euthanasia. Euthanasia in the Netherlands. Utrecht: KNMG, 1996.
27. Onwuteaka-Philipsen BD, Muller MT, van der Wal G, van Eijk JT, Ribbe MW. Attitudes of Dutch general practitioners and nursing home physicians to active voluntary euthanasia and physician-assisted suicide. *Arch Fam Med* 1995;4:951-5.

PART **IV**

Non-treatment decisions

9

A nationwide study of
decisions to forgo life-
prolonging treatment in
Dutch medical practice

Abstract

Background. Decisions to withhold or withdraw life-prolonging treatment in terminally ill patients are common in some areas of medical practice. Information about the frequency and background of these decisions is generally limited to specific clinical settings. This article describes the practice of withholding or withdrawing life-prolonging treatment in the Netherlands.

Methods. Questionnaires were sent to the attending physicians of a stratified sample of 6,060 of all 43,002 cases of deaths in the Netherlands from August 1 through November 30, 1995. The questions concerned the treatments forgone, the patient characteristics, and the decision-making process. The response rate was 77%.

Results. A non-treatment decision was made in 30% (95% confidence interval, 28%-31%) of all deaths in the Netherlands in 1995; this is an increase compared with 28% (95% confidence interval, 26%-29%) in 1990; in 20% of all deaths, this decision was the most important end-of-life decision. Artificial nutrition or hydration and antibiotics were the treatments most frequently forgone, each accounting for 25% of cases in which a non-treatment decision was made. Nursing-home physicians withheld or withdrew treatment more often than clinical specialists or general practitioners in 52%, 35% and 17% of all deaths they were involved with, respectively. Of the patients in whom a non-treatment decision was the most important end-of-life decision, 26% were competent; of those, 93% were involved in the decision-making. In 17% of patients, the non-treatment decision was made without being discussed with the patient or the patient's relatives and without knowledge of the patient's wishes. Life was shortened by an estimated 24 hours or less in 42% and 1 month or more in 8% of patients.

Conclusions. Decisions to forgo life-prolonging treatment are frequently made end-of-life decisions in the Netherlands and may be increasing. Most of these decisions do not involve high-technology treatments, and the consequences, in terms of shortening of life, are relatively small.

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Introduction

Advances in medicine and technology have had a great impact on the care of critically ill patients. Life-sustaining interventions, like mechanical ventilation and artificial nutrition or hydration, enable physicians to effectively postpone death in many patients who otherwise would have died. There is a growing interest in a humane approach to dying, and the inherent question is whether use of life-sustaining therapy is always in the patient's best interest. Currently, the right of competent patients to refuse treatment is widely accepted, even if this should hasten death.

During the last decade, several empirical studies¹⁻⁷ were published on the attitudes of patients and physicians toward the limitation of life-prolonging treatment and on the occurrence of decisions to forgo life-prolonging treatment in medical practice.

The present study was part of a nationwide study^{8,9} conducted in 1995-1996 in the Netherlands on medical end-of-life decisions, including decisions to withhold or withdraw potentially life-prolonging treatment (non-treatment decisions), that was partly a replication of a study done in 1990.^{10,11} The goals of the present study were to obtain reliable estimates of the incidence of non-treatment decisions; describe the treatments forgone; describe the characteristics of patients, physicians, and circumstances involved; explore the role of patients, their relatives and medical staff in the decision-making; and compare the results with those of the 1990 study.

Methods

Data collection. Details of the data collection have been published previously.⁸ In summary, the procedure was as follows. All causes of death of all Dutch inhabitants are routinely reported to Statistics Netherlands, Voorburg, together with the age and sex of the deceased and the name of the reporting physician. From August 1 through November 30, 1995, 43,002 death certificates were received. For reasons of statistical efficiency, 2 physicians classified all cases of death in the age group of 1 year and older into 5 strata on the basis of increasing probability that a medical decision concerning the end of life was made: when the cause of death was not suspected of involving any medical decision concerning the end of life (e.g., car accident resulting in sudden death), the death was assigned to stratum 0, and when the death certificate provided explicit indications about an end-of-life decision being made the death was assigned to stratum 4. A sample was drawn from each stratum, 1/12 of the deaths in strata 0 and 1, 1/8 in stratum 2, ¼ in stratum 3, and ½ in stratum 4. Samples taken from stratum 0 were retained in the study, but no questionnaires were sent. All deaths within the first year of life

were included in the study. For these deaths and all deaths in strata 1 to 4, the reporting physician received a written questionnaire with 24 questions. Nonresponding physicians received a reminder 3 weeks after the questionnaire was sent. Of 6,060 questionnaires that were mailed, 77% were returned and nearly all contained complete information. The results of this study are based on 5,146 cases of death. Anonymity was guaranteed by interposition of a notary who removed the sample serial numbers from the returned questionnaires. The 1995 study covered the same period of the year as the earlier study in 1990.

Questionnaire. The physician was asked whether any medical decision concerning the end of life had preceded death, namely decisions to withhold or withdraw potentially life-prolonging treatment, to intensify alleviation of pain and symptoms with possible life-shortening effects, and to administer or provide drugs explicitly intended to hasten death. Questions were asked whether the end-of-life decision had been made taking into account the possibility that death would be hastened or whether the physician had had the partial or explicit intention of hastening death to assess the moral and clinical weight of the decision. When more than one end-of-life decision had been made, the most important decision was defined as the weightiest decision, while the administration of drugs was considered to be more decisive than the withholding or withdrawal of treatment in case of equal weights. With respect to the most important end-of-life decision, questions were included about the decision-making process and the patient's competence. The questionnaire was very similar to the 1990 questionnaire¹² except for an additional question about the type(s) of treatment forgone in the case of a non-treatment decision.

Definitions. Death was defined as non-sudden if the respondent answered no to the question "Was death sudden and totally unexpected?"

A decision to withhold or withdraw potentially life-prolonging treatment was classified as the most important end-of-life decision when it was the only end-of-life decision made or when treatment was forgone with the explicit intention to hasten death in combination with a decision to alleviate pain and symptoms without the explicit intention to hasten death.

The patient's competence was described as the patient's ability to assess his or her situation and make an adequate decision.

Physician specialty. In the Netherlands, general practitioners are family doctors who often have a long-standing relationship with their patients. They function as the gatekeepers of clinical medicine. Clinical specialists mainly work in hospitals, where they provide outpatient and inpatient care. Nursing-home physicians care predominantly for elderly patients with chronic diseases, physical or mental

disorders, or disabilities who live in institutions. General practitioners and nursing-home physicians have 3 years of additional training after their basic training as medical doctors; clinical specialists have 5 to 6 years of additional training.

Data analysis. Weighted percentages valid for the whole population were calculated. Weights are based on the unequal sampling fractions in the strata, on corrections for nonresponse, and on the total number of deaths according to age and sex in 1995. This weighting procedure is described in detail elsewhere.¹²

Results

Incidence

In 1995, a decision to withhold or withdraw (possible) life-prolonging treatment preceded 30% (95% confidence interval [CI], 28%-31%) of all deaths in the Netherlands (Table 9.1) and 43% (95% CI, 42%-45%) of all nonsudden deaths. These figures show an increase compared with 28% (95% CI, 26%-29%) of all deaths and 39% (95% CI, 38%-41%) of all nonsudden deaths in 1990.¹¹ Non-treatment decisions were made relatively frequently in patients aged 80 years and older (36%), in females (34%), and in deaths due to mental disorders (including Alzheimer dementia) (52%), disease of the digestive tract (50%), neurologic disease (including cerebrovascular accidents) (43%), or pulmonary disease (41%). In nonsudden deaths, logistic regression analysis, with a non-treatment decision being made or not as dependent variable and age (3 categories), sex, and cause of death (7 categories) as independent variables, showed that age and cause of death, but not sex, independently contributed to the probability that a non-treatment decision was made. Table 9.1 also shows that nursing-home physicians made non-treatment decisions relatively often (52%) compared with other physicians (17% and 35% for general practitioners and clinical specialists, respectively). When the physician specialty was included in the logistic regression model, patient's age and cause of death and the physician specialty were associated independently with non-treatment decisions.

Of the non-treatment decisions, 49% involved only withholding life-prolonging treatment, whereas 51% involved withdrawal of life-prolonging treatment with or without withholding such treatment. The non-treatment decision was the most important end-of-life decision in 20% of all deaths. In another 8%, the decision to alleviate pain or symptoms was the most important end-of-life decision, and in 2% the physician performed euthanasia or assisted suicide after treatment had been forgone.

Table 9.1
Weighted percentages of a non-treatment decision according to patient characteristics and physician specialty for 1995

Nontreatment decision	Horizontal			Vertical All deaths, 1995* (n=132,730)
	Sudden death	Nonsudden death		
		Not preceded by a non- treatment decision	Preceded by a non- treatment decision	
Age, y				
0-64 (n=1313)	41	36	23	20
65-79 (n=1792)	32	42	26	36
≥80 (n=2041)	26	38	36	44
Sex				
Male (n=2611)	36	38	26	50
Female (n=2535)†	27	40	34	50
Cause of death				
Cancer (n=2119)†	8	60	31	28
Cardiovascular disease (n=910)	61	24	15	30
Neurologic disease (n=466)	21	36	43	11
Pulmonary disease (n=306)	19	40	41	9
Mental disorder (n=251)	15	33	52	3
Disease of the digestive tract (n=162)	19	31	50	4
Other (n=932)	40	33	27	16
Physician specialty‡				
General practitioner (n=2493)	40	43	17	43
Clinical specialist (n=1560)†	27	39	35	35
Nursing-home physician (n=929)†	12	35	52	18
All deaths, 1995 (n=5146)	31	39	30	100
All deaths, 1990 (n=5197)§	30	43	27	100

* Official figures for 1995¹³ are shown, except for the percentages concerning the physician specialty, which were based on the results from the sample (n=5146).

† Horizontal percentages will not total 100 because of rounding. For cause of death, the vertical percentages will not total 100 because of rounding.

‡ No information was available on the specialty of 164 physicians.

§ The distributions of age, sex, cause of death, and physician specialty in 1990 were very similar to those in 1995.

Treatment forgone

Of the respondents who reported a non-treatment decision, 86% specified the type(s) of treatment forgone: 60% mentioned 1 type of treatment forgone and 26% mentioned 2 or more different types of treatment forgone (a mean of 1.36 types of treatment per patient). As the wide variety of combinations could not easily be classified, results will be presented for all types of treatment separately.

Artificial nutrition or hydration and antibiotics were the treatments most frequently forgone (Table 9.2), each accounting for 25% of cases in which a non-treatment decision was made. Decisions to forgo artificial nutrition or hydration involved nutrition in 60%, hydration in 14%, and both nutrition and hydration in 26%. These decisions were predominantly made by nursing-home physicians: 55% of cases in which artificial nutrition or hydration was forgone (data not presented in Table 9.2). Vasopressors were forgone in 11% of cases, relatively frequently by clinical specialists (18%), and medications other than antibiotics or vasopressors

Table 9.2
Weighted percentages of treatments forgone in cases in which a non-treatment decision was made according to physician specialty*

Treatment forgone	General practitioner (n=499)	Clinical specialist (n=629)	Nursing-home physician (n=515)	All non-treatment decisions† (n=1684)	All deaths, 1995 (n=5146)
Artificial nutrition or hydration	22	12	44	25	8
Antibiotics	15	21	36	25	7
Vasopressors	9	18	5	11	3
Other medication	21	14	21	18	5
Mechanical ventilation	1	22	1	10	3
Surgery	5	14	6	9	3
Hospital admission or diagnostics	13	3	11	8	2
Chemotherapy or radiotherapy	9	5	1	4	1
Blood products	4	3	2	3	1
Resuscitation	-	5	0	2	1
Dialysis	1	3	1	2	1
Not specified	23	13	8	14	4

* More than 1 treatment could be mentioned.

† Including non-treatment decisions by 41 physicians about whom we had no information on the specialty.

were forgone in 18% of cases. Clinical specialists relatively frequently reported forgoing mechanical ventilation (22%) and surgery (14%), and general practitioners forwent chemotherapy or radiotherapy (9%).

Patient characteristics

Table 9.3 shows that decisions to forgo artificial nutrition or hydration mainly concerned patients aged 80 years and older (68%), female patients (70%), and patients who died from cancer (24%), neurologic disease (24%), or a mental disorder (17%). Cancer was the most frequent cause of death in patients for whom artificial nutrition or hydration was forgone by general practitioners (41% of patients) or clinical specialists (42% of patients), whereas, if this decision was made by nursing-home physicians, the most frequent cause of death was a mental disorder (mainly dementia) (26% of patients).

Compared with other types of treatment, mechanical ventilation and

Table 9.3
Weighted percentages of patient characteristics according to the treatment forgone*

	Artificial nutrition or hydration (n=446)	Anti- biotics (n=352)	Vaso- pressors (n=143)	Other medi- cation (n=287)	Mechan- ical ventilation (n=209)	Surgery (n=134)
Age, y						
0-64	11	11	20	16	32	10
65-79	22	34	31	29	48	37
≥80	68	55	50	54	20	54
Sex						
Male	30	46	48	46	56	33
Female	70	54	52	54	44	67
Cause of death						
Cancer	24	18	16	30	19	34
Cardiovascular disease	7	7	44	16	18	19
Neurologic disease	24	25	7	10	12	3
Pulmonary disease	8	19	7	14	18	4
Mental disorder	17	7	2	6	1	3
Diseases of the digestive tract	4	7	17	5	11	17
Other diseases	16	16	7	17	20	21

* Patients in whom more than one type of treatment was forgone are represented at each particular treatment.

chemotherapy or radiotherapy were more often forgone in patients younger than 65 (32% and 43%, respectively). Antibiotics were mainly forgone in patients dying from neurologic disease (25%), pulmonary disease (19%), or cancer (18%). As might be expected, resuscitation (35%) and vasopressors (44%) were predominantly forgone in patients who died from cardiovascular disease, and chemotherapy or radiotherapy (94%), in patients with cancer.

Decision-making

Of the patients for whom the non-treatment decision was the most important end-of-life decision, 26% were competent, 67% were not fully competent, and in 7%, no information on the patient's competence was available.

Non-treatment decisions made by nursing-home physicians more frequently concerned patients who were not fully competent (83%) than decisions made by clinical specialists (69%) or general practitioners (42%). Non-treatment decisions

Table 9.3 (continued)

	Hospital admission or diagnostics (n=126)	Chemotherapy or radiotherapy (n=97)	Blood products (n=48)	Resuscitation (n=33)	Dialysis (n=23)	All non-treatment decisions, 1995 (n=1684)
Age, y						
0-64	9	43	14	18	4	16
65-79	19	41	35	36	55	32
≥80	73	16	52	45	40	52
Sex						
Male	41	52	48	44	38	44
Female	59	48	52	56	62	56
Cause of death						
Cancer	19	94	50	22	16	30
Cardiovascular disease	21	3	11	35	34	15
Neurologic disease	14	-	3	20	10	16
Pulmonary disease	14	-	2	4	5	11
Mental disorder	6	-	1	-	4	7
Diseases of the digestive tract	13	-	17	8	12	7
Other diseases	13	3	17	11	19	14

were discussed with 93% of competent patients (Table 9.4); in 67% of the competent patients, the decision was made at the patient's explicit request. There was no major difference between the treatments in discussing this decision; only the decision not to resuscitate had been discussed with the patient less often. The most frequently mentioned reasons for not discussing the decision with a competent

Table 9.4
Weighted percentages of discussion of the non-treatment decision with the patient or others according to the treatment forgone and the estimated shortening of life*

	Discussion with†		
	Competent patient	Not fully competent patient	Patient's relatives
Treatment forgone‡			
Artificial nutrition or hydration (n=336)	93	13	83
Antibiotics (n=234)	98	12	81
Vasopressors (n=109)	92	15	70
Other medication (n=169)	94	14	74
Mechanical ventilation (n=171)	96	8	63
Surgery (n=87)	93	23	69
Hospital admission or diagnostics (n=91)	96	13	74
Chemotherapy or radiotherapy (n=37)	97	40	60
Blood products (n=36)	96	18	65
Resuscitation (n=30)	65	11	53
Dialysis (n=20)	100	-	46
Estimated shortening of life§			
<24 h (n=461)	91	11	64
1-7 d (n=290)	90	15	78
1-4 wk (n=170)	96	23	84
>1 mo (n=99)	98	21	73
All non-treatment decisions in 1995 (n=1097)	93	14	73
All non-treatment decisions in 1990¶ (n=991)	100	11	72

* Non-treatment decisions as most important end-of-life decisions.

† From 89 respondents (7%), information about the involvement of others in the decision-making was missing; these cases were excluded from analysis.

‡ Patients in whom more than one type of treatment was forgone are represented at each particular treatment.

§ In 77 cases the estimated shortening of life was unknown.

patient were that “the decision was clearly the best one for the patient” (38%) and “discussion would have done more harm than good” (13%).

Of patients who were not fully competent, 14% were involved in the decision-making process, and in another 13% of patients the physician had information about the patient’s previous wish. The most frequently mentioned reasons for not

Table 9.4 (continued)

	Discussion with†		
	Neither patient nor relatives; no information available about previous patient wishes	Physician’s colleague	No one
Treatment forgone‡			
Artificial nutrition or hydration (n=336)	9	45	2
Antibiotics (n=234)	13	54	5
Vasopressors (n=109)	22	72	2
Other medication (n=169)	16	52	7
Mechanical ventilation (n=171)	27	92	1
Surgery (n=87)	14	73	2
Hospital admission or diagnostics (n=91)	19	47	4
Chemotherapy or radiotherapy (n=37)	5	59	3
Blood products (n=36)	24	71	4
Resuscitation (n=30)	35	85	6
Dialysis (n=20)	31	76	-
Estimated shortening of life§			
<24 hrs (n=461)	25	57	7
1-7 days (n=290)	11	57	2
1-4 weeks (n=170)	8	45	1
> 1 month (n=99)	12	58	2
All non-treatment decisions in 1995 (n=1097)	17	56	4
All non-treatment decisions in 1990¶ (n=991)	18	53	8

¶ Pijnenborg et al¹¹ only asked directly about the patient’s competence in cases in which the decision had been discussed with the patient. If the decision had not been discussed with the patient, the patient’s possible incompetence could only be established indirectly from the motives for not discussing the decision, enabling the researchers to distinguish between ‘not (fully) competent’ and ‘competence uncertain’.

discussing the decision with a patient who was not fully competent were that the patient was unconscious (51%) or that the patient had dementia (41%).

The non-treatment decision was discussed with colleagues relatively often when it concerned mechanical ventilation (92%), resuscitation (85%), or dialysis (76%) (Table 9.4). The patient's relatives were relatively frequently involved in the decision-making when artificial nutrition or hydration (83%) or antibiotics (81%) were forgone. Of all non-treatment decisions, 17% were made without discussion with the patient or the patient's relatives and with no knowledge of the patient's wishes. In 4% of patients, the physician had discussed the decision with no one.

The physician estimated that life was shortened by 24 hours or less in 42% of non-treatment decisions, by 1 day to 1 week in 28%, by 1 week to 1 month in 15%, and by 1 month or more in 8% (no data were available on the estimated shortening of life in 7%). When life was shortened by 24 hours or less, relatively frequently, the decision had been made without involvement of the patient or the patient's relatives and without information about the patient's previous wishes (25%).

Comment

In the Netherlands, decisions to forgo life-prolonging treatment are frequently made end-of-life decisions.⁸ The present study shows that the incidence of non-treatment decisions increased between 1990 and 1995,¹¹ which may have resulted from increasing possibilities to sustain life in an ageing society together with a growing awareness among patients and physicians that preservation of life should not be the only goal of medicine.

Although several empirical studies on non-treatment decisions preceding death have been done elsewhere, to our knowledge, there is no other nationwide study. Most other studies concern a particular hospital or a particular department, mainly intensive care units,^{1,4,6,7,14} or a particular group of patients, such as patients with end-stage chronic diseases¹⁵ or elderly people.³ Therefore, comparability is limited.

In our study, artificial nutrition or hydration and antibiotics were the treatments most frequently withheld or withdrawn. Our results apparently differ in this respect from the many other studies on non-treatment decisions in which high-technology treatments were most often forgone. For instance, in intensive care units mechanical ventilation is the form of life support most frequently withdrawn.^{1,4,6} Two other studies^{2,5} on non-treatment decisions preceding hospital deaths, 1 of which involved only patients receiving acute care, showed that patients for whom dialysis, intubation, or mechanical ventilation was considered declined those particular treatments more frequently than if antibiotics or intravenous fluids were involved. Note that all these studies focus on particular patient

categories for whom a particular treatment was considered or patients who already received that treatment. On the other hand, the pattern in these other studies corresponds to the results of a survey of physicians' attitudes toward the withdrawal of different forms of life-sustaining treatment under varying clinical circumstances, showing that physicians prefer to withdraw forms of life support that can be described as scarce, expensive, artificial, or high technology; of 8 forms of life support, blood products are the most likely to be withdrawn and intravenous fluids the least.¹⁶ Some studies^{2,4,5} conducted in the hospital or intensive care unit also mention a high proportion of do-not-resuscitate orders. In the 1990 study,¹⁰ unlike the 1995 study, the decision not to resuscitate in cases of cardiac or respiratory arrest was specifically studied: we found that do-not-resuscitate orders were in effect in a large proportion of hospital deaths (61%).¹⁷ In the present study, we did not ask respondents about anticipatory do-not-resuscitate decisions but about actual decisions to withhold or withdraw resuscitation that (probably or certainly) resulted in shortening of life.

Logistic regression analysis adjusting for the patient's age, sex, and cause of death showed a difference in non-treatment decisions between 3 major types of physician specialty; such decisions were made significantly more frequently by nursing-home physicians (52%) and clinical specialists (35%) compared with general practitioners (17%). Clinical circumstances and patient characteristics other than age, sex, and cause of death may account for these differences. The motives for making non-treatment decisions did not come within the scope of the present study, but from the 1990 study we know that the wish of the patient was the most important reason (74%) when the non-treatment decision was made at the patient's explicit request. For non-treatment decisions that were not made at the patient's explicit request, the most important considerations to forgo treatment were 'no chance of improvement' and 'the futility of further treatment' (72%).¹¹

Compared with euthanasia or physician-assisted suicide, non-treatment decisions have less far-reaching consequences in terms of shortening (or not prolonging) life. In euthanasia and physician-assisted suicide, the estimated shortening of life was 24 hours or less in 17%, 1 day to 1 week in 42%, 1 week to 1 month in 32%, and 1 month or more in 9%⁸; in non-treatment decisions, these percentages were 42%, 28%, 15%, and 8%, respectively (the shortening of life was unknown in 0% of euthanasia and physician-assisted suicide and 7% of non-treatment decisions).

Of the patients for whom a non-treatment decision was the most important end-of-life decision, 67% were not fully competent. Information about a patient's previous wish was available in 13% of not fully competent patients for whom a nontreatment decision was made (see "Results" section). Although there is a broad-based consensus that in such cases the patient's partner or relatives should be involved in the decision-making, a number of non-treatment decisions in our study

were made without discussion with the patient or his or her relatives. This lack of discussion is no exceptional finding. Of decisions to withhold cardiopulmonary resuscitation in incompetent patients admitted to a public teaching hospital, 21% had not been discussed with family members.¹⁸ Of physicians in intensive care units, 25% reported forgoing life-sustaining treatment because of futility of continuing treatment without the patient's or the patient's relatives' consent.¹⁴ Motives can also be practical; for example, relatives could not be found in one case.¹ However, in exceptional cases, physicians in our study failed to discuss the non-treatment decision even with competent patients because they thought the decision was clearly the best for the patient.

Our study shows that decisions to forgo life-prolonging treatment are frequently made end-of-life decisions and may be increasing. The future importance of these decisions is likely to be even greater, warranting more attention for these decisions in research, in the ethical debate, and in education of physicians and the general public. The quality of the decision making may benefit from openly studying and deliberating the subject, which especially holds for non-treatment decisions that for various reasons cannot be discussed with the patient or the patient's relatives.

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References

1. Smedira NG, Bradley HE, Grais LS, et al. Withholding and withdrawal of life support from the critically ill. *N Engl J Med* 1990;322:309-15.
2. Faber-Langendoen K, Bartels DM. Process of forgoing life-sustaining treatment in a university hospital: an empirical study. *Crit Care Med* 1992;20:570-7.
3. Fried TR, Gillick MR. Medical decisionmaking in the last six months of life: choices about limitation of care. *J Am Geriatr Soc* 1994;42:303-7.
4. Wood GG, Martin E. Withholding and withdrawing life-sustaining therapy in a Canadian intensive care unit. *Can J Anaesth* 1995;42(3):186-91.
5. Faber-Langendoen K. A multi-institutional study of care given to patients dying in hospitals: ethical and practical implications. *Arch Intern Med* 1996;156:2130-6.
6. Keenan SP, Busche KD, Chen LM, McCarthy L, Inman KJ, Sibbald WJ. A retrospective review of a large cohort of patients undergoing the process of withholding or withdrawal of life support. *Crit Care Med* 1997;25:1324-31.
7. Wall SN, Partridge JC. Death in the intensive care nursery: physician practice of withdrawing and withholding life support. *Pediatrics* 1997;99:64-70.
8. Van der Maas PJ, van der Wal G, Haverkate I, et al. Euthanasia, physician-assisted

- suicide, and other medical practices involving the end of life in the Netherlands, 1990-1995. *N Engl J Med* 1996;335:1699-705.
9. Van der Wal G, van der Maas PJ, Bosma JM, et al. Evaluation of the notification procedure for physician-assisted death in the Netherlands. *N Engl J Med* 1996;335:1706-11.
 10. Van der Maas PJ, van Delden JJM, Pijnenborg L, Looman CWN. Euthanasia and other medical decisions concerning the end of life. *Lancet* 1991;338:669-74.
 11. Pijnenborg L, van der Maas PJ, Kardaun JWPF, Glerum JJ, van Delden JJ, Looman CW. Withdrawal or withholding of treatment at the end of life: results of a nationwide study. *Arch Intern Med* 1995;155(3):286-92.
 12. Van der Maas PJ, van Delden JJM, Pijnenborg L. Euthanasia and other medical decisions concerning the end of life. *Health Policy* 1992;22:1-262.
 13. Centraal Bureau voor de Statistiek. *Statistisch Jaarboek 1997*. Voorburg, the Netherlands: Centraal Bureau voor de Statistiek, 1997.
 14. Asch DA, Hansen-Flaschen J, Lanken PN. Decisions to limit or continue life-sustaining treatment by critical care physicians in the United States: conflicts between physicians' practices and patients' wishes. *Am J Respir Crit Care Med* 1995;151:288-92.
 15. Hanson LC, Danis M, Garrett JM, Mutran E. Who decides? Physicians' willingness to use life-sustaining treatment. *Arch Intern Med* 1996;156:785-9.
 16. Asch DA, Christakis NA. Why do physicians prefer to withdraw some forms of life support over others? *Med Care* 1996;34:103-11.
 17. Van Delden JJM, van der Maas PJ, Pijnenborg L, Looman CWN. Deciding not to resuscitate in Dutch hospitals. *J Med Ethics* 1993;19(4):200-5.
 18. Hanson LC, Danis M, Mutran E, Keenan NL. Impact of patient incompetence on decisions to use or withhold life-sustaining treatment. *Am J Med* 1994;97:235-41.

PART **V**

General discussion
and summary

10

General discussion

10.1 Introduction

This chapter describes the main findings and conclusions of this thesis.

The retrospective questionnaire study among Dutch psychiatrists that was done in 1995/1996 addressed psychiatrists' experiences and practices with regard to requests for physician-assisted death made by patients under their treatment (Chapter 2 of this thesis),¹ their role as consultant with regard to patients' requests for physician-assisted death (Chapter 3), and their attitudes towards euthanasia or physician-assisted suicide in patients suffering from a mental disorder (Chapter 4). In section 10.2.1, the practice of physician-assisted suicide or euthanasia in patients with a mental disorder will be further discussed. The importance of psychiatric consultation is discussed in section 10.2.2.

The nationwide studies on medical practices involving the end of life in the Netherlands also provided insight into the frequency of the use of potentially life-shortening drugs (Chapter 6), into the intentions with which such drugs were used (Chapters 6 and 7), and into a number of technical aspects, such as the types and dosages of drugs used (Chapters 6, 7 and 8) and the clinical problems that may occur with the performance of euthanasia or physician-assisted suicide (Chapter 8).² In section 10.3.1, the practice of using potentially life-shortening drugs without the explicit intention of hastening the patient's death (i.e. taking into account the probability or certainty that the end of the patient's life would be hastened as a result, or only partly with the intention of hastening the end of life), or the alleviation of pain and symptoms, will be briefly discussed. Section 10.3.2 concerns the clinical aspects of the use of life-shortening drugs with the explicit intention to hasten death, such as in euthanasia, physician-assisted suicide, and ending of life without the patient's request.

The non-treatment decisions studied (Chapter 9) involve decisions to withhold or withdraw treatment that might possibly result in shortening the patient's life. Compared with 1990, the number of non-treatment decisions had increased in 1995. The interview study 1990/1991 already showed that over the course of their career, almost half of all Dutch physicians had become less aggressive in treating terminally ill patients.³ Acknowledging that relieving a patient's meaningless suffering while accepting the imminence of death can also be an important goal of medicine has become less controversial. Section 10.4 is focused on the clinical circumstances of non-treatment decisions and on the types of treatment forgone. Finally, this section will go into the patient's involvement in decisions to forgo potentially life-prolonging treatment.

This chapter concludes with a number of recommendations for future research (section 10.5).

10.2 Psychiatrists' role in end-of-life practices

10.2.1 Physician-assisted death in patients with a mental disorder

Practices

Until 1996, empirical data on physician-assisted suicide in patients with a mental disorder in the Netherlands were scarce. The Dutch nationwide study on end-of-life practices dating from 1990/1991 indicated that a mental disorder had been the underlying cause of death in 1% of cases of euthanasia and physician-assisted suicide.⁴ In a retrospective study of cases of euthanasia and physician-assisted suicide in Dutch family practice conducted in the same period, it was found that in 0.8% of the patients, the main diagnosis had been a depressive disorder.⁵ Case reports and published court decisions are another source of information about physician-assisted death in patients with a mental disorder.⁶⁻⁸ The 1995/1996 study among Dutch psychiatrists provided important new data on physician-assisted death in psychiatric patients.

It was estimated that, in the Netherlands, a psychiatrist offers assistance in suicide to a patient who is under his or her treatment in 2 to 5 cases per year (Chapter 2).¹ As Dutch psychiatrists receive about 320 requests for physician-assisted suicide per year, this means that the large majority of the requests are refused. Psychiatrists, therefore, rarely assist with suicide, particularly compared to other fields of medical practice, where in 1995 about 37% of all 9,700 explicit requests for euthanasia or physician-assisted suicide were acceded to.⁹

Most cases of psychiatrist-assisted death, moreover, involved patients also suffering from a serious physical illness, often in the terminal phase. The concomitant physical disorder may well have played a decisive role in the psychiatrist's decision to assist these patients. Physician-assisted suicide because of suffering from a mental disorder alone probably is even rarer in Dutch psychiatric practice. A similar pattern was seen in an evaluation of 43 registered assisted suicides between 1992 and 1997 in the Swiss region of Basel: there was a psychiatric history in six such suicides, of which four involving patients also suffering from a serious physical illness.¹⁰

The most common reason for psychiatrists to reject requests for physician-assisted suicide proved to be that the patient was suffering from a treatable mental disorder (in 61%). Other important reasons included doubt about the patient's suffering (32%), about the patient's wish to die (23%) or about the patient's competence (23%) (Chapter 2).¹ These concerns illustrate the complexity of the decision-making with regard to end-of-life practices in patients suffering from a mental disorder, which, together with the aforementioned reticence of this group in

this respect, express the utmost caution with which psychiatrists approach this issue.

Attitudes

The 1995/1996 study on psychiatrists' role in physician-assisted death shows that around two thirds of Dutch psychiatrists thought that physician-assisted suicide that is prompted by a mental disorder could be acceptable (Chapter 2).¹ An interview study that was done in the context of the same nationwide study of medical practices involving the end of life, showed this was 46% for physicians from other medical specialties.⁹ By comparison, therefore, psychiatrists were more liberal in their attitude towards physician-assisted suicide in patients with a mental disorder.

Chapter 4 shows that 31% of Dutch psychiatrists had over the years adopted a more lenient stance towards physician-assisted suicide prompted by mental suffering, with another 21% changing in a more restrictive direction. While this may suggest a tendency towards a more liberal attitude, this does not necessarily imply a more liberal practice. Of the psychiatrists who thought that physician-assisted suicide prompted by mental suffering could be acceptable in exceptional cases, nearly one third were unable to conceive of a situation in which they themselves would be prepared to assist (Chapter 2).¹ The reasons given by these psychiatrists for not being able to do so included their professional attitude (54%), the possibility of a false judgement (28%), fear of prosecution or sentencing (25%) and the policy of the institution where they worked (21%) (Chapter 4). When assistance in the suicide of psychiatric patients is indeed considered, psychiatrists attach importance to several official and unofficial requirements for careful decision-making, such as that the request should be well-considered and voluntary, that there should be no hope of improvement and no effective treatment alternatives (Chapter 2).¹ In the event that any of the foregoing aspects should fail to be fulfilled, psychiatrists will decide not to accede to their patients' requests.

Careful practice

In the Netherlands, a physician who assists in a patient's death will not be prosecuted if a number of criteria for careful practice are met. The most important criteria state that euthanasia and physician-assisted suicide at the explicit request of a patient may be justified if the patient's suffering is hopeless and unbearable, and if the patient's request for hastening death was voluntary and well-considered.

From the beginning of the debate on euthanasia and physician-assisted suicide, hopeless and unbearable suffering were mostly understood to refer primarily to suffering in a late stage of a physical disease. Mental disorders are

generally not lethal and have only limited impact on the patient's life expectancy. Therefore, euthanasia and physician-assisted suicide are more controversial for patients with a mental disorder than for terminally ill patients. Nevertheless, the Dutch Supreme Court in 1994 acknowledged that in exceptional cases mental suffering can be a reason to assist in suicide.^{7,11} Since then, it has been officially confirmed that physician-assisted death in the Netherlands is not a practice that exclusively involves patients in the terminal stage of their disease. However, when a patient's suffering is not caused by a physical illness, jurisprudence and guidelines of the medical profession demand extreme carefulness.^{11,12}

The extent to which a patient's suffering is hopeless addresses treatment options and prognostic factors. Suffering is not hopeless if there are any realistic treatment alternatives which the patient has in complete freedom rejected.^{7,11} A treatment alternative is considered realistic if it, according to current medical knowledge, can offer prospect of improvement, within a surveyable period of time and with an acceptable balance between the expected outcome and the suffering caused by treatment.¹² In Chapter 2 it was shown that psychiatrists refused to grant a patient's request for physician-assisted death because the mental disorder could be treated in 61%.¹ The Dutch Association for Psychiatry states that the course of many, if not all, mental disorders cannot be predicted with absolute certainty.¹² For some psychiatrists, experiences with unforeseen recovery provided a reason for less permissiveness towards assisted death in psychiatric patients (Chapter 4). In general, psychiatrists attached more importance to the duration and character of the previous treatment than to the duration and burden of remaining treatment alternatives. These aspects were thought to be (very) important by 88% and 62% of Dutch psychiatrists, respectively (Chapter 2).¹

Another important issue in the debate on physician-assisted suicide in patients with a mental disorder is the patient's competence. The presence of a mental disorder does not necessarily mean that the patient is incompetent. Psychiatrists considered 32% of the psychiatric patients requesting physician-assisted suicide adequately able to assess the situation and to make a competent decision about it (Chapter 2).¹

An additional requirement for careful practice involves consultation by another physician. The consultation should *inter alia* address the diagnosis, prognosis and possible treatment alternatives. The uncertainty surrounding these aspects makes consultation with another physician about such even more important. In 1994, the Dutch Supreme Court stated that if a patient is suffering from a mental disorder, the consulted physician should see and examine the patient him- or herself before giving his or her opinion.¹¹ Of the 43 psychiatrists who had contemplated acceding to a patient's request, 40 had consulted one or more colleagues. In four of the 43 cases the patient's request resulted in physician-assisted suicide. Among the reasons that the other psychiatrists gave for refusing their patients' requests was

that the consultant advised against it in 26% (Chapter 2).¹ Psychiatric consultation with regard to patients' requests for euthanasia or physician-assisted suicide is further discussed in the next section (10.2.2).

In 1998, the Dutch Association for Psychiatry published guidelines to assist psychiatrists in careful decision-making with regard to requests for assistance with suicide.¹² According to these guidelines, the decision-making process should always be premised on the assumption that the request for assisted suicide be seen as a cry for help, with psychiatrists providing assistance in suicide in exceptional cases only.

Physician-assisted death to patients with a mental disorder outside psychiatric practice

The study described in part II of this thesis focused on the experiences of Dutch psychiatrists with requests for physician-assisted death by patients under their treatment. Chapter 3 deals with psychiatrists' role as consultant with regard to patients' requests for physician-assisted death addressed to colleagues - psychiatrists or physicians from other specialties.

Part of the consultations described concerned patients who requested their general practitioner or clinical specialist to assist in their death because of mental suffering. Of the 67 such requests granted, 14 concerned patients suffering from a mental disorder. As psychiatrists are rarely consulted about requests for euthanasia or physician-assisted suicide¹³, the cases described in Chapter 3 only represent a small part of all cases of euthanasia or physician-assisted suicide that occur outside psychiatric practice. Although the figures suggest that assistance in suicide for psychiatric patients may be provided more often by other physicians than by psychiatrists, the total number of such cases is probably still very low. Another part of the 1995/1996 study showed that, according to the attending physician, depression had been predominantly present in about 3% of all cases of physician-assisted death occurring outside psychiatric practice, although in none of these was a mental disorder mentioned as the main diagnosis.¹⁴

Violent suicide

The study on physician-assisted death in Dutch psychiatric practice revealed that of psychiatric patients whose requests for assistance in suicide were refused, 16% ended their lives without assistance from a physician (Chapter 2).¹ Although no further information about these suicides was available, it is not unlikely that some of the patients chose to end their lives in a violent manner. In the discussion about physicians providing assistance to suicides, the physicians' role as gate keepers to

lethal medication is often cited as one of the justifications for such assistance: access to the necessary medication will enable suicidal people to end their lives worthily and mildly.¹² Without the assistance of a physician, patients seeking to commit suicide are forced to use other, crueller, riskier or more violent suicide methods. Instead of a peaceful death, the end is traumatic for everyone involved, while patients can do irreversible harm to themselves without reaching the desired effect of death.¹⁵ Some psychiatrists, however, feel that patients are perfectly capable of committing suicide without help and that killing patients should not be part of professional medical practice (Chapter 4). On the other hand, of the psychiatrists who could conceive of a situation in which they themselves would be prepared to assist, the threat of a violent suicide was considered by 33% to be a (very) important factor in making a decision. In 2 of 11 cases where psychiatrists actually helped their patients to commit suicide, prevention of violent suicide was among the main reasons for providing their assistance (Chapter 2).¹

10.2.2 Psychiatric consultation in terminally ill patients suffering from a physical disease

In the Netherlands, psychiatric consultation about requests for physician-assisted death in terminally ill patients is not very common. Psychiatric consultation takes place in about 3% of all explicit requests for physician-assisted death, and also in 3% of the cases in which the patient's request was acceded to.¹³ In three out of four cases, psychiatrists are called in for consultation by general practitioners or clinical specialists, and most of the patients concerned suffer from a physical disease (Chapter 3).

In Oregon, legislation requires that physicians seek psychiatric consultation when they suspect depression or another mental disorder in a patient requesting euthanasia or physician-assisted suicide.¹⁶ In the Netherlands, according to jurisprudence and professional guidelines, a colleague or medical expert should be consulted in such cases, preferably a psychiatrist.^{11,17}

It has been suggested that requests for euthanasia or physician-assisted suicide may be the result of (undiagnosed) depression more frequently than generally assumed. Empirical studies show that the prevalence of depressive and other mental disorders in terminally ill patients is high. However, the prevalence of mental disorders in terminally ill patients varies between the studies as a result of the different diagnostic instruments and symptom-severity thresholds that are used.¹⁸ Although the real prevalence of mental disorders in terminally ill patients is unknown, the chance that a patient who shows interest in euthanasia or physician-assisted suicide is depressed or is suffering from another mental disorder is relatively high.¹⁹⁻²¹ From this perspective, early recognition and treatment of depression might result in a decrease of patients' requests for euthanasia or

assisted suicide. The question remains to what extent treatment of a mental disorder in a terminally ill patient who requests euthanasia or physician-assisted suicide is meaningful. Studies have shown that patients who received antidepressant treatment, no longer wished to die.²² However, in many patients who ask for assistance in dying, the remaining life expectancy is limited and possibly too short for such treatment to be effective. Therefore it is important to know how long it will take before antidepressant treatments can become effective in these patients.²³ It is also important to remember that successful treatment of depression or another mental disorder may not alter the hopelessness and seriousness of the patient's suffering, because concerns about unworthy or undignified dying have been shown to be major factors.

Consultation is important if the attending physician is considering acceding to the patient's request or if he or she is unsure about refusing it. The question is whether a psychiatrist should be called upon for consultation in all such cases, or only in cases where the responsible physician suspects depression or another mental disorder. Physicians without psychiatric training may not recognise a depressive syndrome in terminally ill patients or wrongly see this as a natural response to physical suffering. Therefore, terminally ill patients who ask for assistance in dying may benefit from psychiatric help in some cases.^{24,25} Some authors are of the opinion that such psychiatric consultation should be mandatory.^{26,27} In the literature, however, a number of objections against mandatory psychiatric consultation in terminally ill patients who request euthanasia or physician-assisted suicide are raised.²⁸⁻³⁰ Mandatory assessment is considered an inappropriate medicalisation. In the first place, a patient's wish to die is not necessarily the result of depression. Secondly, the presence of a mental disorder does not always imply that the patient's competence is impaired.

10.3 Potentially life-shortening drugs used at the end of life: physicians' practices

10.3.1 Alleviation of pain and symptoms; use of potentially life-shortening drugs

Pain management at the end of life

Appropriate alleviation of pain and symptoms, such as gastrointestinal symptoms, dyspnoea, delirium and depression, is part of good end-of-life care. Management of these symptoms often involves the use of analgesics, including opioids, and sedatives. In some cases, adequate symptom management requires such large

dosages of analgesics or sedatives that hastening of the patient's death may be the result. Medical literature contains many empirical studies on the efficacy of pain and symptom management and ethical reflections on the hastening of death as a possible result of using opioids. In contrast, the number of empirical studies that address the potentially life-shortening effect of pain and symptom management is limited.

The hastening of death as an unintended but inevitable side effect of the alleviation of pain and symptoms with morphine in large dosages is widely accepted. The moral justification of hastening the patient's death as a result of high dosages of analgesics or sedatives given for symptom management is often addressed by invoking the principle of double effect³¹, which distinguishes this practice from cases where hastening of death is explicitly intended. In spite of the broad acceptance of hastening death as an unintended side effect, however, clinicians' fear of hastening death may be one of the causes of undertreatment of pain. Many dying patients in developed countries do not receive adequate symptomatic relief.³² At least in the USA, specific groups of patients, in particular the elderly, patients in nursing-homes, minorities and women, are at risk for undertreatment of pain.³³⁻³⁵ Of American physicians, 41% believe that fear of hastening death is most often the cause of inadequate pain medication, even though 89% believe that it is sometimes appropriate to give pain medication to relieve suffering, even if this may hasten a patient's death.³⁶ In the Netherlands, 5% of physicians would never give morphine to alleviate pain and symptoms in dosages that would shorten the patient's life. This percentage was higher for Dutch nursing-home physicians (11%) than for general practitioners or clinical specialists (5% and 4%, respectively).⁹

The Dutch studies on medical practices involving the end of life provide no information on the extent to which pain management is inadequate in end-of-life care. An evaluation of pain treatment in 313 Dutch cancer patients, however, showed that the pain treatment was not satisfactory in 31%. According to outcome measures that were based on drug choice and the patient's pain intensity, 51-60% received less than optimal analgesics.³⁷ The degree to which physicians ascribe life-shortening effects to the use of opioids at the end of life may partly explain this undertreatment of pain and other symptoms.

Drugs and dosages used

Apart from cases where the drugs used were not specified (in 13%), opioids were used in almost all cases of alleviation of pain or symptoms. Barbiturates and benzodiazepines were also used, but to a much lesser extent (Chapter 6). In 0.1% of cases, neuromuscular relaxants were used. These cases mainly involved neonates.⁹

Of the patients in whom the alleviation of pain or symptoms with opioids or

comparable drugs in large doses had been the most important end-of-life decision, 78% were 65 years or older and more than half died from cancer.³⁸ The specific circumstances in which the varying types of drugs were used were not studied. Opioids generally are used to relieve a patient's pain or dyspnoea. Sedatives play a role in the treatment of delirium or depression. Neuromuscular relaxants can be used when, for instance, mechanical ventilation is withdrawn.

Unfortunately, information about the dosages of the medications was missing in a large proportion of cases. However, the median dosage of morphine given in the last 24 hours before death could be calculated for 801 cases: this dosage was 30 mg (range: 5-240) (Chapter 6). Data on morphine doses in more than 800 patients being cared for until death in a German anaesthesiology-based pain service, where therapy was based on the WHO guidelines for treatment of cancer-related pains, showed that the median dose when morphine was stopped or when the patient died was 60 mg / day (range: 30-120).³⁹ Thus, the range of dosages in cases where the physician at least took into account a possible life-shortening effect largely overlaps with common opioid dosages.

Shortening of the patient's life

The 1990/1991 and 1995/1996 studies provided quantitative data about the estimated shortening of life as a result of the use of potentially life-shortening drugs without the explicit intention to hasten the patient's death. The physician estimated that the patient's life had been shortened by less than 24 hours in 64% of cases, and by less than one week in another 16%.³⁸ In cases where opioids were the drugs with the highest lethal potential (Chapter 7), life was estimated to have been shortened by less than 24 hours in 80% of all cases where the possibility of hastening death had only been taken into account, and 56% of the cases where death was partly intended. Life was probably not shortened at all in 58% and 24%, respectively.

These are physicians' estimations; the actual shortening of life caused by the use of the drugs is obviously not known. In most cases it is probably very small or absent. This applies in particular to cases where opioids were used. In the first place, there is doubt about the overall life-shortening potential of opioids. Secondly, the dosages used were relatively low. It cannot be ruled out that physicians sometimes overestimate the life-shortening effect of opioids or comparable drugs.

The possible life-shortening effect of opioids and other drugs was also addressed in a number of other studies. In an American study, treatment doses of narcotics or major sedatives within 4 hours of death, were viewed as having life-shortening potential. Such doses were given to 54 (46%) of 118 comatose pancreatic cancer patients. Thus, aggressive narcotic therapy for pancreatic patients near death is rather common with tacit acceptance by family members, in spite of

related life-shortening potential.⁴⁰ A retrospective analysis of opioid use in the last week of life in 238 patients who died in a London hospice unit, showed that 28 patients had received a marked increase in opioid dose; patients who received opioid increases did not show shorter survival than those who received no increases.⁴¹ In another American study, opiate analgesia was provided to 84% of infants as their life support was either withheld or withdrawn, but the time until death after the discontinuation of ventilatory support was not associated with opiate analgesia.⁴²

Non-treatment decisions and the alleviation of pain and symptoms

Most studies concern the administration of sedatives and analgesics in the context of a decision to withhold or withdraw treatment. The ordering and administration of sedatives and analgesics during the withholding and withdrawal of life support from critically ill patients was studied in a prospective case series in two intensive care units in San Francisco. Such drugs were given to 33 of 44 patients: to decrease pain in 88%, to decrease anxiety in 85%, to decrease air hunger in 67%, to comfort family members in 52% and to hasten death in 36%. In no instance was hastening death cited as the only reason for ordering drugs. Most patients received both benzodiazepines and opioids, or opioids only, and 9% also received neuromuscular relaxants at the time of withholding and withdrawal of life support. Whether death was actually hastened by the administration of sedatives and analgesics during the withholding and withdrawal of life support remained unclear; death occurred even later in the patients who received drugs, although the difference with patients who did not was not statistically significant.⁴³ Of 53 patients who died in pediatric intensive care units in Boston after the withdrawal of life-sustaining treatment, 89% received sedatives or analgesics. According to the physicians and nurses involved, hastening death was an important reason for giving palliative medications in 4% and 6% of the cases, respectively. Administration of these medications was viewed as an "acceptable, unintended side effect" of terminal care by 91% of physician-nurse pairs.⁴⁴ In the Netherlands, 30% of all deaths are preceded by a decision to withhold or withdraw potentially life-prolonging treatment (Chapter 9).⁴⁵ In 14% of all deaths, the non-treatment decision was made along with a decision to use potentially life-shortening drugs without the explicit intention of hastening death.^{9,46}

10.3.2 Physician-assisted death (euthanasia, physician-assisted suicide, ending of life without the patient's request); use of drugs with the explicit intention of hastening death

The use of life-shortening drugs with the explicit intention of hastening death is less frequently practised than the alleviation of pain or symptoms. In Part III of this thesis some clinical aspects of physician-assisted death were described, in particular the methods that were used and the course after the administration of the drugs until the patient's death.

Euthanasia and physician-assisted suicide

Guidelines and practice. When a physician intends to end the patient's suffering by ending the patient's life, the choice of drugs is determined by this intended effect. Drug(s) should not only be lethal, but also guarantee a comfortable death. Undesired (side) effects or complications should be prevented as much as possible.⁴⁷ In the Netherlands, the first recommendations on the practical aspects of euthanasia were published in the seventies. In 1987, the Dutch Association for the Advancement of Pharmacy issued guidelines on the use and preparation of drugs to perform euthanasia or assist in suicide. These guidelines recommend a neuromuscular relaxant for parenteral use, and a high dose of barbiturate for oral administration.^{48,49}

In Dutch medical practice, the guidelines of the Dutch Association for the Advancement of Pharmacy are followed in most cases (Chapters 6 and 8). However, in almost one third of euthanasia cases, barbiturates or opioids were chosen to end the patient's life and in 8% of assisted suicides opioids were used (Chapter 8).² In 1995/1996, the guidelines about the type of drugs were more frequently followed than in 1990/1991.⁹ Probably, the use of appropriate drugs has further increased since then. However, in the year 2000 the regional review committees for physician-assisted death were still turning up cases in which the physician had not used the recommended dosages. In those cases, the guidelines are sent to the physician involved.⁶⁰

Clinical problems. The performance of physician-assisted suicide or euthanasia may sometimes involve clinical problems (Chapter 8).² Although the seriousness of these types of problems varies, any problem may seriously disturb a peaceful death. Nausea, for example, is a very unpleasant and unwelcome event when patients, their relatives and the physician are relying on a harmonious and peaceful death, and as such cannot be compared to nausea as an adverse effect in other circumstances.

In most cases of euthanasia and physician-assisted suicide, the duration of the interval between the administration of the first drug and the patient's death was as the physician had expected. In cases where the interval differed from the physicians' expectations, this was most frequently longer than expected: this was the case in 10% of euthanasia cases and in 19% of assisted suicides (Chapter 8).² A longer-than-expected interval, however, was reported as a real problem only in about 4% of euthanasia cases and in about 12% of assisted suicides. Thus, the actual duration of the time interval, the physicians' assessment of the interval and the physicians' expectations vary widely.

As euthanasia and physician-assisted suicide can not be openly practised in other countries, except for the state of Oregon in the USA where physician-assisted suicide – not euthanasia – is legally allowed, little is known about the clinical aspects of life-ending practices in other countries. Publications about the first two years of experience with the Oregon Death with Dignity Act show that of 42 patients who died in 1998 and 1999, 40 were prescribed 9 grams secobarbital (pentobarbital in one case). One patient was prescribed 6 grams of phenobarbital and one patient 1 gram secobarbital to be used with 1 gram morphine. No complications, such as vomiting or seizures were reported for these 42 patients.^{51,52} It is claimed that no complications in Oregon were reported because all patients received the recommended drugs.⁵³ The studies described in this thesis do not allow reliable estimates of possible associations between the occurrence of unintended effects and types or dosages of drugs. It seems quite likely, however, that not all problems and complications can be prevented, even if the recommended regimen for providing assistance with death is applied. After all, problems are inherent in any medical intervention.

Problems occurred less frequently with euthanasia than with physician-assisted suicide. However, the possible advantages and disadvantages of euthanasia over assisted suicide should be considered together with some other aspects. A study among Dutch general practitioners and nursing-home physicians showed that when there was a choice, euthanasia was chosen primarily for medico-technical reasons.⁵⁴ Technical problems in cases of euthanasia mainly concerned the intravenous route of administration (Chapter 8).² In rare cases, intravenous administration was even impossible. Physician-assisted suicide was chosen primarily for moral reasons⁵⁴; the autonomy of patients are better guaranteed in assisted suicide than in euthanasia.⁵⁵

Physicians should be aware of possible complications that may occur with the performance of euthanasia and physician-assisted suicide and should be trained to handle them adequately. The Dutch experience warrants the conclusion that the physicians' responsibility in physician-assisted suicide goes beyond the prescription of lethal drugs. This might occasionally demand actual injection of a lethal agent. The physician should take full responsibility for the entire process, until the

patient has died. Education and training, and the availability of trained consultants are even more important since most physicians will perform euthanasia or provide assistance with suicide only once or a few times in their careers and many will not know what to expect on the basis of their experience.⁵⁶

Ending of life without the patient's request

In contrast to cases in which life was ended at the request of the patient, cases in which life was ended without the patient's explicit request most frequently involved the use of opioids (Chapter 6). In these cases, 77% of the patients had been treated with morphine or comparable drugs for a longer time, but in 52% pain or symptoms could not be alleviated sufficiently.⁹ Physicians in those cases may have decided to increase dosages of opioids such that the patient's life was shortened. In general, patient and decision-making characteristics of cases of ending of life without the patient's request were more similar to cases involving alleviation of pain or symptoms with shortening of life as a possible side effect than to cases of euthanasia.³⁸

10.4 Decisions to forgo potentially life-prolonging treatment

Clinical circumstances

Age, cause of death and the physician's specialty are all independently related to the probability of a non-treatment decision being made: such decisions were made relatively often in elderly patients, for specific causes of death, in particular mental disorders, including Alzheimer dementia, diseases of the digestive tract and neurological diseases, and by nursing-home physicians compared to clinical specialists and general practitioners (Chapter 9).⁴⁵

Apparently in older patients, the balance of the burdens and benefits of prolonging the patient's life by continuing or starting treatment swings to a non-treatment decision more frequently than in younger patients. There are several reasons that may explain this. First, older people may more frequently choose themselves to refrain from prolonging their lives than younger patients. The quality of their lives may be affected by age-related factors, such as comorbid diseases and psychosocial circumstances, such as loneliness, and their life expectancy is limited. In addition, physicians may more frequently decide to refrain from life-prolonging treatment in older than in younger patients, because of the higher risk of complications of treatment in older patients. This might also explain why non-treatment decisions in older patients predominantly involve decisions not

to start treatment, whereas in younger patients they predominantly involve the withdrawal of treatment.³

The relation between non-treatment decisions and specific causes of death may be determined by various factors, such as the prognosis, the type and the degree of the patient's suffering, the availability of treatment options and the timing of the decision-making. For instance, the chance of meaningful recovery from neurological or mental diseases often is small compared to cardiovascular diseases. The finding that non-treatment decisions made by cardiologists or surgeons most frequently consisted of stopping a treatment, while for nursing-home physicians and neurologists withholding treatment was the most common decision², may illustrate the role of the patient's prognosis in the decision-making.

Non-treatment decisions relatively frequently preceded deaths in nursing homes and were less frequently made by clinical specialists and general practitioners. These differences may at least partly be explained by the different availability of treatment alternatives. The number of treatment options at home is often smaller than in institutional settings; high technology life-prolonging treatments, such as mechanical ventilation, and invasive treatments, such as artificial nutrition or hydration, are less common in general practice. This is very likely to result in less non-treatment decisions. Another explanation may be found in the medical condition of patients: patients who die at home may have less complicated disease processes than patients dying in nursing homes or hospitals. In the interview study 1990/1991, general practitioners and clinical specialists mentioned the burden of treatment as the most common reason for patients' requests to forgo life-prolonging treatment, whereas nursing-home physicians most frequently mentioned loss of dignity and tiredness of life.⁶⁷

Types of treatment forgone

Decisions to withhold or withdraw potentially life-prolonging treatment most frequently concerned (artificial) nutrition or hydration and antibiotics (Chapter 9).⁴⁵ Thus, decisions to forgo treatment with a potentially life-shortening effect do not predominantly involve 'high technology' types of treatment. This is probably due to the less frequent eligibility of patients for 'high technology' treatment, whereas situations in which (artificial) nutrition or hydration and antibiotics may be considered are more common. In a retrospective study of deaths that occurred in a tertiary care university hospital in Minnesota, dialysis, intubation, and mechanical ventilation were more frequently declined than antibiotics or intravenous fluids in patients for whom those particular treatments were considered.^{58,59} This corresponds with physicians' preferences concerning withdrawal of treatments, as found in another study: treatments that were preferably withdrawn were scarce, expensive, invasive, artificial, unnatural,

emotionally taxing, high technology, and rapidly fatal when withdrawn. Continuous rather than intermittent administration, and the causation of pain when withdrawn were negatively correlated with physicians' preferences.⁶⁰ The Minnesota study showed that resuscitation or endotracheal intubation were generally the first measures withheld; once a patient required a ventilator, withdrawing the ventilator, however, was a late decision.^{58,59}

Further analysis of the results of the death certificate study 1995/1996 showed that in patients of 80 years or older, more frequently less invasive treatments were forgone: in this age group, the non-treatment decision more frequently involved artificial nutrition or hydration, and hospital admission or further diagnostics than in patients aged 65-79, and less frequently mechanical ventilation, chemo- and radiotherapy or dialysis.⁶¹

Together with antibiotics, withdrawal or withholding of (artificial) nutrition and hydration is the most frequent non-treatment decision made at the end of life; such a decision preceded 8% of all deaths in the Netherlands (Chapter 9).⁴⁵ For deaths attended by nursing-home physicians this percentage was 23%, for deaths attended by general practitioners and specialists it was 4%.⁶² A decision to forgo artificial nutrition and hydration most frequently involved patients of 80 years or older who were partly or fully incompetent. Opinions vary about whether it is inhumane to 'starve' patients to death. Proponents believe that, in terminally ill patients, dehydration causes a mild death, and that old age, severe dementia or the terminal stage of cancer are accompanied by a physiological decrease of hunger and thirst. Apart from a number of small-scale observational studies, there is no empirical proof of this hypothesis.

Patient involvement in the decision-making

Two thirds of patients whose deaths were preceded by a non-treatment decision were incompetent at the time of the decision-making. This proportion was highest for non-treatment decisions by nursing-home physicians (83%) (Chapter 9).⁴⁵ Physicians made more than half of all non-treatment decisions without information about the patient's preferences.

The right of competent patients to refuse treatment is widely accepted, even if this should hasten the patient's death. According to Dutch law, a voluntary refusal of life-prolonging treatment by a competent adult must always be respected.⁶³ When the patient is incompetent, the physician should involve the proxy decision-makers. With their help, the physician may be able to reconstruct the patient's wish. However, whenever the physician judges that the treatment is medically futile, this professional judgement should be decisive.⁶⁴ As a consequence, competent patients who desire treatment have no right to such treatment if it is

considered medically futile by the physician. This was confirmed in a recent case of an 80-year old man with terminal cancer and lung emphysema, which was brought to court by his daughter in 1999. The daughter thought that her father was denied adequate medical care. After 6 weeks of intensive care because of post-surgical multiple organ failure, he was transferred to a medium care unit and his physicians refused to readmit him to the intensive care unit in case of further complications because this would involve treatment that was medically futile. The Court affirmed that the physician's judgement about the medical futility of the treatment should be decisive.

Physicians decided to forgo potentially life-prolonging treatment without discussing this with the patient or the patient's relatives most often when resuscitation, dialysis or mechanical ventilation were involved; in contrast, non-treatment decisions involving these types of treatment were the decisions most frequently discussed with colleagues. Apparently, physicians are less inclined to discuss decisions that have direct consequences for the survival of the patient with the patient's relatives. Perhaps such decisions may be seen as predominantly medical by nature, and thus requiring expert knowledge.

10.5 Recommendations for future research

Further empirically based knowledge of end-of-life decisions in medicine may contribute to transparent and rational medical decision-making, which may result in a better quality of care and an improved quality of the last stage in life. Research is recommended in the following areas:

Psychiatrists' role in end-of-life practices

Prospective study of requests for euthanasia or physician-assisted suicide. Patients' wishes to die are often not persistent over time (Chapter 2).¹ Dutch psychiatrists considered 30% of the explicit requests for physician-assisted suicide made by patients in therapy as not being persistent. A non-persistent request was often one of the reasons for them to refuse a patient's request. Of all psychiatric patients whose requests for physician-assisted suicide were described in our study, 35% no longer wished to end their lives at the time of the survey, and in 10% the requests had become less persistent than before. A prospective follow-up study of psychiatric patients' repeated and persistent requests for physician-assisted suicide may provide further insight into such requests. This study should address the meaning of the patient's request, the patient's suffering, and the psychiatrists' and other caregivers' management of the request.

Euthanasia or physician-assisted suicide to psychiatric patients outside psychiatric practice. The number of requests for euthanasia or physician-assisted suicide that patients with a mental disorder (or because of mental suffering) address to their family practitioners may be higher than the number of requests that such patients address to psychiatrists. This might imply that some cases of physician-assisted death in psychiatric patients fell outside the scope of our study. The response of general practitioners to explicit requests for physician-assisted death made by psychiatric patients, their assessment of the patient's competence, and the reasons for asking or not asking for psychiatric consultation should be further explored.

Prevalence of concurrent mental disorders in terminally ill patients. There is little empirical evidence about the prevalence of concurrent mental disorders in terminally ill patients, especially in patients who request euthanasia or physician-assisted suicide, nor is there much information about to what extent mental disorders in terminally ill patients are a cause factor of requests for assisted death. Research on this issue should also include the efficacy of the treatment of depression in terminally ill patients.

Time trend study. The 1995/1996 study on physician-assisted death in psychiatric practice was the first nationwide study on this subject (Chapters 2, 3 and 4).¹ This study showed a reluctant practice, despite a relatively liberal attitude. Whether this liberal attitude will be reflected in an increasing number of assisted suicides to patients with a mental disorder is not known, nor to what extent the professional debate, jurisprudence and changes in legislature may have influenced psychiatrists' attitudes towards assisted suicide in patients with a mental disorder. Replication of the 1995/1996 study on psychiatrists' practices and experiences regarding physician-assisted death would answer these questions.

Furthermore, developments in diagnostics and therapy, and more insight into the prognosis of mental disorders, may contribute to the debate on the acceptability of assisted suicides to psychiatric patients.

Potentially life-shortening drugs used at the end of life

Use of opioids in end-of-life care. Opioids were the most important drugs in cases where pain and symptoms were alleviated with a potentially life-shortening effect (Chapters 6 and 7). The studies described, however, did not provide information about the type and intensity of symptoms for which the patients received opioids. The prevalence of symptoms that result in opioid treatment or treatment with other potentially life-shortening drugs in terminally ill patients should be further studied, as well as the management of these symptoms. In order

to explore the possible limitations of managing a comfortable death by the use of opioids, the effects, including the extent to which pain or symptoms are relieved as well as the side effects, such as constipation, nausea, delirium or paranoia, should be monitored.

Pain and symptom management and the need for physician-assisted death. After publication of the results of the 1995/1996 nationwide study on end-of-life decisions in the Netherlands, politics and the medical profession called for higher quality palliative care. Prevention of euthanasia is mentioned as one of the aims of further development of palliative care.⁶⁵ A hypothesis is that if palliative care is appropriate, intentionally shortening of life no longer needs to be practised.⁶⁶⁻⁶⁸ On the other hand, in some patients high quality palliative care may not relieve the motives that result in requests for physician-assisted death. The various reasons for patients' requests for euthanasia or physician-assisted suicide – (fear) of deterioration, pain, unworthy dying, dependency, or the wish to be a burden to relatives no longer^{69,57} - raise the question whether palliative care in all instances can effectively address the reason for the patients' requests.⁶⁹ Some cases of euthanasia and physician-assisted suicide occurred in Dutch hospices, which are specialised in palliative care.^{50,70}

In order to study the relation between the adequacy of palliative care and end-of-life decisions, the patients' needs at the end of life have to be studied, as well as medical and other forms of care at the end of life. Such a study should address physical, mental, spiritual, social and possible other aspects of the patients' suffering.

Terminal sedation. Terminal sedation is defined as the explicit decision to use high doses of sedatives to render the patient unconscious to relieve severe, otherwise irreversible suffering.⁷¹ In medical literature, terminal sedation is often described as an option when palliative care is not effective.⁷²⁻⁷⁴

The death certificate study 1995/1996 showed that in about one tenth of cases where pain and symptoms were alleviated without the explicit intention of hastening death, benzodiazepines, propofol or barbiturates were used (Chapter 6). To what extent those sedatives were given to achieve terminal sedation is not known. It would therefore be interesting to study the occurrence of terminal sedation in the Netherlands.

Non-treatment decisions

Forgoing artificial nutrition or hydration. The controversy surrounding the withholding or withdrawal of (artificial) nutrition or hydration warrants further study into the frequency and background characteristics of such decisions.

Patients' characteristics, such as age, diagnosis and competence should be addressed, as well as the management of pain and symptoms during the process of starvation and the quality in the terminal stage of life according to the patient, the patients' relatives, the physician and other caregivers.

Factors influencing the physician's decision-making. Various considerations play a part in physicians' decisions to withhold or withdraw medical interventions or treatments. These considerations involve medical aspects, such as the efficacy of the intervention or the chance of complications or side effects, the patient's autonomy and other non-medical patient characteristics. The sequence of physicians' decisions to start or to forgo treatment, physicians' motives for these decisions and patient characteristics in carefully chosen, well-defined clinical situations, would give more insight into the factors that influence the physicians' decision-making. The results will be especially important for the evaluation of current clinical guidelines and the development of new ones.

Who decides? When a patient is incompetent, appointed as well as unappointed representatives have the authority to take decisions on the patient's behalf. The physician, however, retains his or her responsibility to test these decisions for medical effectiveness, and whether the representatives are actually representing or reconstructing the wish of the patient. A survey of physicians and patients' relatives about the care of incompetent patients near the end of life would furnish insight into the role that proxy decision-makers play in decisions to forgo treatment. One of the questions is whether and in what situations physicians and the patients' relatives agree or don't agree about non-treatment decisions to be made. Another important issue would be to compare the physicians' and the patients' relatives' assessment of the patient's quality-of-life and of the futility of the treatment. The results can be used to develop and improve clinical guidelines.

References

1. Groenewoud JH, van der Maas PJ, van der Wal G, et al. Physician-assisted death in psychiatric practice in the Netherlands. *N Engl J Med* 1997;336:1795-1801.
2. Groenewoud JH, van der Heide A, Onwuteaka-Philipsen BD, Willems DL, van der Maas PJ, van der Wal G. Clinical problems with the performance of euthanasia and physician-assisted suicide in The Netherlands. *N Engl J Med* 2000;342:551-6.
3. Pijnenborg L, van der Maas PJ, Kardaun JW, Glerum JJ, van Delden JJ, Looman CW. Withdrawal or withholding of treatment at the end of life. Results of a nationwide study. *Arch Intern Med* 1995;155:286-92.
4. Van der Maas PJ, van Delden JJM, Pijnenborg L, Looman CWN. Euthanasia and other medical decisions concerning the end of life. *Lancet* 1991;338:669-74.
5. Van der Wal G. Euthanasia and physician-assisted suicide by family doctors. Rotterdam: WYT Uitgeefgroep, 1992.

6. Chabot BE. Hulp bij zelfdoding: drie rechtszaken. Assisted suicide: three cases in court [in Dutch]. *Maandblad Geestelijke volksgezondheid* 1993;48:715-37.
7. Griffiths J. Assisted suicide in the Netherlands: the Chabot case. *Modern Law Review* 1995;58:232-48.
8. Schudel WJ, Nolen WA, van Dijk WK, Sutorius EPR. De zaak van de vasthoudende inspecteur. Een procedure in het medisch tuchtrecht. The case of the persistent inspector. A procedure in the medical disciplinary jurisdiction [in Dutch]. *Maandblad Geestelijke volksgezondheid* 1993;48:738-49.
9. Van der Wal G, van der Maas PJ. Euthanasie en andere medische beslissingen rond het levenseinde. Euthanasia and other medical decisions concerning the end of life [in Dutch]. 's-Gravenhage: Sdu Uitgevers, 1996.
10. Frei A, Schenker T, Finzen A, Hoffmann-Richter U. [Assisted suicide and psychiatric disorders] Beihilfe zum Suizid bei psychisch Kranken. *Nervenarzt* 1999;70:1014-8.
11. Nr. 656. Hulp bij zelfdoding psychiatrische patiënt. Assisted suicide by psychiatric patient [in Dutch]. *Nederlandse Jurisprudentie* 1994.
12. Dutch Association for Psychiatry. Hulp bij zelfdoding door patiënten met een psychiatrische stoornis; richtlijnen voor de psychiater. Assisted suicide by patients with a mental disorder; guidelines for the psychiatrist [in Dutch]. Utrecht: Dutch Association for Psychiatry, 1998.
13. Onwuteaka-Philipsen BD, van der Wal G, Kostense PJ, van der Maas PJ. Consultation with another physician on euthanasia and assisted suicide in the Netherlands. *Social Sci Med* 2000;51:429-38.
14. Haverkate I, Onwuteaka-Philipsen BD, van der Heide A, Kostense PJ, van der Wal G, van der Maas PJ. Refused and granted requests for euthanasia and assisted suicide in the Netherlands: interview study with structured questionnaire. *BMJ* 2000;321:865-6.
15. Chabot BE. *Sterven op drift: over doodsverlangen en onmacht*. Nijmegen: SUN, 1996.
16. Oregon Revised Statute 127,800-127,897 (The Oregon Death with Dignity Act) (1994).
17. Commissie Aanvaardbaarheid Levensbeëindigend Handelen KNMG. *Medisch handelen rond het levenseinde bij wilsonbekwame patiënten*. Medical practices involving the end of life in incompetent patients [in Dutch]. Houten/Diegem: Bohn Stafleu Van Loghum, 1997.
18. Chochinov HM, Wilson KG, Enns M, Lander S. Prevalence of depression in the terminally ill: effects of diagnostic criteria and symptom threshold judgments. *Am J Psychiatry* 1994;151:537-40.
19. Chochinov HM, Wilson KG, Enns M, et al. Desire for death in the terminally ill. *Am J Psychiatry* 1995;152:1185-91.
20. Breitbart W, Rosenfeld BD, Passik SD. Interest in physician-assisted suicide among ambulatory HIV-infected patients. *Am J Psychiatry* 1996;153:238-42.
21. Emanuel E, Fairclough DL, Daniels ER, Clarridge BR. Euthanasia and physician-assisted suicide: attitudes and experiences of oncology patients, oncologists, and the public. *Lancet* 1996;347:1805-10.
22. Kugaya A, Akechi T, Nakano T, Okamura H, Shima Y, Uchitomi Y. Successful antidepressant treatment for five terminally ill cancer patients with major depression, suicidal ideation and a desire for death. *Support Care Cancer* 1999;7:432-6.
23. Drickamer MA, Lee MA, Ganzini L. Practical issues in physician-assisted suicide. *Ann Intern Med* 1997;126:146-51.
24. Block SD, Billings JA. Patient requests for euthanasia and assisted suicide in terminal illness. The role of the psychiatrist. *Psychosomatics* 1995;36:445-57.
25. Kelly BJ, Varghese FT. Assisted suicide and euthanasia: what about the clinical issues? *Aust N Z J Psychiatry* 1996;30:3-8.
26. Ganzini L, Leong GB, Fenn DS, Silva JA, Weinstock R. Evaluation of competence to consent to assisted suicide: views of forensic psychiatrists. *Am J Psychiatry* 2000;157:595-600.
27. Ryan CJ. Velcro on the slippery slope: the role of psychiatry in active voluntary

- euthanasia. *Aust N Z J Psychiatry* 1995;29:580-5.
28. Hengeveld MW, Klijn FA, Casteelen G. [Active euthanasia in the hospital: the role of the consultant psychiatrist] *Actieve levensbeeindiging in het ziekenhuis: de rol van de consultatieve psychiater*. *Ned Tijdschr Geneesk* 1996;140:1709-12.
 29. Parker M. Medicine, psychiatry and euthanasia: an argument against mandatory psychiatric review. *Aust N Z J Psychiatry* 2000;34:318-24.
 30. Bannink M, van Gool AR, van der Heide A, van der Maas PJ. Psychiatric consultation and quality of decision making in euthanasia. *Lancet* 2000;356:2067-8.
 31. Beauchamp TL, Childress JF. *Principle of biomedical ethics*. New York / Oxford: Oxford University Press, 1989.
 32. Bascom PB, Tolle SW, Cassel CK. Caring for the terminally ill. *Hosp Pract (Off Ed)* 1996;31:75-8, S2-4, 89;discussion 89-90.
 33. Foley KM. Controlling cancer pain. *Hosp Pract (Off Ed)* 2000;35:101-8, 111-2.
 34. Maxwell T. Cancer pain management in the elderly. *Geriatr Nurs* 2000;21:158-63.
 35. Gloth FM. Geriatric pain. Factors that limit pain relief and increase complications. *Geriatrics* 2000;55:46-8, 51-4.
 36. Solomon MZ, O'Donnell L, Jennings B, et al. Decisions near the end of life: professional views on life sustaining treatments. *Am J Public Health* 1993;83:14-23.
 37. de Wit R, van Dam F, Vielvoye-Kerkmeier A, Mattern C, Abu-Saad HH. The treatment of chronic cancer pain in a cancer hospital in The Netherlands. *J Pain Symptom Manage* 1999;17:333-50.
 38. Van der Maas PJ, van der Wal G, Haverkate I, et al. Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in the Netherlands, 1990-1995. *N Engl J Med* 1996;335:1699-1705.
 39. Zech DF, Grond S, Lynch J, Hertel D, Lehmann KA. Validation of World Health Organization Guidelines for cancer pain relief: a 10-year prospective study. *Pain* 1995;63:65-76.
 40. Brown NK, Thompson DJ, Prentice RL. Nontreatment and aggressive narcotic therapy among hospitalized pancreatic cancer patients. *J Am Geriatr Soc* 1998;46:839-48.
 41. Thorns A, Sykes N. Opioid use in last week of life and implications for end-of-life decision-making [letter]. *Lancet* 2000;356:398-9.
 42. Partridge JC, Wall SN. Analgesia for dying infants whose life support is withdrawn or withheld. *Pediatrics* 1997;99:76-9.
 43. Wilson WC, Smedira NG, Fink C, McDowell JA, Luce JM. Ordering and administration of sedatives and analgesics during the withholding and withdrawal of life support from critically ill patients. *JAMA* 1992;267:949-53.
 44. Burns JP, Mitchell C, Outwater KM, et al. End-of-life care in the pediatric intensive care unit after the forgoing of life-sustaining treatment. *Crit Care Med* 2000;28:3060-6.
 45. Groenewoud JH, van der Heide A, Kester JG, de Graaff CL, van der Wal G, van der Maas PJ. A nationwide study of decisions to forego life-prolonging treatment in Dutch medical practice. *Arch Intern Med* 2000;160:357-63.
 46. Centraal Bureau voor de Statistiek (Statistics Netherlands). *Het levenseinde in de medische praktijk (1995, 1990). The end of life in medical practice [in Dutch]. Voorburg/Heerlen: Centraal Bureau voor de Statistiek, 1996.*
 47. Kimsma GK. Clinical ethics in assisting euthanasia: avoiding malpractice in drug application. *J Med Philos* 1992;17:439-43.
 48. Admiraal PV. [Administration of euthanasia-inducing agents] [in Dutch] *Toepassing van euthanatica*. *Ned Tijdschr Geneesk* 1995;139:265-8.
 49. Royal Dutch Association for the Advancement of Pharmacy (KNMP). [Use and preparation of euthanizing drugs] [in Dutch] *Toepassing en bereiding van euthanatica*. 's-Gravenhage: KNMP, 1998.
 50. Regionale Toetsingscommissies euthanasie. *Jaarverslag 1998/99. Regional review committees for euthanasia. Annual Report 1998/99 [in Dutch]*. Den Haag: Regionale Toetsingscommissies euthanasie, 2000.

51. Chin AE, Hedberg K, Higginson GK, Fleming DW. Legalized physician-assisted suicide in Oregon - The first year's experience. *N Engl J Med* 1999;340:577-83.
52. Ganzini L, Nelson HD, Schmidt TA, Kraemer DF, Delorit MA, Lee MA. Physicians' experiences with the Oregon Death with Dignity Act. *N Engl J Med* 2000;342:557-63.
53. Rasmussen PA. Physician-assisted suicide and euthanasia. *N Engl J Med* 2000;343:150;discussion 151-3.
54. Onwuteaka-Philipsen BD, Muller MT, van der Wal G, van Eijk JT, Ribbe MW. Active voluntary euthanasia or physician-assisted suicide? *J Am Geriatr Soc* 1997;45:1208-13.
55. Royal Dutch Medical Association. Vision on euthanasia. In: Association RDM, ed. *Euthanasia in the Netherlands*. Utrecht: Royal Dutch Medical Association, 1996:24-56.
56. Groenewoud JH, van der Heide A. Physician-assisted suicide and euthanasia [letter]. *N Engl J Med* 2000;343:152.
57. Van der Maas PJ, van Delden JJM, Pijnenborg L. *Medische beslissingen rond het levenseinde*. 's-Gravenhage: Sdu, 1991.
58. Faber-Langendoen K, Bartels DM. Process of forgoing life-sustaining treatment in a university hospital: an empirical study. *Crit Care Med* 1992;20:570-77.
59. Faber-Langendoen K. A multi-institutional study of care given to patients dying in hospitals. *Arch Intern Med* 1996;156:2130-6.
60. Asch DA, Christakis NA. Why do physicians prefer to withdraw some forms of life support over others? *Med Care* 1996;34:103-11.
61. Groenewoud JH, van der Heide A, van der Maas PJ. Niet-behandelbeslissingen rondom het levenseinde van ouderen [Conference Proceedings], Nationaal Gerontologie Congres. Ouder Worden '98, World Trade Center Rotterdam, 12 en 13 maart 1998. 1998. Nederlands Instituut voor Gerontologie.
62. Van der Heide A, Muller MT, Kester JGC, Groenewoud JH, van der Wal G, van der Maas PJ. Frequentie van het afzien van (kunstmatige) toediening van voeding en vocht aan het levenseinde. *Ned Tijdschr Geneesk* 1997;141:1918-24.
63. Wet Geneeskundige Behandelingsovereenkomst. Burgerlijk Wetboek:Boek 7. Bijzondere overeenkomsten Titel 7. Opdracht Afdeling 5.
64. Leenen. *Handboek Gezondheidsrecht*.
65. Gordijn B, Janssens R. The prevention of euthanasia through palliative care: New developments in The Netherlands. *Patient Educ Couns* 2000;41:35-46.
66. Smith AM. More openness needed in palliative care. Deliberate shortening of life has no part in ethical medical practice. *BMJ* 1998;316:390.
67. Crul BJ. [Pain control in the terminal stage of life] Pijnbestrijding in de laatste levensfase. *Ned Tijdschr Geneesk* 1997;141:2097-100.
68. Oliver D. Palliative drugs are not for shortening life. *BMJ* 1997;315:1018.
69. Van der Wal G, Willems D. Palliatieve zorg, euthanasie en andere medische beslissingen rond het levenseinde. Palliative care, euthanasia and other medical end-of-life decisions [in Dutch]. Tijdschrift voor Gezondheidswetenschappen 1999;77:511-5.
70. Regionale Toetsingscommissies euthanasie. Jaarverslag 2000. Regional review committees for euthanasia. Annual Report 2000 [in Dutch]. Den Haag: Regionale Toetsingscommissies euthanasie. 2001.
71. Quill TE, Lo B, Brock DW. Palliative options of last resort. A comparison of voluntarily stopping eating and drinking, terminal sedation, physician-assisted suicide, and voluntary active euthanasia. *JAMA* 1997;278:2099-2104.
72. Quill TE, Lee BC, Nunn S. Palliative treatments of last resort: choosing the least harmful alternative. University of Pennsylvania Center for Bioethics Assisted Suicide Consensus Panel. *Ann Intern Med* 2000;132:488-93.
73. Verhagen EH, Eliel MR, de Graeff A, Teunissen SC. [Sedation in the terminal phase of life] Sedatie in de laatste levensfase. *Ned Tijdschr Geneesk* 1999;143:2601-3.
74. Rousseau P. Terminal sedation in the care of dying patients. *Arch Intern Med* 1996;156:1785-6.

Summary

In recent years, the interest in end-of-life care has risen perceptibly, in particular regarding the debate about medical decisions concerning the end of life. Apart from euthanasia and physician-assisted suicide, defined as the administration and the prescription or supply respectively of lethal drugs to a patient at the patient's explicit request, this also concerns issues such as the intensification of pain and symptom control and the concomitant potentially life-shortening effect thereof, and decisions to forgo potentially life-prolonging treatment. This thesis deals with some of the themes that play an important role in the debate about medical practices involving the end of life.

In *Chapter 1*, the legal situation around medical decisions concerning the end of life, and the empirical studies in this area previously carried out in the Netherlands, are described. This thesis is in the tradition of these studies. It is based on the data collected for the evaluation of the notification procedure for physician-assisted death that was done in 1995/1996, a study in the context of which also the frequency and characteristics of medical decisions concerning the end of life were described. The themes that are dealt with in this thesis are: (1) euthanasia and physician-assisted suicide in psychiatric practice; (2) potentially life-shortening drugs in medical practices involving the end of life; (3) decisions to withhold or withdraw potentially life-prolonging treatment. The objective was to obtain reliable estimates of the characteristics and the incidences of (requests for) physician-assisted suicide in Dutch psychiatry, to gain insight into psychiatrists' experiences in the Netherlands as consultants to colleague physicians in cases where a patient has requested physician-assisted suicide or euthanasia, and into their attitudes towards physician-assisted suicide which has been requested because of a mental disorder (objective 1); to explore the types of drugs used, the intention with which these drugs are used and their life-shortening effect, and the

frequency and characteristics of clinical problems occurring in the performance of euthanasia and physician-assisted suicide (objective 2); and to gain insight into the incidence of non-treatment decisions, the types of treatment forgone and the involvement of patients, their relatives or others in the decision-making process (objective 3).

In *Chapters 2 to 4*, the experiences of Dutch psychiatrists with and attitudes towards physician-assisted suicide or euthanasia in psychiatric patients are described. These chapters are based on the results of a study performed in 1996. In this study, 673 psychiatrists, about half of all Dutch psychiatrists, were sent a questionnaire in which they were asked about their experiences with and their attitudes towards physician-assisted death in patients with a mental disorder. Five hundred fifty-two completed questionnaires were returned. *Chapter 2* deals with psychiatrists' experiences with requests for assistance in suicide made by patients under their treatment. Of the psychiatrists, 37% had received an explicit and persistent request for physician-assisted suicide from a patient at least once. Two hundred and two psychiatrists described the most recent requests they had received. The requests dated from between 1977 and 1996. The mean age of the patients was 45 years; 63% of them were female. The predominant psychiatric diagnosis was a mood disorder; almost two thirds had personality disorders. In 21% of the requests, the psychiatrist had contemplated granting the patients' requests. Two percent of all cases resulted in suicides assisted by the responding psychiatrists; most cases involved patients suffering from a serious physical illness as well. Some of the patients subsequently committed suicide with the aid of a different physician (3%); 16% ended their lives without assistance. Of the patients who were still living (63%), 18% still persistently asked for physician-assisted suicide or euthanasia. The most frequent reasons for refusing the patient's request were the belief that the patient had a treatable mental disorder, doubt that the patient's suffering was hopeless or unbearable, and doubt that the request was well-considered and persistent.

Psychiatrists' experiences as consultants to colleagues dealing with requests for physician-assisted suicide or euthanasia are described in *Chapter 3*. Of the psychiatrists, 36% had been consulted at least once with regard to requests for physician-assisted suicide or euthanasia. The annual number of requests for psychiatric consultation is estimated 400; around a quarter of the consultations are requested by psychiatrists, the remaining by non-psychiatrists (of whom 50% were general practitioners). In total, 221 cases were described in which psychiatrists had been consulted. In 87 of the cases, a mental disorder had been (one of) the reason(s) for the patient to request assisted death; these patients were younger and more frequently female than patients whose requests were motivated by a physical disease. The psychiatric consultants were mostly asked to assess whether the

patient's request was well-considered (68%) and whether the patient had a treatable mental disorder (66%). In 24% of the consultations, the consultant was asked to assess whether transference or countertransference influenced the decision-making; this was more frequently the aim of the consultation in cases where the consultee was a psychiatrist compared to cases where the consultee was a non-psychiatrist, and more frequently in cases where the patient requested physician-assisted death because of a mental disorder. In 83% of all cases, the consultant examined the patient at least once. In 30%, the case resulted in physician-assisted suicide or euthanasia; some of these patients had made their request because of a mental disorder or because of a mental and a physical disorder both. In the majority of cases in which the patient's request was refused, the consultant judged that the patient's request was not well-considered or that a treatable mental disorder was present. In some cases, the patient's request was acceded to, despite the consultant's judgement that the request had not been well-considered or that other criteria for careful practice had not been met.

Chapter 4 deals with the attitudes of Dutch psychiatrists towards physician-assisted suicide because of a mental disorder. About two thirds (65%) of the psychiatrists consider such assistance acceptable in exceptional cases; of those, 71% could conceive of a situation in which they themselves would assist. Some 31% felt that assistance with suicide because of a mental disorder could never be acceptable. In response to the question on whether their attitudes towards assisted suicide because of a mental disorder had changed during their years of practice, 31% of the psychiatrists indicated that they had become more permissive, whereas 21% had become more restrictive. Psychiatrists who themselves had at any time been the recipient of such a request had undergone a change in this respect more often than those who had never received a request, for the most part in a more positive direction. The most frequently cited reason for their increased leniency towards physician-assisted suicide in connection with a mental disorder, was personal experience that suffering accompanying a mental disorder could indeed be hopeless or unbearable. Diagnostic or prognostic uncertainty of the mental disorder and the undermining of therapy were relatively frequently mentioned motives for having become more restrictive. For the most recent requests described, no relation was found between psychiatrists' assessment of the patient's competence or of the persistence of the request and the psychiatrist's attitudes towards physician-assisted suicide because of a mental disorder. The opinion, however, was significantly related to the psychiatric diagnosis. The presence of a treatable mental disorder was the most frequently mentioned reason for refusing the patient's request, in particular by psychiatrists who considered physician-assisted suicide because of a mental disorder acceptable. Psychiatrists who considered such assistance unacceptable, more frequently mentioned doubt that the suffering was

unbearable or hopeless and reasons of principle as the motives for refusing the request.

Chapters 5 to 8 deal with the drugs that are used for euthanasia, physician-assisted suicide or other medical practices involving the end of life.

Chapter 5 is a review of the literature about drugs that are used in medical practice with the explicit intention of shortening the patient's life and the (potentially) lethal effect of those drugs. It shows that almost all quantitative data come from Dutch studies; one other empirical study describes 15 cases of physician-assisted suicide in the state of Oregon, USA. Chapter 5 presents an overview of the types of drugs used in physician-assisted death and their life-shortening potential. Opioids are considered to be unsuitable for use as drugs for euthanasia and physician-assisted suicide, as are benzodiazepines, as they cannot be relied upon to induce coma in terminally ill patients. When administering lethal drugs to critically ill patients, physicians should take into account that drug metabolism may be affected, particularly in case of oral administration of the drugs. The chapter concludes with the recommendations from the Royal Dutch Association for the Advancement of Pharmacy: for euthanasia, intravenous administration of a neuromuscular relaxant is recommended after coma has been induced with a barbiturate, and for physician-assisted suicide oral administration of a barbiturate drink.

Chapter 6 offers a more detailed description of Dutch physicians' use of drugs that may have shortened the patient's life. The results are from the death certificate study conducted in 1995/1996. In this study, in a sample of 6,632 deaths, the attending physicians were asked whether they had decided to forgo treatment or to use drugs with the explicit intention of hastening the patient's death, or at least taking into account the probability or certainty that this would hasten the patient's death. If so, questions were asked about the characteristics and circumstances. A decision to use potentially life-shortening drugs preceded 42% of non-sudden deaths in 1995, and 29% of all deaths. In the majority of cases (37% of non-sudden deaths) the drugs were given without the explicit intention of hastening the patient's death. In those cases, mostly opioids were used (86%); barbiturates (0,2%) or neuromuscular relaxants (0,1%) were seldom used. In cases where there was an explicit intention of hastening the patient's death, different drugs were used for euthanasia, physician-assisted suicide or ending of life without the patient's explicit request. In cases of euthanasia and physician-assisted suicide, the use of drugs largely concurred with the guidelines as issued by the Royal Dutch Association for the Advancement of Pharmacy: a neuromuscular relaxant after the induction of coma by a barbiturate in 50% of euthanasia cases, and a barbiturate in 91% of physician-assisted suicides. In cases where the patient's life was ended other than by his or her concurrent explicit request, opioids tended to be the

preferred drug (81%). The dosages of the most important drugs are also dealt with in Chapter 6. The mean dosage of e.g. morphine in the last 24 hours before the patient's death was 30 mg if there was no explicit intention to hasten death and 60 mg if there was. Finally, the interval between administration of the (last) drug and the patient's death is discussed. This interval was 135 minutes (range 0 minutes – 34 hours) if there was no explicit intention to hasten death and 10 minutes (range 0 minutes – 7 hours) if there was.

The use of opioids in potentially life-shortening dosages is described in *Chapter 7*. From the death certificate study, all deaths were selected in which the use of opioids was the weightiest decision concerning the end of life (17% of all deaths): the opioids were used with the explicit intention of hastening the patient's death in 1%, hastening death was partly intended in 3%, and a life-shortening effect only had been taken into account in 13%. More than half of the patients involved had cancer and 77% were aged 65 and older. In 9% of the cases, the physician estimated that the patient's life had, as a result of the use of opioids, been shortened by 24 hours at the most, by 1 day to 1 week in 73%, and by more than 1 week in 9%. In 45% of the cases, the decision to use opioids had been discussed with the patient, least often (40%) if life shortening had only been taken into account and most frequently (78%) if life shortening was explicitly intended. The reasons physicians gave for not discussing the decision with the patient were that the patient was unconscious (35%), or had dementia (28%), or that the physician thought that the decision was clearly in the patient's best interests (22%). Chapter 7 shows that higher doses of opioids were related with an explicit intention to hasten the patient's death more frequently than smaller doses, although some overlap did emerge between dosages and intention. In the interviews with a sample of 405 physicians, including general practitioners, clinical specialists and nursing-home physicians, respondents were asked to describe the most recent case in which the alleviation of pain and symptoms possibly had hastened the patient's death. In 93% of the cases, physicians said that they would act in a similar way with a similar patient in similar circumstances. Sixty-seven percent were of the opinion that the use of opioids had improved the quality of the dying process.

Chapter 8 deals with the performance of euthanasia and physician-assisted suicide. All cases of euthanasia and physician-assisted suicide described in the interview studies from 1990/1991 and 1995/1996, were analysed, a total of some 649 cases: 535 euthanasia cases and 114 cases where the physician's intention was to provide assistance with suicide. Problems were categorised as technical problems, complications and problems with completion. Technical problems, such as difficulty inserting an intravenous line, occurred in 5% of all cases. Complications, such as myoclonus or vomiting, occurred in 4%. In 7%, there were problems with completion: the time to death was longer than expected, the patient did not become comatose after administration of the drugs, or the patient

awakened after some time. Problems of any type were more frequent in cases of assisted suicide than in cases of euthanasia; this concerns problems with completion in particular ($P < 0.001$). In 21 of the cases of assisted suicide (18%), the physician decided to administer a lethal medication, mostly because the patient did not die or become comatose (12 patients) or because the patient was unable to take oral medication (5 patients).

Chapter 9 describes the practice of withholding or withdrawing life-prolonging treatment. In this chapter, data from the death certificate study were used. In 1995, 30% of all deaths in the Netherlands were preceded by a decision to withhold or withdraw a treatment that probably or certainly would shorten the patient's life. In 1990, this percentage was 28%. These so-called non-treatment decisions mainly involved patients aged 80 and older, female, and deaths due to mental disorders (including Alzheimer dementia), disease of the digestive tract, neurological disease, or pulmonary disease. Furthermore, nursing-home physicians made non-treatment decisions more frequently than general practitioners or clinical specialists. In about half of the cases, treatment was withheld; in the other half some form of a treatment was withdrawn. Non-treatment decisions most frequently involved artificial nutrition or hydration and antibiotics, each accounting for 25% of cases in which a non-treatment decision was made. The types of treatment forgone differed between medical specialties: clinical specialists relatively frequently abstained from mechanical ventilation or surgery, general practitioners relatively frequently chemotherapy or radiotherapy. Of the patients, the majority (67%) were not (fully) competent; non-treatment decisions made by nursing-home physicians most frequently involved patients who were not fully competent (83%). Non-treatment decisions were discussed with 93% of competent patients. If the decision had not been discussed with the patient, this was generally because the physician felt this decision clearly to be in the best interests of the patient or that discussion would have done more harm than good. Of 13% of patients who were not fully competent, the physician was aware of the patient's wishes regarding the ending of life. The responsible physician most frequently discussed the non-treatment decision with colleagues when it concerned mechanical ventilation, resuscitation or dialysis. The patients' relatives were relatively frequently involved when artificial nutrition or hydration, or antibiotics were forgone. In 4% of patients, the physician had discussed the decision with no one.

Finally, in *Chapter 10*, the most important findings are summarised and discussed. This chapter concludes with some recommendations for future research. This thesis shows that physician-assisted suicide in psychiatric practice is rare and that psychiatrists are rarely consulted about patients' requests for physician-assisted suicide or euthanasia. Although the majority of Dutch psychiatrists think that

physician-assisted suicide in psychiatric patients could be acceptable in exceptional cases, their deliberations show how complex such decisions are. In Dutch medical practice, decisions to use drugs with a potentially life-shortening effect are made relatively frequently. Even though the drugs that are recommended by the Royal Dutch Association for the Advancement of Pharmacy are increasingly used in euthanasia and physician-assisted suicide, physicians should be aware that problems can occur in performing these practices. Opioids are the most frequently used drugs to alleviate pain and symptoms as well as to end the patient's life without his or her explicit request; a grey area emerged, however, where doses and intentions overlapped. Also decisions to withhold or withdraw potentially life-prolonging treatments are important at the end of life. The debate on such decisions not only concerns the patient's wish, but also other – medical and societal – factors that may justify these decisions. Empirical studies, like the ones described in this thesis, may contribute to the professional and public debate about euthanasia and other medical decisions concerning the end of life. Therefore, continuing research in this relatively unexplored area is highly important.

12

Samenvatting

De laatste jaren bestaat er een toenemende belangstelling voor de medische zorg in de laatste levensfase, waarbij de discussie zich ook richt op medische beslissingen rond het levenseinde. Naast euthanasie en hulp bij zelfdoding, gedefinieerd als het toedienen respectievelijk voorschrijven of verstrekken van dodelijke middelen aan de patiënt op diens uitdrukkelijke verzoek, gaat het daarbij ook om de intensivering van pijn- en symptoombestrijding met een potentieel levensbekortend effect en beslissingen om af te zien van een potentieel levensverlengende behandeling. Dit proefschrift gaat in op een aantal thema's die een belangrijke rol spelen in de discussie over medisch handelen rond het levenseinde.

In *hoofdstuk 1* worden de Nederlandse regelgeving met betrekking tot medische beslissingen rond het levenseinde en de eerdere empirische onderzoeken die in Nederland op dit gebied zijn gedaan, beschreven. Dit proefschrift staat in de traditie van deze studies. Het is gebaseerd op de gegevens die werden verzameld in het evaluatie-onderzoek van de meldingsprocedure euthanasie dat in 1995/1996 plaatsvond en waarbij tevens het voorkomen en de achtergronden van medische beslissingen rond het levenseinde in kaart werden gebracht. De thema's die in dit proefschrift aan de orde komen zijn: (1) euthanasie en hulp bij zelfdoding in de psychiatrische praktijk; (2) potentieel levensbekortende middelen bij medisch handelen rond het levenseinde; (3) beslissingen om een potentieel levensverlengende behandeling niet in te stellen of te staken. Het doel was om betrouwbare schattingen te krijgen van de aard en omvang van (verzoeken om) hulp bij zelfdoding in de Nederlandse psychiatrie, inzicht te krijgen in hoeverre Nederlandse psychiaters als consulent betrokken zijn bij verzoeken om hulp bij zelfdoding of euthanasie en in hun opvattingen ten aanzien van hulp bij zelfdoding vanwege een psychiatrische aandoening (doelstelling 1); inzicht te krijgen in de aard van de gebruikte middelen, de intentie waarmee deze worden toegediend en

hun levensbekortende werking en in de frequentie en de aard van de problemen die zich voordoen bij de uitvoering van euthanasie en hulp bij zelfdoding (doelstelling 2); en inzicht te geven in het voorkomen van niet-behandelbeslissingen, in de soorten behandeling waarvan wordt afgezien en in de mate waarin patiënten, hun familieleden of anderen bij de besluitvorming worden betrokken (doelstelling 3).

In de *hoofdstukken 2 t/m 4* worden de ervaringen van Nederlandse psychiaters met en opvattingen over hulp bij zelfdoding of euthanasie aan psychiatrische patiënten beschreven. Deze hoofdstukken zijn gebaseerd op de resultaten van een onderzoek dat in 1996 werd uitgevoerd en waarbij 673 psychiaters, ongeveer de helft van alle Nederlandse psychiaters, middels een schriftelijke vragenlijst werd gevraagd naar hun ervaringen met en opvattingen over levensbeëindigend handelen bij patiënten met een psychiatrische aandoening. Er werden 552 volledig ingevulde vragenlijsten teruggestuurd. *Hoofdstuk 2* gaat in op de ervaringen van psychiaters met verzoeken om hulp bij zelfdoding van patiënten die bij hen onder behandeling zijn. Van alle psychiaters had 37% ooit te maken gehad met een uitdrukkelijk verzoek om hulp bij zelfdoding van een patiënt die bij hem of haar onder behandeling was. Door 202 psychiaters werd het recentste geval beschreven. De verzoeken hadden betrekking op de periode 1977-1996. De gemiddelde leeftijd van de patiënten was 45 jaar, 63% van hen was vrouw. De meeste patiënten hadden een stemmingsstoornis, bijna twee derde had (daarnaast) een persoonlijkheidsstoornis. In 21% van alle gevallen had de psychiater overwogen om het verzoek van de patiënt in te willigen. In 2% van alle gevallen had de psychiater uiteindelijk de gevraagde hulp verleend; het ging daarbij meestal om patiënten die tevens een dodelijke lichamelijke aandoening hadden. Een aantal patiënten had van een andere arts hulp bij zelfdoding gekregen (3%), 16% pleegde zelfmoord. Van de patiënten die nog in leven waren (63%) persisteerde 18% in het verzoek om hulp bij zelfdoding of euthanasie. De belangrijkste redenen om een verzoek niet in te willigen waren dat de patiënt een psychiatrische aandoening had die behandelbaar was, twijfel over de uitzichtloosheid en ondraaglijkheid van het lijden, en twijfel of het verzoek weloverwogen en duurzaam was.

De ervaringen van psychiaters als consulent in verband met verzoeken om hulp bij zelfdoding of euthanasie worden beschreven in *hoofdstuk 3*. Van de psychiaters was 36% ooit geconsulteerd vanwege het verzoek van een patiënt om hulp bij zelfdoding of euthanasie. Het jaarlijkse aantal van dergelijke consultaties wordt geschat op 400; ongeveer een kwart hiervan is afkomstig van een collega-psychiater, de overige van niet-psychiaters (waaronder 50% huisartsen). In totaal werden 221 gevallen beschreven waarin de psychiater optrad als consulent. In 87 van deze gevallen was een psychiatrische aandoening (mede) aanleiding voor de patiënt om het verzoek om hulp bij zelfdoding of euthanasie te doen; deze patiënten waren in het algemeen jonger en vaker vrouw dan de patiënten bij wie (alleen) een

lichamelijke ziekte aanleiding was voor hun verzoek. De consulenten werden met name gevraagd te beoordelen of het verzoek van de patiënt weloverwogen was (68%) en of er sprake was van een behandelbare psychiatrische aandoening (66%). In 24% van de consultaties werd de consulent gevraagd of (tegen-)overdracht een goede besluitvorming had belemmerd; dit onderwerp werd significant vaker aan de orde gesteld wanneer de consultvrager een psychiater was dan wanneer het een niet-psychiater betrof, en ook vaker wanneer er een psychiatrische aandoening ten grondslag lag aan het verzoek van de patiënt. In 83% van alle gevallen onderzocht de consulent de patiënt ten minste een keer. In 30% van alle gevallen waarin de psychiater als consulent optrad, had hulp bij zelfdoding of euthanasie plaatsgevonden; enkele van de betrokken patiënten deden het verzoek om hulp bij zelfdoding of euthanasie vanwege een psychiatrische aandoening of een combinatie van een lichamelijke en een psychiatrische ziekte. In de meeste gevallen waarin het verzoek van de patiënt werd geweigerd, oordeelde de consulent dat het verzoek niet weloverwogen was of dat er sprake was van een behandelbare psychiatrische aandoening. In enkele gevallen werd het verzoek van de patiënt toch ingewilligd, terwijl het verzoek volgens de consulent niet weloverwogen was of aan andere criteria voor zorgvuldig handelen niet was voldaan.

Hoofdstuk 4 gaat in op de opvattingen van Nederlandse psychiaters ten aanzien van hulp bij zelfdoding vanwege een psychiatrische aandoening. Ongeveer twee derde (65%) van de psychiaters zei dergelijke hulp in bepaalde situaties aanvaardbaar te vinden; van hen kon 71% zich een situatie voorstellen waarin zij bereid zouden zijn zelf die hulp te verlenen. Een derde (31%) van alle psychiaters vond dergelijke hulp nooit aanvaardbaar. Op de vraag of hun opvattingen over de aanvaardbaarheid van hulp bij zelfdoding vanwege een psychiatrische aandoening in de loop van hun praktijkvoering waren veranderd, antwoordde 31% dit aanvaardbaarder te zijn gaan vinden, terwijl 21% het minder aanvaardbaar vond. Psychiaters aan wie ooit om hulp bij zelfdoding werd verzocht, waren vaker van mening veranderd dan psychiaters die nog nooit met een dergelijk verzoek te maken hadden gehad, en waren deze hulp bij zelfdoding vaker aanvaardbaarder gaan vinden. Als redenen voor hun permissievere houding ten aanzien van hulp bij zelfdoding vanwege een psychiatrische aandoening noemden psychiaters met name de ervaring dat psychisch lijden werkelijk uitzichtloos en ondraaglijk kan zijn. Onzekerheid over de diagnose en de prognose en het gevaar de therapie te ondermijnen werden relatief vaak genoemd als redenen voor een toegenomen terughoudendheid. Het oordeel over de wilsbekwaamheid van de patiënt of de duurzaamheid van het verzoek om hulp bij zelfdoding in het recentste geval waarin zo'n verzoek werd gedaan, bleek niet samen te hangen met de opvatting van de psychiater over hulp bij zelfdoding vanwege een psychiatrische aandoening; dit oordeel hing vooral samen met de aard van de aandoening. Dat de patiënt een behandelbare psychiatrische aandoening had werd het vaakst genoemd als reden

om diens verzoek te weigeren, significant vaker door de psychiaters die hulp bij zelfdoding vanwege een psychiatrische aandoening aanvaardbaar vonden dan de psychiaters die dit niet aanvaardbaar vonden. In vergelijking met de eerste groep noemde de laatste groep vaker twijfel over de ondraaglijkheid of uitzichtloosheid van het lijden als reden om niet in te gaan op het verzoek, en principiële redenen.

De *hoofdstukken 5 t/m 8* gaan over de bij euthanasie, hulp bij zelfdoding en andere medische beslissingen rond het levenseinde toegepaste middelen.

Hoofdstuk 5 geeft de resultaten van een literatuurstudie naar middelen die worden gebruikt voor opzettelijk levensbeëindigend handelen en de (potentieel) letale werking hiervan. Uit deze literatuurstudie bleek dat kwantitatieve gegevens over het gebruik van deze middelen hoofdzakelijk afkomstig zijn van Nederlands onderzoek; een van de weinige buitenlandse empirische onderzoeken betreft 15 gevallen van hulp bij zelfdoding in de Amerikaanse staat Oregon. In hoofdstuk 5 wordt vervolgens een overzicht gegeven van de mogelijke middelen en hun levensbekortend effect. Beschreven wordt dat opiaten geen geschikte middelen zijn voor euthanasie of hulp bij zelfdoding, evenmin als benzodiazepines, die ook voor de inductie van coma bij terminale patiënten onbetrouwbaar zijn. Bij de toediening van letale middelen aan ernstig zieke patiënten, met name in geval van orale inname, moet rekening worden gehouden met veranderingen in de farmacokinetiek. Het hoofdstuk sluit af met de richtlijnen van de Koninklijke Nederlandse Maatschappij ter bevordering der Pharmacie (KNMP): voor euthanasie wordt injectie van een spierslapper na inductie van coma met behulp van een barbituraat aanbevolen, voor hulp bij zelfdoding orale toediening van een barbituraatdrank.

In *hoofdstuk 6* wordt beschreven hoe vaak Nederlandse artsen, voorafgaand aan het overlijden, middelen gebruiken die het leven van de patiënt mogelijk hebben bekort. De resultaten zijn afkomstig uit het sterfgevallenonderzoek 1995/1996. In dit onderzoek werd aan artsen die betrokken waren bij een steekproef van 6.632 sterfgevallen gevraagd of zij een beslissing hadden genomen met het doel of rekening houdend met de waarschijnlijkheid of zekerheid dat deze handelwijze het levenseinde van de patiënt zou bespoedigen. Zo ja, dan werd hen gevraagd naar de kenmerken en omstandigheden van het laatste geval. Een beslissing om een potentieel levensbekortend middel toe te dienen ging vooraf aan 42% van de niet-plotselinge sterfgevallen in 1995, of aan 29% van alle sterfgevallen. In het merendeel van de niet-plotselinge sterfgevallen (37%) werden de middelen gegeven zonder dat levensbeëindiging uitdrukkelijk werd beoogd. In deze gevallen werden hoofdzakelijk opiaten gegeven (86%); barbituraten (0,2%) of spierslappers (0,1%) werden zelden gebruikt. De middelen die werden gebruikt met bespoediging van het levenseinde van de patiënt als uitdrukkelijk doel verschilden voor euthanasie, hulp bij zelfdoding of levensbeëindigend handelen

zonder uitdrukkelijk verzoek. Bij euthanasie en hulp bij zelfdoding werden in het algemeen de middelen gebruikt, zoals die worden aanbevolen door de KNMP: voor euthanasie een spierverslapper na inductie van coma met een barbituraat (50%), voor hulp bij zelfdoding een barbituraat (91%). Voor levensbeëindigend handelen zonder uitdrukkelijk verzoek van de patiënt werden voornamelijk opiaten gebruikt (81%). Ook wordt ingegaan op de doseringen van de belangrijkste middelen. Voor morfine bijvoorbeeld was de dosering in de laatste 24 uur voor het overlijden van de patiënt gemiddeld 30 mg wanneer bespoediging van het overlijden niet uitdrukkelijk werd beoogd, en 60 mg wanneer dat wel het uitdrukkelijke doel was. Tenslotte wordt ingegaan op het interval tussen toediening van het (laatste) middel en het overlijden van de patiënt. Dit was 135 minuten (range 0 minuten – 34 uur) wanneer levensbekorting niet werd beoogd en 10 minuten (range 0 minuten – 7 uur) wanneer dit wel het geval was.

Het gebruik van opiaten in potentieel levensbekortende doseringen is het onderwerp in *hoofdstuk 7*. Voor dit hoofdstuk werd een selectie gemaakt van alle sterfgevallen uit het sterfgevallenonderzoek 1995/1996 waarin de toediening van opiaten de belangrijkste medische beslissing met betrekking tot het levenseinde was (17% van alle sterfgevallen): in 1% werden de opiaten uitdrukkelijk toegediend om het levenseinde van de patiënt te bespoedigen, in 3% was bespoediging van het levenseinde mede het doel en in 13% werd met een levensbekortend effect hooguit rekening gehouden. In meer dan de helft van alle gevallen ging het om kankerpatiënten en 77% was 65 jaar of ouder. In 9% van alle gevallen schatte de arts dat het leven van de patiënt door de toediening van de opiaten met hooguit 24 uur was verkort, in 73% met 1 dag tot 1 week, en in 9% met meer dan 1 week. In 45% van alle gevallen was met de patiënt over de beslissing overlegd, het minst vaak (40%) wanneer met een levensbekortend effect rekening werd gehouden en het vaakst (78%) wanneer levensbekorting uitdrukkelijk werd beoogd. De redenen die de artsen noemden om niet met de patiënt te overleggen waren dat de patiënt bewusteloos was (35%), dement was (28%), of dat deze handelwijze duidelijk het beste voor de patiënt was (22%). Uit hoofdstuk 7 blijkt vervolgens dat hogere doseringen opiaten vaker dan lagere doseringen samenhangen met het uitdrukkelijke doel het om het levenseinde van de patiënt te bespoedigen, maar ook dat er een overlap bestond tussen doseringen en intentie. In mondelinge interviews met een steekproef van 405 artsen, waaronder huisartsen en een aantal klinisch specialisten, werd onder meer gevraagd naar het laatste geval waarin pijn- en symptoombestrijding mogelijk hadden bijgedragen aan bespoediging van het levenseinde van de patiënt. De betrokken artsen gaven in 93% van de beschreven gevallen aan dat zij in een vergelijkbare situatie op dezelfde manier zouden handelen. Zevenenzestig procent was van mening dat de beslissing om opiaten toe te dienen had bijgedragen aan de kwaliteit van het stervensproces.

In *hoofdstuk 8* wordt ingegaan op de uitvoering van euthanasie en hulp bij zelfdoding. Hiertoe werden alle gevallen van euthanasie en hulp bij zelfdoding die zijn beschreven in de artseninterviews van 1990/1991 en 1995/1996 geanalyseerd. In totaal ging het om 649 gevallen: 535 gevallen van euthanasie en 114 gevallen waar hulp bij zelfdoding werd beoogd. De problemen werden onderverdeeld in technische problemen, ongewenste effecten en problemen met het bereiken van het gewenste effect. Technische problemen, zoals problemen met het inbrengen van het infuus, kwamen voor bij 5% van alle patiënten. Ongewenste effecten, zoals spierspasmen of braken, traden op bij 4%. Bij 7% waren er problemen met het bereiken van het gewenste effect: in deze gevallen duurde het langer dan verwacht voordat de patiënt overleed, raakte de patiënt niet in coma na toediening van de middelen, of kwam de patiënt na enige tijd weer bij. Hulp bij zelfdoding ging vaker gepaard met problemen dan euthanasie; vooral problemen met het bereiken van het gewenste effect kwamen daarbij significant vaker voor ($p < 0,001$). Bij 21 patiënten die hulp bij zelfdoding kregen (18%), besloot de arts uiteindelijk zelf het euthanaticum toe te dienen, voornamelijk omdat het gewenste effect niet werd bereikt (12 patiënten) of omdat de patiënt moeite had met het zelf oraal innemen van de middelen (5 patiënten).

Hoofdstuk 9 gaat over beslissingen om potentieel levensverlengende behandelingen niet in te stellen of te staken. In dit hoofdstuk is gebruik gemaakt van de gegevens uit het sterfgevallenonderzoek. In 1995 bleek 30% van de sterfgevallen in Nederland vooraf te zijn gegaan door een beslissing om een behandeling niet in te stellen of te staken, waardoor het leven van de patiënt mogelijk of met zekerheid zou worden verkort. In 1990 was dit percentage 28%. Dergelijke niet-behandelbeslissingen werden met name genomen bij patiënten van 80 jaar of ouder, bij vrouwen, en wanneer er sprake was van psychische stoornissen (waaronder ook de ziekte van Alzheimer), ziekten van het maagdarmsstelsel, van het zenuwstelsel of van de luchtwegen. Verder namen verpleeghuisartsen vaker niet-behandelbeslissingen dan huisartsen of specialisten. In de helft van de gevallen werd een behandeling niet gestart, in de overige gevallen werd een behandeling gestaakt. Niet-behandelbeslissingen betroffen het vaakst kunstmatige toediening van vocht of voeding en antibiotica, beiden in 25% van alle beslissingen. Er waren verschillen tussen de specialismen: specialisten zagen relatief vaak af van kunstmatige beademing of een operatie, huisartsen relatief vaak van oncotherapie. Van de patiënten was het merendeel (67%) niet volledig wilsbekwaam; voor verpleeghuisartsen was het percentage wilsbekwame patiënten het hoogst (83%). Wanneer de patiënt wilsbekwaam was, werd meestal (93%) met de patiënt overlegd. Wanneer dit niet gebeurde, was dat hoofdzakelijk omdat naar de mening van de arts de beslissing om af te zien van behandeling duidelijk het beste was voor de patiënt of omdat overleg meer kwaad dan goed zou

doen. Van de patiënten die niet volledig wilsbekwaam waren, was van 13% een vroegere wens ten aanzien van levensbeëindiging bekend. De verantwoordelijke arts overlegde het vaakst met collega's over het afzien van kunstmatige beademing, reanimatie of dialyse, en met familieleden het vaakst over het afzien van kunstmatige toediening van vocht of voeding, en antibiotica. Over 4% van alle niet-behandelbeslissingen werd door de arts met niemand overlegd.

In *hoofdstuk 10*, tenslotte, worden de belangrijkste resultaten samengevat en bediscussieerd, en aanbevelingen gedaan voor verder onderzoek. Dit proefschrift laat zien dat hulp bij zelfdoding in de psychiatrische praktijk een zeldzame gebeurtenis is en dat psychiaters relatief weinig worden geconsulteerd in verband met het verzoek om hulp bij zelfdoding of euthanasie van een patiënt. Hoewel de meerderheid van de Nederlandse psychiaters hulp bij zelfdoding aan psychiatrische patiënten in bepaalde situaties aanvaardbaar vindt, blijkt uit de overwegingen die een rol spelen bij de besluitvorming hoe complex deze is. Voorafgaand aan het overlijden worden vrij vaak middelen gegeven met een mogelijk levensbekortend effect. Hoewel voor euthanasie en hulp bij zelfdoding in toenemende mate de door de KNMP aanbevolen middelen worden gebruikt, moet de arts erop voorbereid zijn dat tijdens de uitvoering problemen kunnen optreden. Opiaten worden met name gebruikt voor pijn- en symptoombestrijding en voor levensbeëindigend handelen zonder verzoek; uit de overlap tussen doseringen en de intentie waarmee deze middelen worden toegediend, blijkt echter dat er sprake is van een grijs gebied. Beslissingen om een potentieel levensverlengende behandeling niet in te stellen of te staken spelen ook een belangrijke rol in het medisch handelen rond het levenseinde. De discussie over dergelijke beslissingen richt zich naast de wens van de patiënt ook op andere – zowel medische als maatschappelijke - factoren die deze beslissingen kunnen rechtvaardigen. Empirisch onderzoek, zoals beschreven in dit proefschrift, kan een belangrijke bijdrage leveren aan de professionele en maatschappelijke discussie over euthanasie en andere medische beslissingen rond het levenseinde. Voortgang van het onderzoek op dit betrekkelijk onontgonnen terrein is dan ook van groot belang.

Curriculum vitae

Johanna Helène Groenewoud werd geboren in Best op 11 december 1964. In 1983 behaalde zij haar VWO-diploma (Atheneum B) op het Jacob-Roelandslyceum te Boxtel. Aansluitend deed zij de propaedeuse Natuurkunde aan de Rijksuniversiteit te Utrecht. In 1985 begon zij, eveneens in Utrecht, aan de studie Geneeskunde. Na haar artsexamen in 1992 was zij tot 1996 werkzaam als verzekeringsgeneeskundige en bedrijfsarts. Sinds 1 januari 1996 is zij in dienst van het instituut Maatschappelijke Gezondheidszorg van de Erasmus Universiteit te Rotterdam, waar zij tot 1999 betrokken was bij de evaluatie van de meldingsprocedure euthanasie. Sinds 1 januari 1999 is zij lid van het Landelijk Evaluatie Team voor het bevolkingsonderzoek naar Borstkanker en houdt zij zich voornamelijk bezig met onderzoek naar de mogelijkheden om het bevolkingsonderzoek naar borstkanker te optimaliseren.

Appendix



Publications on empirical studies on euthanasia and other medical practices involving the end-of-life in the Netherlands

- Cuperus-Bosma JM, Wal G van der, Maas PJ van der. Physician-assisted death: policy-making by the Assembly of Prosecutors General in the Netherlands. *Eur J Health Law* 1997;4:225-38.
- Cuperus-Bosma JM, Wal G van der, Maas PJ van der. Euthanasie en andere medische beslissingen rond het levenseinde. Het Openbaar Ministerie en de meldingsprocedure. Vrije Universiteit Amsterdam, Instituut voor Extramuraal Geneeskundig Onderzoek / Sociale Geneeskunde. Erasmus Universiteit Rotterdam, Instituut Maatschappelijke Gezondheidszorg. 1997.
- Cuperus-Bosma JM, Wal G van der, Maas PJ van der. Euthanasie en andere medische beslissingen rond het levenseinde. De Inspectie voor de Gezondheidszorg en de meldingsprocedure. Vrije Universiteit Amsterdam, Instituut voor Extramuraal Geneeskundig Onderzoek / Sociale Geneeskunde. Erasmus Universiteit Rotterdam, Instituut Maatschappelijke Gezondheidszorg. 1997.
- Cuperus-Bosma JM. Regulering, toetsing en kwaliteitsbewaking van levensbeëindigend handelen. Regulation, examination and quality assurance of physician-assisted death [in Dutch]. Thesis. Amsterdam: Vrije Universiteit, 1998.
- Cuperus-Bosma JM, Wal G van der, Looman CW, Maas PJ van der. Assessment of physician-assisted death by members of the public prosecution in The Netherlands. *J Med Ethics* 1999;25(1):8-15.

- Cuperus-Bosma JM, Wal G van der, Kostense PJ, Maas PJ van der. The role of the medical examiner in the euthanasia notification procedure in The Netherlands. *Med Sci Law* 2000;40(1):9-19.
- Delden JJM van. Beslissen om niet te reanimeren. Thesis. Utrecht: Rijksuniversiteit Utrecht, 1993.
- Delden JJM van, Pijnenborg L, Maas PJ van der, Looman CWN. Deciding not to resuscitate in Dutch hospitals. *J Med Ethics* 1993;19(4):200-5.
- Delden JJM van, Pijnenborg L, Maas PJ van der. The Rummelink Study, two years later. *Hastings Cent Rep* 1993;23:24-7.
- Delden JJM van, Pijnenborg L, Maas PJ van der. Dances with data. Reports from the Netherlands. *Bioethics* 1993;7:323-9.
- Groenewoud JH, Maas PJ van der, Wal G van der, et al. Physician-assisted death in psychiatric practice in the Netherlands. *N Engl J Med* 1997;336:1795-801.
- Groenewoud JH, Maas PJ van der, Wal G van der, et al. Hulp bij zelfdoding in de psychiatrie in Nederland. *Ned Tijdschr Geneesk* 1997;197(46):2244-8.
- Groenewoud JH, Heide A van der, Maas PJ van der, Wal G van der. Hulp bij zelfdoding in de psychiatrie in Nederland [letter]. *Ned Tijdschr Geneesk* 1998;142(10):542.
- Groenewoud JH, Heide A van der, Onwuteaka-Philipsen BD, Willems DL, Maas PJ van der, Wal G van der. Clinical problems with the performance of euthanasia and physician-assisted suicide in The Netherlands. *N Engl J Med* 2000;342(8):551-6.
- Groenewoud JH, Heide A van der, Kester JG, Graaff CL de, Wal G van der, Maas PJ van der. A nationwide study of decisions to forego life-prolonging treatment in Dutch medical practice. *Arch Intern Med* 2000;160(3):357-63.
- Haverkate I, Wal G van der. Policies on medical decisions concerning the end of life in Dutch health care institutions. *JAMA* 1996;275(6):435-9.
- Haverkate I, Wal G van der, Maas PJ van der, Onwuteaka-Philipsen BD, Kostense PJ. Guidelines on euthanasia and pain alleviation: compliance and opinions of physicians. *Health Policy* 1998;44(1):45-55.
- Haverkate I, Wal G van der. Dutch nursing home policies and guidelines on physician-assisted death and decisions to forego treatment. *Public Health* 1998;112(6):419-23.
- Haverkate I, Wal G van der. Policies on assisted suicide in Dutch psychiatric facilities. *Psychiatr Serv* 1998;49(1):98-100.
- Haverkate I. Policies and guidelines on medical decisions concerning the end of life in Dutch health care. Thesis. Amsterdam: Vrije Universiteit, 1999.

- Haverkate I, Muller MT, Cappetti M, Jonkers FJ, Wal G van der. Prevalence and content analysis of guidelines on handling requests for euthanasia or assisted suicide in Dutch nursing homes. *Arch Intern Med* 2000;160(3):317-22.
- Haverkate I, Onwuteaka-Philipsen BD, Heide A van der, Kostense PJ, Wal G van der, Maas PJ van der. Refused and granted requests for euthanasia and assisted suicide in the Netherlands: interview study with structured questionnaire. *BMJ* 2000;321(7265):865-6.
- Haverkate I, van Delden JJ, van Nijen AB, Wal G van der. Guidelines for the use of do-not-resuscitate orders in Dutch hospitals. *Crit Care Med* 2000;28(8):3039-43.
- Heide A van der, Maas PJ van der, Wal G van der, et al. Medical end-of-life decisions made for neonates and infants in the Netherlands. *Lancet* 1997;350(9073):251-5.
- Heide A van der, Maas PJ van der, Wal G van der, et al. Medische beslissingen rond het levenseinde bij pasgeborenen en zuigelingen. *Ned Tijdschr Geneeskd* 1997;141:1913-7.
- Heide A van der, Muller MT, Kester JGC, Groenewoud JH, Wal G van der, Maas PJ van der. Frequentie van het afzien van (kunstmatige) toediening van voeding en vocht aan het levenseinde. [Frequency of decisions to forgo (artificial) administration of food and fluids at life's end]. *Ned Tijdschr Geneeskd* 1997;141(40):1918-24.
- Heide A van der, Maas PJ van der, Kollée LAA. End-of-life decisions in Dutch paediatric practice [letter]. *Lancet* 1997;350(9092):1711.
- Heide A van der, Maas PJ van der, Wal G van der, Kollée LAA, Leeuw R de, Holl RA. The role of parents in end-of-life decisions in neonatology: physicians' views and practices. *Pediatrics* 1998;101(3):413-8.
- Kollée LA, Heide A van der, Leeuw R de, Maas PJ van der, Wal G van der. End-of-life decisions in neonates. *Semin Perinatol* 1999;23(3):234-41.
- Maas PJ van der. Medische beslissingen rond het levenseinde, het onderzoek in opdracht van de commissie Rimmelink. Medical decisions around life's end, the study by instruction of the Commission Rimmelink [in Dutch]. *Ned Tijdschr Geneeskd* 1990;134(37):1802-5.
- Maas PJ van der, Delden JJM van, Pijnenborg L. Medische beslissingen rond het levenseinde 's-Gravenhage: Sdu; 1991.
- Maas PJ van der, Delden JJM van, Pijnenborg L, Looman CWN. Euthanasia and other medical decisions concerning the end of life. *Lancet* 1991;338:669-74.

- Maas PJ van der, Delden JJM van, Pijnenborg L. Euthanasie en andere medische beslissingen rond het levenseinde in Nederland. II. Zorgvuldigheid en melding. *Ned Tijdschr Geneeskd* 1991;135:2082-8.
- Maas PJ van der, Delden JJM van, Pijnenborg L. Euthanasia and other medical decisions concerning the end of life. *Health Policy* 1992;22:1-262.
- Maas PJ van der, Pijnenborg L, Delden JJM van. Changes in Dutch opinions on active euthanasia, 1966 through 1991. *JAMA* 1995;237(18):1411-4.
- Maas PJ van der, Wal G van der, Haverkate I, et al. Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in the Netherlands, 1990-1995. *N Engl J Med* 1996;335:1699-705.
- Maas PJ van der, Wal G van der, Haverkate I, et al. Euthanasie en andere medische beslissingen rond het levenseinde, 1990-1995. *Ned Tijdschr Geneeskd* 1997;141(2):98-105.
- Maas PJ van der. End of life decisions in mentally disabled people: protecting vulnerable life does not mean prolonging it regardless of suffering [editorial]. *BMJ* 1997;315:73.
- Maas PJ van der, Wal G van der. Dokters en doodgaan: zijn de feiten veranderd? [letter]. *Medisch Contact* 1997;52(8):256-7.
- Maas PJ van der, Wal G van der. Euthanasia and physician-assisted suicide in the Netherlands [letter]. *N Engl J Med* 1997;336(19):1386-7.
- Muller MT, Wal G van der, Eijk JT van, Ribbe MW. Voluntary active euthanasia and physician-assisted suicide in Dutch nursing homes: are the requirements for prudent practice properly met? *J Am Geriatr Soc* 1994;42(6):624-9.
- Muller MT, Wal G van der, Eijk JT van, Ribbe MW. Active euthanasia and physician-assisted suicide in Dutch nursing homes: patients' characteristics. *Age Ageing* 1995;24(5):429-33.
- Muller MT, Onwuteaka-Philipsen BD, Kriegsman DM, Wal G van der. Voluntary active euthanasia and doctor-assisted suicide: knowledge and attitudes of Dutch medical students. *Med Educ* 1996;30(6):428-33.
- Muller MT, Onwuteaka-Philipsen BD, Wal G van der, Eijk J van, Ribbe MW. The role of the social network in active euthanasia and physician-assisted suicide [see comments]. *Public Health* 1996;110(5):271-5.
- Muller M. Death on request. Aspects of euthanasia and physician-assisted suicide with special regard to Dutch nursing homes. Thesis. Amsterdam: Vrije Universiteit, 1996.
- Muller MT, Pijnenborg L, Onwuteaka-Philipsen BD, Wal G van der, Eijk JT van. The role of the nurse in active euthanasia and physician-assisted suicide. *J Adv Nurs* 1997;26(2):424-30.

- Muller MT, Kimsma GK, Wal G van der. Euthanasia and assisted suicide: facts, figures and fancies with special regard to old age. *Drugs Aging* 1998;13(3):185-91.
- Onwuteaka-Philipsen BD, Muller MT, Wal G van der, Eijk JT van, Ribbe MW. Attitudes of Dutch general practitioners and nursing home physicians to active voluntary euthanasia and physician-assisted suicide. *Arch Fam Med* 1995;4(11):951-5.
- Onwuteaka-Philipsen BD, Muller MT, Wal G van der. Euthanasia and old age. *Age Ageing* 1997;26(6):487-92.
- Onwuteaka-Philipsen BD, Muller MT, Wal G van der. Euthanatics: implementation of a protocol to standardise euthanatics among pharmacists and GPs. *Patient Educ Couns* 1997;31(2):131-7.
- Onwuteaka-Philipsen BD, Muller MT, Wal G van der, Eijk JT van, Ribbe MW. Active voluntary euthanasia or physician-assisted suicide? *J Am Geriatr Soc* 1997;45(10):1208-13.
- Onwuteaka-Philipsen BD, Wal G van der. Cases of euthanasia and physician assisted suicide among AIDS patients reported to the Public Prosecutor in North Holland. *Public Health* 1998;112(1):53-6.
- Onwuteaka-Philipsen BD, Wal G van der, Kostense PJ, Maas PJ van der. Consultants in cases of intended euthanasia or assisted suicide in The Netherlands. *Med J Aust* 1999;170(8):360-3.
- Onwuteaka-Philipsen BD. Consultation of another physician in cases of euthanasia and physician-assisted suicide. Thesis. Amsterdam, Vrije Universiteit, 1999.
- Onwuteaka-Philipsen BD, Wal G van der, Wigersma L. Consultation and discussion with other physicians in cases of requests for euthanasia and assisted suicide refused by family physicians. *Camb Q Healthc Ethics* 2000;9(3):381-90.
- Onwuteaka-Philipsen BD, Wal G van der, Kostense PJ, Maas PJ van der. Consultation with another physician on euthanasia and assisted suicide in the Netherlands. *Soc Sci Med* 2000;51(3):429-38.
- Onwuteaka-Philipsen BD, Wal G van der. Support and consultation for general practitioners concerning euthanasia: the SCEA project. *Health Policy* 2001;56:33-48.
- Pijnenborg L, Maas PJ van der, Delden JJM van, Looman CWN. Life-terminating acts without explicit request of patient. *Lancet* 1993;341(8854):1196-9.
- Pijnenborg L, Maas PJ van der, Delden JJM van, Looman CWN. Life-terminating acts without explicit request [letter]. *Lancet* 1993;342(8866):308.

- Pijnenborg L, Delden JJM van, Kardaun JWPF, Glerum JJ, Maas PJ van der. Nationwide study of decisions concerning the end of life in general practice in the Netherlands. *BMJ* 1994;309(6963):1209-12.
- Pijnenborg L. End-of-life decisions in Dutch medical practice. Thesis. Rotterdam: Erasmus University Rotterdam, 1995.
- Pijnenborg L, Maas PJ van der, Kardaun JWPF, Glerum JJ, Delden JJM van, Looman CWN. Withdrawal or withholding of treatment at the end of life. *Arch Intern Med* 1995;155(3):286-92.
- Wal G van der. Euthanasie en hulp bij zelfdoding door huisartsen. Euthanasia and physician-assisted suicide by family doctors [in Dutch]. Thesis. Rotterdam: WYT Uitgeefgroep, 1992.
- Wal G van der, Muller MT, Christ LM, Ribbe MW, Eijk JT van. Voluntary active euthanasia and physician-assisted suicide in Dutch nursing homes: requests and administration. *J Am Geriatr Soc* 1994;42(6):620-3.
- Wal G van der, Maas PJ van der, Bosma JM, et al. Evaluation of the notification procedure for physician-assisted death in the Netherlands. *N Engl J Med* 1996;335(22):1706-11.
- Wal G van der, Onwuteaka-Philipsen BD. Cases of euthanasia and assisted suicide reported to the public prosecutor in North Holland over 10 years. *BMJ* 1996;312(7031):612-3.
- Wal G van der, Maas PJ van der. Evaluatie van de meldingsprocedure euthanasie. Evaluation of the notification procedure for physician-assisted death [in Dutch]. *Ned Tijdschr Geneesk* 1995;139(37):1894-7.
- Wal G van der, Maas PJ van der. Evaluatieonderzoek meldingsprocedure euthanasie. Achtergronden en opzet. *Medisch Contact* 1995;50(37):1157-9.
- Willems DL, Groenewoud JH, Wal G van der. Drugs used in physician-assisted death. *Drugs Aging* 1999;15(5):335-40.
- Willems DL, Daniels ER, Wal G van der, Maas PJ van der, Emanuel EJ. Attitudes and practices concerning the end of life: a comparison between physicians from the United States and from The Netherlands. *Arch Intern Med* 2000;160(1):63-8.