Euthanasia
and other
medical decisions
at the
end of life
Societal control and cultural aspects

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Euthanasia and Other Medical Decisions at the End of Life
Societal Control and Cultural Aspects

Euthanasie en andere medische beslissingen rond het levenseinde
Maatschappelijke controle en culturele aspecten

Proefschrift

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Contents

1

Introduction

Death is a socially and culturally embedded phenomenon.[1] It is inevitably understood and experienced within a complex web of cultural meanings that differ within and across countries. During the past century, acute death due to infectious diseases has to a great extent been replaced by death due to conditions that involve a more protracted dying process, such as cancer and cardiovascular diseases.[2] Currently, approximately 70% of all deaths are non-sudden[3] and are likely to involve some form of end-of-life care. Advances in medicine have greatly improved the possibilities to treat seriously ill patients and to prolong life and postpone death. It is also increasingly recognized that prolonging life is not always the most appropriate goal of medicine. Preserving quality of life and alleviating the patient's suffering are other important care goals at the end of life. In some cases hastening of death can be an acceptable or even desired result of end of life care as well. Euthanasia, that is, deliberately ending a person's life at the person's request, and physician-assisted suicide, where the person self-administers lethal medication that is prescribed by a physician, are among the most controversial acts.[a]

1.1 The Dutch Euthanasia Act

Euthanasia is under a number of conditions legally accepted in the Netherlands. The enforcement of the Dutch Euthanasia Act is the result of decades of societal debate. Initially, two court cases were important in the discussion: the so called 'Postma case'[4] (1973) and 'Schoonheim case'[5] (1984). In these cases, the physicians' conflicting responsibilities of preserving the patient's life versus relieving unbearable suffering eventually led to the decision to perform euthanasia. The discussion about these cases has contributed to physicians' awareness of the limits of medical care and the importance of patients' self determination.[6]

After 1980 the debate about euthanasia progressed and formalized. The Royal Dutch Medical Association (RDMA, in Dutch: KNMG) and a State Committee that was established in 1982 to advise the government, further explored under what conditions euthanasia could be allowed. In 1984, the RDMA presented a standpoint on euthanasia: it provided a definition of euthanasia and described how physicians could prudently deal with patient's requests for euthanasia.[7] By codifying the emerging professional consensus, the RDMA standpoint became of major importance for the development of criteria for due care. In 1985, the State Committee published its report. The committee also came up with a series of criteria of due care to which physicians should adhere. Both the RDMA and committees' standpoint had significant influence on later developments.

In 1990, encouraged by the RDMA, the Ministry of Justice decided to follow a uniform euthanasia reporting procedure, which became formalized in 1993.[8] The purpose of this procedure was to encourage physicians to disclose cases of euthanasia, to promote adherence to criteria for due care, and to ensure that euthanasia is reported in a uniform manner throughout the Netherlands. In 1998, the reporting procedure was revised with the introduction of multi-disciplinary review committees consisting of a lawyer, an ethicist and a physician, that advise the public prosecutor. In April 2002, the Euthanasia

[a] In the Netherlands, euthanasia and physician-assisted suicide are subject to the same criteria for due care. Therefore, when mentioning 'euthanasia' also 'physician-assisted suicide' is meant, unless stated otherwise.

Act (Termination of Life on Request and Assisted Suicide (Review Procedure) Act) came into force.[9] The main aim of the Act was to enhance legal security and societal control. The most important change due to the Act was that the review committees only forward cases to the public prosecutor (and the health inspectorate) in which the criteria of due care are not met. Further, the Act regulates age limits for euthanasia and physician-assisted suicide by permitting it for competent children aged 16 to 18 years, provided that the parents are involved in the decision-making, and for competent children aged 12-16 years, provided that the parents agree with the decision. The due care criteria (laid down in Article 2 of the Act) mirror the criteria that were proposed by the RDMA and that were further developed by the courts during the preceding decades (**Box 1.1**).[5]

Box 1.1 Dutch criteria of due care for euthanasia and physician-assisted suicide under the Act.

1. The patient's request should be voluntary and well-considered.
2. The patient's suffering should be unbearable and without prospect of improvement.
3. The patient should be informed about his situation and prospects.
4. There are no reasonable alternatives.
5. Another, independent physician should be consulted.
6. The termination of life should be performed with due medical care and attention.

Newborns

The Act only concerns ending of life for persons who are competent and who expressed a voluntary and well-considered request. It does not apply to infants: active ending a newborn's life is legally prohibited in the Netherlands. However, in 1992 the Dutch Paediatric Association (in Dutch: 'Nederlandse Vereniging voor Kindergeneeskunde') published a report that proposed criteria for actively ending a newborn's life that included an obligation to report their case.[10] In the mid-1990s two physicians who had actively ended a newborn's life were dismissed from prosecution because their acts could be justified with a 'defence of necessity' (the 'Prins' and 'Kadijk' cases).[11 12] These cases were for the first time analysed along the line of euthanasia jurisprudence. In 1996, the Dutch government appointed a committee to give further advice about the conditions under which active ending a newborn's life could be permitted. The committees' advice was to enforce a similar procedure as for euthanasia: a multidisciplinary committee should review the cases and subsequently advise the public prosecutor.[13] However, due to the government's focus on the passing of the euthanasia law, active ending of life of newborns received relatively little attention. In 2002, a protocol was developed to guarantee that all necessary information was provided for assessment, the so called 'Groningen protocol'.[14] This protocol - which attracted a lot of attention in 2005 - proposes guidelines and specific requirements for actively ending a newborn's life to guarantee careful decision-making; together with the committees' report in 1997[13] it served as a basis for a national regulation by the government. In 2006, a national multidisciplinary committee, including three physicians, a lawyer and an ethicist, was installed to review all cases of active ending of life of newborn infants.[15] This national committee evaluates whether the due care criteria are met, i.e. that 1) the suffering of the child was unbearable and without prospect of improvement, 2) independent physicians were consulted, 3) the parents agreed with the decision, 4) and that physician-assistance in dying was provided with due care. Up till September 2009, no cases have been reported to this committee.

1.2 The practice of euthanasia

Netherlands

In 1990, the Dutch government appointed a committee to conduct research on the practice of medical end-of-life decision-making by studying the frequency and characteristics of end-of-life decisions. This study[16] was followed by three comparable nationwide studies, conducted in 1995, 2001 and 2005.[17-19] In all studies, end-of-life decisions were characterized by: whether the act involved an act or omission, the intention of the physician, the effect of the act and the involvement of the patient. End-of-life decisions were classified in five categories (**Box 1.2**):

Box 1.2 Medical end-of-life decisions.

1. Euthanasia.
The administration of drugs with the explicit intention of hastening death at the patient's explicit request.
2. Physician-assisted suicide.
The prescription or supply of drugs with the explicit intention to enable the patient to end his or her own life.
3. Ending of life without an explicit patient request.
The administration of drugs with the explicit intention of hastening death without an explicit patient request.
4. Alleviation of pain and symptoms.
In dosages which are large enough to include the hastening of death as a likely or certain side-effect.
5. Withholding or withdrawing potentially life-prolonging treatment.

These studies have clearly assessed the trends in euthanasia in the Netherlands. In 1990, 1.7% of all deaths were the result of euthanasia, as compared with 2.4% in 1995 and 2.6% in 2001. In 2005 the trend reversed with 1.7% of all deaths. The four studies further revealed that the reporting rate (the number of reported cases divided by the total number of euthanasia cases), which had gradually increased since 1990 sharply rose to 80% in 2005.[19-21] Studying reported cases gave insight into the degree to which the goals of transparency, public oversight, and legal control of euthanasia, as envisaged by the Act, were achieved. Physicians who did not report cases of euthanasia in 1995, often indicated to fear prosecution precisely because they had to report to the public prosecutor.[20] By revising the system so that assessment is to a large extent done outside the legal system, the government aimed to decrease the number of unreported cases. Cases that remained unreported after the establishment of multidisciplinary review committees (1998) and the establishment of the Euthanasia Act (2002) mainly involved the use of opioids instead of neuromuscular relaxants.

Other countries

At present, euthanasia and/or physician-assisted suicide are legally allowed in a few other countries/states: Oregon (1997), Belgium (2002), and since very recently Washington (2008) and Luxemburg (2009).[22-25] Switzerland has a different history with regard to assisted death; euthanasia and physician-assisted suicide are illegal but the judicial system has made assisted suicide possible since 1918.[26] The monitoring system in Belgium is largely comparable to the Dutch monitoring system, although less transparent:

Belgian procedures are primarily anonymous whereas the Dutch are not.[27] In Oregon, the Oregon State Public Health Division asks physicians to report their act by giving all prescriptions for lethal medications and by filling in a compliance form that checks whether they complied with the criteria; surveillance is aimed at the overall effect of the Act.[28] In Oregon and Belgium (just like the Netherlands) societal evaluation is made possible through a regular summary report that is presented to the parliament. Till now, there are no reporting rates to evaluate the systems in Belgium and Oregon.
In many countries, the political and medical arena as well as the general public have expressed their attitudes towards euthanasia and euthanasia legalization.[29-34] The notion that physician-assisted dying not only occurs in countries where it is legalized[35-37] unites proponents of legalization of euthanasia on at least one thing: the importance of regulatory guidelines. As such, debates often relate to concerns about whether it is possible to keep the practice of physician-assisted dying within agreed borders.[38 39]

The 2001 nationwide Dutch study was conducted in conjunction with identical studies in five other European countries: Belgium, Denmark, Italy, Sweden and Switzerland; the EURELD study.[35] At that time, euthanasia was prohibited in all studied countries but physicians were found to have used drugs with the explicit intention to hasten death with percentages varying from 1% or less in Denmark, Italy and Sweden to 1.9% in Belgium and 3.4% in the Netherlands (**Table 1.1**). Furthermore, ending of life without an explicit patient request occurred more often than euthanasia and physician-assisted suicide in all countries apart from the Netherlands.

Table 1.1 Frequency of medical end-of-life decisions in six European countries.[35]

	Belgium %	**Denmark** %	**Italy** %	**Netherlands** %	**Sweden** %	**Switzerland** %
Euthanasia	0.30	0.06	0.04	2.59	-	0.27
Physician-assisted suicide	0.01	0.06	0.00	0.21	-	0.36
Ending life without the patient's request	1.50	0.67	0.06	0.60	0.23	0.42
Alleviation of pain and symptoms	22	26	19	20	21	22
Withholding or withdrawing treatment	15	14	4	20	14	28

1.3 Other medical decisions at the end of life

For the Dutch government, the importance of monitoring the practice of euthanasia has been the major reason to initiate large scale empirical studies. These studies also concerned other medical end-of-life decisions that may involve hastening of death. Comparable studies were performed in other countries within and outside Europe.[36 40 41] Yet, in depth and methodologically sound comparisons between groups with different cultural backgrounds have hardly been performed in the Netherlands.[42-44] Furthermore, although empirical research in the field of end-of-life decision-making has grown substantially in the last couple of years,[36 37 40 41 45 46] internationally comparable data are still scarce.[35 47-49]

Variation within the Netherlands

In the Netherlands, frequencies of decisions to forgo potentially life-prolonging treatment varied between 16-20% of all deaths between 1990 and 2005. The percentage of alleviation of pain and symptoms increased from 19% of all deaths in 1990 to 25% in 2005. Continuous deep sedation, i.e. the administration of drugs to keep the patient continuously in deep sedation or coma until death, a practice studied since 2001, increased from 5.6% of all deaths in 2001 to 8.2% in 2005.[16-19] The increased use of symptom alleviation is probably related to different attitudes towards opioids and the understanding of their effect.[50-53] The increased use of continuous deep sedation may be related to an increased interest among physicians and patients in this intervention to relieve severe suffering, partly as an alternative to euthanasia.[54]

Apart from differences in time in the frequency of end-of-life practices, there are also differences within the Netherlands for specific groups of people. These are related to medical factors such as peoples' diagnosis and age,[19] but possibly also to their personal attitudes and beliefs.[55 56] The Netherlands is a culturally diverse population, with 11% of people originating from non-western countries.[57] For non-western migrants, the original religion or culture is probably often important. Strong religious doctrines mostly involve the attitude that euthanasia is unacceptable.[58 59] However, attitudes towards other medical end-of-life decisions may also vary due to different expressed needs and expectations of non-western migrants.[60 61]

Variation between countries

In the EURELD study, the frequencies of decisions to withhold or withdraw potentially life prolonging treatment (4% in Italy up to 28% in Switzerland) varied, but the frequencies of alleviation of pain and symptoms (19% in Italy up to 26% in Denmark) were much more similar (**Table 1.1**). The differences in the rate of forgoing potentially life-prolonging treatment between countries could not be explained by medical factors, such as age, gender and diagnosis.

Each country has its own judicial system, social structure, and history and culture.[62] Decision-making may be influenced by the legal status of euthanasia but also by other laws that relate to palliative care, advance care planning or patient's rights to refuse treatment.[63 64] In 2003, the issue of forgoing artificial nutrition and hydration (ANH) for example generated public concern in Australia: the Supreme Court of Victoria was involved in a case of a woman in a persistent vegetative state that eventually led to the withdrawing of ANH.[65] For this case a judicial clarification between 'medical treatment' and 'palliative care' was sought. Furthermore, there are fundamental differences in how health care systems work and the routes by which patients are referred, which may influence the process of decision-making.[47 66 67] Historical and cultural factors probably also influence attitudes towards end-of-life decision-making.

1.4 This thesis

Research aims

The studies described in this thesis have two main aims:

1. To study how and to what extent societal control of euthanasia and physician-assisted suicide is achieved in the Netherlands.
2. To study variation in end-of-life decision-making between culturally diverse groups and between countries.

PART I – SOCIETAL CONTROL

The first research aim is addressed in part 1. We first investigated whether there are criteria of due care that are difficult to interpret for Dutch physicians and we discuss our findings with the medical, ethical and judicial debates concerning euthanasia in the past decades in mind (Chapter 2). In order to find out whether such problems may be reflected in physicians' reporting, we investigated how physicians substantiate the criteria of due care when they report a case (Chapter 3). This chapter further addressed which criteria attain most attention of the review committees. To further increase our understanding of the reporting procedure and physicians' willingness to report euthanasia we compared reported and unreported cases of euthanasia and investigated how reporting physicians perceive ('label') these cases (Chapter 4). In Chapter 5 we subsequently investigated *why* physicians label end-of-life acts as some form of physician-assisted dying or not, and studied the association of such labeling with reporting of these acts. Finally, in Chapter 6 we investigated the characteristics of cases of actively ending of life for infants and give possible explanations why no reports of active ending of life in infants were received thus far under the current review procedure. We thus aim to comprehensively map reported and unreported cases of physician-assisted dying to see whether and where there may be any obstacles that hamper complete societal control.

PART II – CULTURAL ASPECTS

The second research aim is addressed in part 2. By comparing end-of-life decision-making practices within and across western countries with epidemiological and qualitative research methods we explored the impact cultural aspects can have. In Chapter 7 we investigated whether end-of-life decision-making practices for Dutch natives differed from practices for non-western migrants in the Netherlands. We hypothesized that end-of-life decision-making for people from non-western countries who migrated to the Netherlands may be different from decision-making for Dutch natives, due to differences in cultural background and access to health care services. In Chapter 8 we compared the practice of forgoing ANH in six European countries. In Chapter 9 we zoomed in on the use of ANH for patients with advanced dementia in the Netherlands and Australia with qualitative in-depth interviews. We tried to obtain a deeper understanding of how physicians' perceptions affect their treatment choices and whether decision-making in this particular area is culturally and/or medically determined.

Methodology
This thesis is based upon four different studies:

Nation-wide physician survey
In 2006, we performed a national questionnaire survey among 2100 physicians, including 1300 clinical specialists, 500 general practitioners and 300 nursing home physicians. The questionnaire response rate, adjusted for physicians who were untraceable, was 55%. Physicians received a 10-page written questionnaire that focused on experiences with and attitudes towards the Dutch Euthanasia Act. Physicians were further presented hypothetical cases of elderly patients in the terminal stage of a lethal disease, who severely suffered from pain and fatigue. Each physician was presented three 'standard

cases' and three cases randomly selected out of 47. We ensured that all 47 cases were presented in similar frequencies but gave each physician a unique combination to avoid order effects.[68]

Study of euthanasia reports
We studied physicians' reports and the verdicts of the euthanasia review committees in 158 files of euthanasia or physician-assisted suicide cases that were reported in 2005 and in which the standard form (as advised by the RDMA) was used by the reporting physician. Those 158 euthanasia files included all 75 cases in 2005 where review committees had had doubts or questions and asked the reporting physician to provide further information. It further included 'the last' 83 reported cases in 2005. This part was stratified for the five review committees in the Netherlands.[69]

Nation-wide death certificate studies
We performed studies of the incidence and major characteristics of end-of-life decisions in randomized samples of death cases in 2005 (Netherlands) and in 2001 (6 European countries - the EURELD study). The study designs were identical in both studies. The 2005 study comprised additional questions about the euthanasia review procedure. The questionnaire response rate for this study was 78% in 2005. For the EURELD study response rates were 59% in Belgium, 62% in Denmark, 44% in Italy, 61% in Sweden, 67% in Switzerland and 74% in the Netherlands.[19 35] We also separately analysed data on end-of-life decision-making for children under the age of one year in 1995, 2001 and 2005.[69-71] Response rates for this particular group were 88% (1995), 84% (2001) and 88% (2005).

Qualitative interviews among Dutch and Australian medical practitioners
In 2008, we performed qualitative in-depth interviews with doctors in the Netherlands (n=15) and Australia (n=15) to study the use of artificial nutrition or hydration (ANH) in patients with advanced dementia. We asked about general experiences with patients with advanced dementia and about two actual patients where ANH had been withheld or withdrawn.

In all four studies strict anonymity of the physician and patient was guaranteed.

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PART I

SOCIETAL CONTROL

2

Dutch criteria of due care for physician-assisted dying in medical practice: A physician perspective

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Abstract

Introduction The Dutch Euthanasia Act (2002) states that euthanasia is not punishable if the attending physician acts in accordance with the statutory due care criteria. These criteria hold that: there should be a voluntary and well-considered request, the patient's suffering should be unbearable and hopeless, the patient should be informed about their situation, there are no reasonable alternatives, an independent physician should be consulted, and the method should be medically and technically appropriate. This study investigates whether physicians experience problems with these criteria in medical practice.

Methods In 2006, questionnaires were sent to a random, stratified sample of 2100 Dutch physicians (response rate: 56%). Physicians were asked about problems in their decision-making related to requests for euthanasia or assisted suicide after enforcement of the 2002 Euthanasia Act.

Results Of all physicians who had received a request for euthanasia or assisted suicide (75%), 25% had experienced problems in the decision-making with regard to at least one of the criteria of due care. Physicians who had experienced problems, mostly indicated to have had problems related to evaluating whether or not the patient's suffering was unbearable and hopeless (79%) and whether or not the patient's request was voluntary or well considered (58%).

Discussion Physicians in the Netherlands most frequently reported problems related to aspects in which they have to evaluate the patient's subjective perspective(s). However, it can be questioned whether placing emphasis on these subjective aspects is an adequate fulfilment of the duties imposed on physicians, as laid down in the Dutch Euthanasia Act.

Acknowledgments The authors thank the thousands of physicians who provided the study data, the members of the Steering Committee, the Royal Dutch Medical Association, and the Chief Inspector for Health Care for their support of the present study.

2.1 Introduction

The Dutch Euthanasia Act – the Termination of Life on Request and Assisted Suicide (Review Procedures) Act – came into force in 2002.[1] As the title suggests, it provided a legal basis for the review system that already existed. However, in doing so, it also changed the Criminal Code by granting immunity to a physician who acts in accordance with the statutory due care criteria (see **Box 2.1**). These criteria (laid down in Article 2 of the Act) reflect the criteria developed by the courts during the preceding decades and are generally considered to be a summary of case law concerning euthanasia or assisted suicide.[2]

Box 2.1. Dutch criteria of due care for euthanasia and physician-assisted suicide as laid down in the Act.

1. The patient's request should be voluntary and well considered.
2. The patient's suffering should be unbearable and without prospect of improvement.
3. The patient should be informed about his situation and prospects.
4. There are no reasonable alternatives.
5. Another, independent physician should be consulted.
6. The termination of life should be performed with due medical care and attention.

The 'voluntary' nature of the request presupposes that there has been no pressure from others and that the mental state of the patient (i.e. competent) allows them to determine what they want; 'well considered' means – according to the proceedings of parliament when the Act was discussed – that the request is enduring and that the patient made it on the basis of full information and understanding about their medical situation.

The suffering of a patient may have different causes, such as pain, increasing dependency, and anxiety. However, according to a decision of the Supreme Court in 2002 the suffering should predominantly result from a medically classifiable disease or disorder: other forms of suffering do not justify euthanasia or assisted suicide.[3] The 'unbearability' of the suffering is assessed from the patient's perspective and the patient's ability to cope with the situation. The patients themselves should consider their suffering as unbearable. The physician only needs to be convinced that the patient is experiencing unbearable suffering. 'Without prospect of improvement' means that an improvement of the medical situation of the patient in the foreseeable future cannot be expected.

Informing the patient is the physician's responsibility and is part of the professional medical standard. For patients to make a 'well-considered' request, they need to have a full understanding of their illness, the diagnosis, prognosis and possible treatment.

The requirement that euthanasia or assisted suicide is only allowed when there are no reasonable alternatives to alleviate the patient's suffering has been amply discussed in parliament, in particular the question to what extent a patient may refuse care without consequences for their request. According to the parliamentary proceedings, the physician should discuss all the available palliative options with the patient before deciding about euthanasia or assisted suicide. Basically, a patient may refuse treatment or palliative care; however, if the intervention in question is not very invasive the physician may conclude that there is a reasonable alternative and that euthanasia or assistance in suicide is therefore not justified.

The consultation requirement serves to guarantee careful decision-making. The consultant should be an independent physician, who has to give a written opinion on whether the criteria of due care (as mentioned above) have been met. The consultant should also describe their relationship with the attending physician and patient.
The requirement that euthanasia should be performed with due medical care primarily concerns the appropriate administration of the medication as recommended by the Royal Dutch Society for the Advancement of Pharmacy (KNMP). Additionally, the medication should be administered by the attending physician and not by nursing staff.

It is the task of the five multidisciplinary review committees to assess whether a physician did proceed in accordance with the Act. This is done on the basis of the physician's report; however, the review committee may request the physician to supplement this report either orally or in writing, or may obtain information from other persons involved, if this is necessary for a proper assessment. The public prosecution is only informed when a review committee thinks that the physician, in performing euthanasia or physician-assisted suicide, did not comply with one of the criteria. The physician has a central position in the Act. Although self-determination of the patient is a necessary condition to justify the termination of his or her life, in the final analysis the physician's responsibility to alleviate the patient's suffering is the most important principle underlying the Act. The fact that the Dutch model is basically medically oriented, explains to a large extent the support it has always received from the Royal Dutch Medical Association, as well as its wide acceptance in the social and political arena.

In applying the criteria, the physician may find some support in the literature or in court decisions and cases decided by the review committees. Nevertheless, judging whether the criteria for due care are met may be difficult in clinical practice. The present study investigated to what extent physicians from different specialties experience problems with the criteria of due care in clinical practice.

2.2 Methods

Study design and respondents
This study involved a national questionnaire survey among 2100 Dutch physicians; 1300 clinical specialists, 500 general practitioners and 300 nursing-home physicians. The sample sizes were based on the frequency with which physicians care for terminally ill patients, and on the total number of physicians working in a specific discipline. Respondents were selected according to the following criteria: 1) they were clinically active at the time they filled out the questionnaire, 2) they had actively practiced medicine within the registered specialty for at least one year, and 3) they had to be living in the Netherlands. All addresses were taken from the professional registries of the relevant specialties. Over a 10-month period (February 2006 through November 2006) questionnaires were sent out and returned. Strict rules were applied to ensure the anonymity of all physicians. The overall questionnaire response rate, adjusted for physicians who were untraceable (n=215), was 56% (n=1032). Non-responders did not differ from responders in age, sex or place of residence.

Questionnaire

Physicians received a written questionnaire about their experiences with, and attitudes towards, the Dutch Euthanasia Act (2002). This questionnaire was previously tested among 16 respondents; they had little or no problems with regard to the interpretation of the questions. Physicians were first asked whether they thought they had been sufficiently informed about the Dutch Euthanasia Act. Subsequently, they were asked whether they had experienced problems in the decision-making about requests for euthanasia or assisted suicide in the context of the criteria of due care (see **Box 2.1**) after the enforcement of the Euthanasia Act. For each criterion, physicians could indicate what specific aspects had caused their problems. We used prestructured answer categories that were based on earlier studies investigating end-of-life decision-making[4 5] and the parliamentary proceedings on the Euthanasia Act. If these answer categories did not cover the problems experienced, physicians could elaborate on these in an open answer category.

Analyses

The results were made representative for all physicians in the relevant disciplines by weighting the data for different sampling fractions and response rates. We report absolute frequencies and weighted percentages. The 95% confidence intervals (CI) were calculated for the estimates of the number of physicians who indicated to be sufficiently informed about the Act, who had received a request for euthanasia or assisted suicide after the enforcement of the Euthanasia Act, and who had experienced problems related to the criteria of due care. Statistical analyses were performed using the Statistical Package for Social Sciences 11.0 (SPSS Inc, Chicago, III, USA).

2.3 Results

More than 90% of all respondents reported to be sufficiently informed about the Dutch Euthanasia Act; nursing-home physicians (97%) more often reported to be sufficiently informed than general practitioners (93%) or medical specialists (87%) (**Table 2.1**).

Table 2.1 Physicians' experiences with regard to the 2002 Dutch Euthanasia Act.

	General practitioner n=264 % (95% CI)[1]	**Medical specialist** n=527 % (95% CI)[1]	**Nursing home physician** n=212 % (95% CI)[1]	**Total** n=1032[2] % (95% CI)[1]
Sufficiently informed about the Act	93 (90-95)	87 (84-90)	97 (94-98)	92 (90-93)
Received request for euthanasia after enforcement of the Act	83 (78-87)	62 (58-66)	68 (62-74)	75 (73-78)
Received request after enforcement of Act	n=219	n=335	n=145	n=714[3]
Problems with the criteria of due care	28 (22-34)	14 (10-18)	35 (27-43)	25 (22-28)

1. Percentages weighted for different sampling fractions and response rates, CI = confidence interval.
2. For 29 physicians the specialty was unknown.
3. For 15 physicians the specialty was unknown.

Of all respondents who had received a request for euthanasia or assisted suicide after the enforcement of the Act (75%), 25% had had problems in the decision-making with regard to at least one of the criteria of due care. General practitioners had experienced problems in decision-making in 28% of the cases; for medical specialists this percentage was 14%, and for nursing-home physicians this percentage was 35%. Having had problems in decision-making was not related to physicians' age, sex or palliative care education. However, respondents who had *performed* euthanasia after the enforcement of the Act more often experienced problems in the decision-making (33%) than physicians who had not performed euthanasia (16%) (data not shown). In both subgroups, medical specialists least often experienced problems. For all respondents who had experienced problems regarding the criteria of due care, the problems were mostly related to the requirement that they should assess whether the patient's suffering was unbearable and hopeless (79%), whether the patient's request was voluntary and well-considered (58%), and whether reasonable alternatives were available (33%) (**Table 2.2**). For physicians who had performed euthanasia, these percentages were comparable (data not shown).

Table 2.2 Problems with the Dutch criteria of due care about requests for euthanasia or assisted suicide.

	General practitioner	Medical specialist	Nursing-home physician	Total
	n=61	n=45	n=50	n=158[1]
Problems with[3]:	%[2]	%[2]	%[2]	%[2]
The patient's request	52	75	72	58
The patient's suffering	80	65	86	79
The information given to the patient	13	20	24	15
The presence or absence of reasonable alternatives	35	29	28	33
The consultation	15	15	10	15
Performance of euthanasia	13	12	4	12

[1] For 2 physicians the specialty was unknown.
[2] Percentages weighted for different sampling fractions and response rates.
[3] One or more answers could be given.

With regard to the requirement that the physician should be convinced that the patient's request was voluntary and well considered, respondents indicated to have experienced difficulty in assessing whether the patient's request was well considered in 23% and voluntary in 18% of the cases; 18% indicated to have experienced problems in judging whether the patient's view of the severity of the disease was appropriate (**Table 2.3**).
With regard to the requirement that the physician should be convinced that the patient's suffering was unbearable and hopeless, physicians more often indicated to have experienced problems in assessing whether they themselves were convinced of the patient's unbearable suffering (53%) than in assessing whether the patients themselves experienced their suffering as unbearable (28%). Medical specialists less often indicated to have had difficulty in assessing the unbearability of the patients themselves (27%) than general practitioners (57%) or nursing-home physicians (63%). Further, 18% reported to have experienced problems in assessing whether the suffering was hopeless, and 15% in assessing whether it would be unbearable and hopeless within a very short time.
For the requirement that euthanasia or assisted suicide is only allowed when there are no reasonable alternatives to alleviate the patient's suffering, physicians most frequently indicated to have experienced problems with assessing whether there were reasonable alternatives for the signs and symptoms of the patient (15%).

Table 2.3 Specific aspects of problems with the Dutch criteria of due care about requests for euthanasia or assisted suicide.[1]

	General practitioner n=61 %[3]	Medical specialist n=45 %[3]	Nursing-home physician n=50 %[3]	Total n=158[2] %[3]
The patient's request - *problems to assess whether:*[4]				
Patient's request was well considered	20	32	34	23
Patient's request was entirely voluntary, without pressure from others	15	22	30	18
Patient's view of the severity of the disease was appropriate	18	18	18	18
Other[5]	10	14	16	11
The patient's suffering - *problems to assess whether:*[4]				
Patient himself experienced his or her suffering as unbearable	30	19	27	28
They themselves were convinced of the patient's unbearable suffering	57	27	63	53
They themselves were convinced of the patient's hopeless suffering	17	22	24	18
Patient's situation would be unbearable and hopeless in a very short time	15	19	6	15
Other	2	4	4	2
The presence or absence of reasonable alternatives - *problems to (assess whether):*[4]				
There were reasonable alternatives for the underlying suffering of patient	7	11	8	7
There were reasonable alternatives for the signs and symptoms of patient	17	10	8	15
Discuss reasonable alternatives with the patient	12	8	16	12
Other	2	2	2	2

[1] The types of problems caused by the other criteria are presented in the text only due to the small number of these cases.
[2] For 2 physicians the specialty was unknown.
[3] Percentages weighted for different sampling fractions and response rates.
[4] One or more answers could be given.
[5] Other includes: strong pressure from patient or family to perform euthanasia, patient is incompetent, 'it's difficult', not accepting palliative treatment.

Respondents less frequently indicated to have experienced problems with the 'other' requirements. In total, 15% of the respondents experienced problems concerning the information that should be given to the patient: respondents reported to have experienced problems with informing the patient about their situation and prospects in 6% of the cases, and with assessing whether the patient understood the information in 4% of the cases (data not shown).
The 15% of respondents who experienced problems with the consultation found it particularly difficult to find an independent physician (4%). Problems concerning how to perform euthanasia (12%) were mostly related to how to deal with unexpected events (7%).

2.4 Discussion

In the present study, one out of four physicians who had received a request for euthanasia or assisted suicide after the enforcement of the 2002 Dutch Euthanasia Act experienced problems in decision-making related to at least one of the criteria of due care. However, having experienced problems should not necessarily be interpreted as a negative finding since (by their nature) decisions related to euthanasia may be very difficult. Requests for euthanasia and assisted suicide typically result in several discussions with patient, family and other caregivers about the criteria of due care. The fact that some criteria are more difficult to assess than others suggests that they are taken seriously in the decision-making and will probably receive relatively much attention.

The proportion of respondents who had received a request for euthanasia or assisted suicide and had experienced problems in the decision-making was highest among nursing-home physicians, followed by general practitioners, and lowest among medical specialists. Apparently, each specialty handles the criteria in a different way. Medical specialists more often than other physicians reported to be less well informed about the content of the Act, which might result in less in-depth or comprehensive decision-making. Further, in hospitals a different 'care culture' may be expected in the sense that medical specialists generally have to decide and act more quickly. Additionally, they often have their first encounter with patients relatively late in the course of illness and thus have less opportunity to discuss issues concerning end-of-life decision-making.[6] A smaller proportion of problems in the decision-making about requests for euthanasia or assisted suicide does not imply that the criteria are more easily met when euthanasia is performed in the hospital; it is reported that medical specialists are more frequently requested to supply additional information to review committees.[7] The higher percentage of nursing-home physicians that reported to have experienced problems is probably related to the fact that most patients living in a nursing home suffer from a fatal, degenerating disease. Accordingly, nursing-home physicians may have a different level of 'acceptance' towards the patient's suffering; as a result, weighing whether requests for euthanasia should be granted for these patients may be relatively difficult. Moreover, decisions concerning euthanasia might be particularly difficult because a large proportion of nursing-home patients are incompetent before their death.[8] The Act stipulates that a physician may act according to a written request of the once competent but now incompetent patient, provided that the other criteria are met. However, to determine whether the criteria are

met in such patients is extremely difficult in actual practice[9 10] and euthanasia is almost never performed on the basis of a written request of an incompetent patient.
Apart from the physician's specialty, having performed euthanasia also appeared to be an important factor in how to deal with the criteria. The higher proportion of problems in the decision-making among respondents who had previously performed euthanasia, suggests that physicians who were more intensively involved in the decision-making, may have addressed the criteria more exhaustively or more comprehensively.

If respondents had experienced problems regarding the criteria of due care, they rarely reported other problems related to evaluating whether the patient was well informed about his medical situation, consulting another independent physician, and/or performing euthanasia with due medical care. These latter criteria are probably more easily applied, that is they focus more on the appropriateness of the method than on the decision to hasten the death of the patient, are more procedural in nature (consultation of another physician), or are already included in the substantive requirements (i.e. an insufficiently informed patient cannot make a well-considered decision). However, although physicians seldom mentioned problems related to informing the patient, it is reported that physicians sometimes fail to recognize the patient's misconceptions regarding their prognosis.[11]

Respondents who had experienced problems regarding the criteria of due care, far more often reported problems with the other criteria: that is more than half of the respondents reported problems related to evaluating the patient's request, or judging the unbearability or hopelessness of the patient's suffering. Furthermore, about one-third reported to have experienced problems related to evaluating whether there were any reasonable alternatives for the patient. In the Euthanasia Act, these three criteria (judging the patient's request, the unbearableness and the hopelessness, and reasonable alternatives) are purposefully framed in open global terms. This means that in every new case the criteria have to be interpreted taking into account the specific circumstances of that case. Although these criteria are meant to be independent, and are presented as such in the Act, they do overlap to some extent. The unbearability and hopelessness of the patient's suffering, for example, is closely related to the absence of reasonable alternatives. In general, the possibility of improvement and the availability of other solutions to alleviate suffering are more objective requirements, although the assessment as to whether palliative care is a 'reasonable' alternative can be difficult. However, whether the request is voluntary or well considered, or whether the suffering is unbearable, is to a large extent a matter of the patient's subjective experience and personal perspective. To a certain extent a personal commitment of the physician is needed to perform euthanasia, which is a non-medical act in itself. However, our results indicate that physicians predominantly experience problems with such subjective aspects. From a physician's perspective this is understandable because it is more difficult to rely on a patient's experience and ideas than on one's own medical-professional judgment. The fact that unbearable suffering can comprise more than physical symptoms alone [13], probably makes the interpretation for physicians even more difficult.

It seems that physicians are given two different roles in the Act. First, an *empathising role*, in which physicians have to evaluate whether the patient's suffering and request are understandable. Second, a *medical-professional role*, in which the physician's professional judgment is required to assess whether there is a reasonable alternative to

euthanasia or assisted suicide. However, fulfilling two different roles at the same time is difficult and the physician's contribution may be more significant when more weight is put on their medical-professional role. In the current situation, the physician's struggles with the subjective requirements could hamper an adequate assessment of aspects that are more related to professional judgment. To attain the most appropriate role for physicians in cases of euthanasia or assisted suicide, the Dutch government could be more explicit in its expectations towards physicians who intend to perform euthanasia or assisted suicide. It should be clearly communicated that the patient's suffering and request (apart from judging the patient's competency) can be assessed only to a very limited extent objectively and that, accordingly, these aspects need to be left to the patient to a great extent. In contrast, the evaluation of whether or not reasonable alternatives to alleviate the patient's suffering are available can and should be assessed by the attending physician through a profound medical-professional evaluation. Such a clarification would fit into the Dutch euthanasia policy that is based on the principle that assisting in euthanasia or assisted suicide is only acceptable when the patient's suffering cannot otherwise be relieved. Moreover, this would put the physician in a clearer position in relation to the patient and his or her family.

In conclusion, applying the criteria of due care means that physicians have to make difficult decisions. In such situations it should be clear what the physician's roles and responsibilities are. The present study shows that physicians in the Netherlands primarily report problems with the criteria that are related to the patient's subjective perspectives; however, the question remains whether physicians can play a major role with regard to these subjective aspects. It is argued that they should focus more on the requirement for the absence of reasonable alternatives.

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3

Reporting of euthanasia and physician-assisted suicide in the Netherlands: Descriptive study

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Abstract

Background An important principle underlying the Dutch Euthanasia Act is physicians' responsibility to alleviate patients' suffering. The Dutch Act states that euthanasia and physician-assisted suicide are not punishable if the attending physician acts in accordance with criteria of due care. These criteria concern the patient's request, the patient's suffering (unbearable and hopeless), the information provided to the patient, the presence of reasonable alternatives, consultation of another physician and the applied method of ending life. To demonstrate their compliance, the Act requires physicians to report euthanasia to a review committee. We studied which arguments Dutch physicians use to substantiate their adherence to the criteria and which aspects attract review committees' attention.

Methods We examined 158 files of reported euthanasia and physician-assisted suicide cases that were approved by the review committees. We studied the physicians' reports and the verdicts of the review committees by using a checklist.

Results Physicians reported that the patient's request had been well-considered because the patient was clear-headed (65%) and / or had repeated the request several times (23%). Unbearable suffering was often substantiated with physical symptoms (62%), function loss (33%), dependency (28%) or deterioration (15%). In 35%, physicians reported that there had been alternatives to relieve patients' suffering which were refused by the majority. The nature of the relationship with the consultant was sometimes unclear: the consultant was reported to have been an unknown colleague (39%), a known colleague (21%), otherwise (25%), or not clearly specified in the report (24%). Review committees relatively often scrutinized the consultation (41%) and the patient's (unbearable) suffering (32%); they had few questions about possible alternatives (1%).

Conclusion Dutch physicians substantiate their adherence to the criteria in a variable way with an emphasis on physical symptoms. The information they provide is in most cases sufficient to enable adequate review. Review committees' control seems to focus on (unbearable) suffering and on procedural issues.

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3.1 Introduction

At present, physician-assistance in dying is known to be provided in several countries in varying frequencies.[1-4] In the Netherlands, euthanasia is defined as deliberately ending a person's life at the person's request. In physician-assisted suicide, the person self-administers medication that is prescribed by a physician. Euthanasia and physician-assisted suicide are allowed provided that a physician performs the act while adhering to specific requirements. Euthanasia and / or physician-assisted suicide is also legally allowed in Belgium, Luxembourg and the US states of Oregon and Washington[5-8] and discussions about the legalization of physician-assisted dying are going on in other countries, such as the UK, Spain, France, Columbia and Australia.[9-13] Debates about legalization often relate to concerns about whether it is possible to keep the practice of physician-assisted dying within agreed borders.[14 15] Concerns relate to the risk that vulnerable people may be or feel coerced to request assistance in dying, that alternatives to assistance in dying are lost out of sight, or that deciding to provide assistance in dying becomes too 'easy' an option without careful consideration of alternatives.

In the Netherlands, physicians have to report euthanasia and physician-assisted suicide to enable review by one of five regional multidisciplinary review committees. They should comply with criteria of due care that have been developed by the courts during the preceding decades and are generally considered to be a summary of case law.[16] These criteria require a physician to assess that (1) the patient's request is voluntary and well-considered, (2) the patient's suffering is unbearable and hopeless, (3) the patient is informed about his situation and prospects and (4) there are no reasonable alternatives. Further, (5) another, independent physician should be consulted and (6) the termination of life should be performed with due medical care and attention.[17] To demonstrate their compliance with these criteria, physicians have to submit a detailed report, which describes their way of acting and its circumstances. This report is usually based on a standard form that contains both open and closed questions regarding the criteria of due care. Review committees have to assess whether the physician acted in accordance with the criteria. They do so by scrutinizing the physician's report, and, if necessary, by asking the physician to supplement this report either orally or in writing, or by obtaining information from other persons involved. The Belgian Euthanasia Act, that legalizes euthanasia since 2002, is largely similar to the Dutch Euthanasia Act[18]: the Belgian Act includes similar criteria of due care but review is done by one multidisciplinary committee. Luxembourg legislation (2008), draws heavily on the Belgian experience.[5]

These Acts differ from the Oregon Death with Dignity Act, that legalizes physician-assisted suicide since 1997.[8] To request a prescription for lethal medication, the Oregon Act requires that the patient is an adult resident of Oregon who is capable and who has an illness that is expected to lead to death within six months. To obtain the lethal medication the patient should make one written and two oral requests (separated by at least 15 days) to his or her physician. The patient's primary physician and a consultant are required to confirm the diagnosis of a terminal condition and the prognosis, determine that the patient is capable, and refer the patient to a psychiatrist or clinical psychologist for further evaluation, if either believes that the patient's judgment is impaired by depression or other psychiatric / psychological disorder. The primary physician should also inform the patient of all feasible alternatives.[19] If the patient meets the eligibility

criteria and the physician writes a prescription, physicians have to report to the Oregon Health Division which lethal medications were prescribed. They further have to indicate that they fulfilled the requirements by checking the boxes in the attending physician's compliance form.[20] After receiving the report of the death of the patient, the Health Division asks the reporting physician whether the patient indeed had died from the medication. The law and requirements for the Washington Death with Dignity Act are virtually identical to the Oregon Act.[21]

The purpose of reporting and reviewing practices of euthanasia and physician-assisted suicide is to evaluate how the norms laid out in the laws and regulations are being handled in actual practice. External review enables countries to evaluate whether current regulation suffices to restrict euthanasia to cases that meet the criteria, to see where potential problems occur and to educate physicians to comply with the rules. Various studies have been performed about how physicians perceive the patient's suffering and in what situations patient's requests result in euthanasia.[22-24] In the Netherlands as well as Oregon, physicians have been shown to be motivated to engage in euthanasia because of their patients' disease-related experiences, such as severe pain, functional loss, discomfort, fatigue, and expressed loss of dignity of the patient.
The ethical foundation of the five Acts described, is a combination of respect for autonomy and obligations of beneficence. However, for the Dutch, Belgian and Luxembourg Acts, addressing the patient's suffering is the most important principle underlying the Act. The Oregon and Washington Acts, on the other hand, put emphasis on patients' rights and on helping patients to maintain control and independence. Whether or not these differences in emphasis lead to differences in practice and in the review procedure is unclear.

For Dutch review committees, physicians' reports are an important basis for their assessment whether the criteria of due care have been met or not. However, the content of what physicians report about the criteria of due care and how review committees judge this information is for the most part unknown. We studied which arguments Dutch physicians use to substantiate that they have adhered to the requirements of due care and which aspects attract review committees' attention. Furthermore, we compared our findings with existing information about other external review procedures and reflect on whether a different procedure would result in a different focus of attention.

3.2 Methods

File content
The files of euthanasia and physician-assisted suicide are archived at the offices of the 5 regional euthanasia review committees. The files comprise the physician's report, one or more reports of the consulted physician and the verdict of the review committees. The file may also include copies of medical files and letters from clinical specialists. The physician's report nearly always consists of a 'standard form' that contains various questions about the criteria of due care. This form is developed by the review committees and the Dutch Ministry of Health, Welfare and Sports. It is available via the Royal Dutch Medical Association and the Ministry. In 2002 the initial standard form had been replaced by a newer version that contained more specific questions about the 'unbearableness' and

the 'hopelessness' of the patient's suffering, and about how the patient was informed about his situation. Further, the questions whether the patient's request was 'voluntary' and whether there were possibilities to relieve the patient's suffering were somewhat rephrased as well.

Study design
In 2005, 1933 euthanasia cases were reported to a review committee.[25] As part of a larger study aimed at evaluating the Dutch Euthanasia Act, we studied the physician's reports and the verdicts of the review committees in 243 files of euthanasia or physician-assisted suicide cases that were performed in 2005.[26] The sample consisted of two parts. The first part included all 115 cases in 2005 (6% of all cases) where review committees had had doubts or questions and asked the reporting physician to provide additional information. The second part of our sample included 'the last' 117 reported cases in 2005, which we presumed to be representative for all reported cases. This part of the sample was stratified for the five review committees. Strict anonymity of the patient and the physician was guaranteed

In this study, the sample was restricted to 158 cases where reporting physicians had used the latest version of the standard form, because this version will also be the basis for future reports on euthanasia or physician-assisted suicide. We studied 75 cases where review committees had had doubts or questions and 83 cases that belonged to 'the last' reported cases in 2005. Weighting of the results to correct for differences in sampling fractions did not appear to affect the results; we therefore only report unweighted results. All studied cases were approved by a review committee. According to Dutch policy, the study did not require review by an ethics committee because the data collection was anonymous with regard to the deceased patient and the attending physician.

Checklist
To study the files, we developed a checklist that covered all topics in the standard form. In this paper we only use data related to the six criteria of due care. The specific questions are either included in the Tables or separately mentioned in the results section. The checklist was piloted by 2 researchers who scored 10 files each. The outcome of this pilot necessitated a few changes in the wording of the final version of the checklist. Eight researchers were involved in scoring the files. During the scoring of the files, issues that were unclear were always discussed and communicated with all researchers. Fourteen files were double checked to estimate the interrater reliability. The average agreement for 20 randomly chosen variables was 91% (minimum agreement 75% vs. maximum agreement 100%).

3.3 Results

The patient's request
In all studied cases except one, physicians reported that the euthanasia request had been made by a patient who was fully aware of his physical situation (**Table 3.1**). Physicians often substantiated this conclusion by stating that the patient had been clear headed while expressing his or her request (65%) and / or had repeated the request several times (23%). In all cases, physicians reported that the euthanasia request had been made without pressure from others. In 97%, a written euthanasia declaration, that is not obligatory

under the Dutch legislation, was available; in one case the physician reported that the patient had not been capable to sign the declaration anymore, in one case information about whether or not there had been a written euthanasia declaration was missing in the physician's report, in one case it concerned a declaration about general medical care instead of euthanasia and in one case it was not clearly specified in the report why the euthanasia declaration was missing.

Table 3.1 Characteristics of the patient's request.
(questions phrased from the standard form of the reporting physician)

	n=158 %	
Was the patient, while expressing the request, fully aware of the implications of his or her request and of his or her physical situation?		
No	1[1]	
Yes	99	
If yes, from what circumstances did you make these conclusions?[2]		
Patient was clear headed		65
Patient's request was repeated several times		23
Patient had no mental problems		13
Patient was aware about his situation and prospects		10
Physician knew the patient very well		4
Other[3]		15
Not clearly specified in physicians' report		5
Are there indications that the patient's request was expressed under pressure from others?		
No	100	
Was a written euthanasia declaration available?		
Yes	97	

[1] 1 case.
[2] More than one answer could be given, open question.
[3] Other includes: Family was convinced that the request was well-considered, patient's request had been judged by another physician, availability of an advance directive, patient always wanted to decide for himself.

The patient's suffering

Table 3.2 presents the arguments given why the patient's suffering was considered to be 'unbearable' or 'hopeless'. In 62%, physicians reported that the patient's suffering was 'unbearable' because there were one or more physical symptoms; they most frequently mentioned pain (32%), dyspnea (22%), fatigue (15%) or nausea (15%). A third of all physicians reported that function loss had contributed to unbearable suffering, such as being bedridden (19%) or having a decreased appetite or capacity to eat or swallow (10%). In 63% physicians mentioned 'other aspects'; these included increased dependency (28%), deterioration (15%) and more rare aspects (16%), such as loneliness, being a burden to relatives and being mentally exhausted. Physicians most often based the 'hopelessness' of the suffering upon the "absence of treatment alternatives" (32%), "absence of curative treatment alternatives" (28%), or "absence of treatment alternatives to relieve the patient's symptoms", or combinations of these (14%).

Table 3.2 Arguments for patient's suffering being unbearable or hopeless.
(questions phrased from the standard form of the reporting physician)

	n=158[1] %
Could the suffering be considered unbearable? Please motivate.	
Symptoms[2]	**62**
Pain	32
Dyspnoea	22
Fatigue	15
Nausea / vomiting	15
Incontinence / diarrhoea / constipation	6
Cachexia	6
Confusion	3
Fear	3
Other[3]	9
Function loss[2]	**33**
Bedridden	19
Appetite / thirst / eating- and swallowing capacity	10
Language	4
Other[4]	4
Other aspects[2]	**63**
Dependency	28
Deterioration / general malaise	15
Hopelessness, no treatment possible	13
Loss of autonomy / identity	4
Loss of dignity	2
Mentally exhausted	7
Other[5]	16
Could the suffering be considered hopeless? Please motivate.	
No treatments possible	32
No curative treatments possible	28
No treatments to relieve symptoms possible	3
No curative treatments + treatments to relieve symptoms possible	11
Short life expectancy	8
Other[6]	9
Not clearly specified in the report	8

[1] In 8 cases (4%) the nature of patient's suffering was explained, but no explicit arguments for the suffering being unbearable were given.
[2] More than one aspect could be mentioned.
[3] Other include: decubitus, edema, epileptic insults, itch, and cough.
[4] Other include: cognitive function, sleeping problems and general physical functioning.
[5] Other include: loneliness, to be a burden to relatives, losing interest, mental suffering, no quality of life.
[6] Other include: no differentiation between unbearable and hopeless suffering, worsening expected.

The information provided to patients about their situation and prognosis

In the standard form, one question pertains to the information provided to the patient: *'How was the patient informed about his prognosis (current situation, course, prognosis, etc)?'* Physicians mentioned in 77% of cases that they themselves had informed the patient. In 58%, they reported that other physicians (mainly medical specialists) had informed the patient. In 14%, they used other terms to describe how the patient was informed such as "Extensively discussed orally", and "completely". In a few cases (3%), it was reported that patients had gathered their information through written material on the internet (always in combination with information from reporting physicians).

Medical treatment / care

Table 3.3 shows that physicians in almost all cases reported to have applied palliative care options, most frequently medication (89%) and sometimes radio- or chemotherapy (21%). 'Other' palliative care options (46%) often concerned administering oxygen, nutrition or hydration, or artificial respiration. In 35% of all cases it was reported that there had been options to relieve the patient's suffering that were not applied. These most often involved the administration of sedatives (10%) or pain medication (11%). In 81% of the cases where these alternatives had been present, physicians reported that the patients had refused them.

Table 3.3 Characteristics of the presence of reasonable alternatives.
(questions phrased from the standard form of the reporting physician)

	n=158 %	
What had been done in terms of palliative care?		
Medication	89	
Radio- or chemotherapy	21	
Other[2]	46	
Not clearly specified in the report	1	
Were there (other) possibilities to relieve the patient's suffering?		
Yes:	35[3]	
Administration of sedatives		10
Other pain medication		11
Radio- or chemotherapy		3
Intensive home care / family care		2
Other		10
How did the patient feel about these alternatives?	n=56	
Positive	4	
Negative	81	
Other	13	
Not clearly specified in the report	2	

[1] One or more answers could be given.
[2] Other include: oxygen administration, artificial respiration, artificial administration of food and fluids, blood transfusions, home care, surgery, stoma, administration of sedatives, talks with the patient.
[3] In three cases, the question was answered affirmatively but not further explained.

The consultation

Physicians consulted more than one physician in 29% of all cases (**Table 3.4**). The consultant had been a 'SCEN-physician' (Support and Consultation for Euthanasia in the Netherlands) in 85% of all cases. The nature of the relationship between the reporting physician and the consultant was not always clearly specified. In 39%, physicians indicated that there was no earlier relationship between the reporting physician and the consultant. Physicians indicated they had known the consultant beforehand in 21% of the cases. In 9% it was unclear whether the physician knew the consultant beforehand or not (i.e. "a colleague" or "professional relationship") and in 6% they reported that it had been a SCEN-physician without further specifying the relationship. If only one consultant had been consulted, these percentages were comparable except that the consultant less often had been a known colleague (data not in Table).

Table 3.4 Characteristics of the consultation.
(questions phrased from the standard form of the reporting physician)

	n=158 %
Number of physicians that had been consulted	
One	71
Two	22
Three	7
Which physicians were consulted? In the capacity of: [1]	
SCEN-physician[2]	85
General practitioner	18
Medical specialist	30
Other	3
Was / were they already involved in the care for the patient?	
Yes	1
One involved, the other not	18
No	80
Not clearly specified in the report	2
What was the nature of the relationship towards the reporting physician[1]	
Unknown colleague	39
Unclear whether colleague is unknown or not	9
Known colleague [3]	21
'SCEN-physician'	6
Other	10
Not clearly specified in the report	24

[1] More than one physician could have been consulted.
[2] SCEN = Support and Consultation for Euthanasia in the Netherlands. A 'SCEN-physician' is a physician who has received formal training in consultation and participates in a formal network of consultants.
[3] Colleague own practice / partnership / other collaboration (8%). Familiar colleague not related to own practice / partnership / other collaboration (13%).

The performance of euthanasia

We used one question in the standard form that related to the performance of euthanasia: '*Which medication was used and how was life ended?'* In 76% of all cases, physicians reported to have administered a barbiturate followed by a muscle relaxant. In 19%, they

reported to have administered a barbiturate only; these concerned all physician-assisted suicide cases and some cases of euthanasia. In 3% they only reported a muscular relaxant and in 3% physicians did not specify which medication they had used.

Questions for additional information from the review committees

Table 3.5 shows that review committees most frequently asked for additional information about the consultation (41%), especially with regard to the independency of the consultant (19%) and the quality of the consultant's report (12%). Questions about why the patient's suffering was considered 'unbearable' or 'hopeless' were also frequently asked (32%). Furthermore, review committees relatively often asked about the type of medication (13%) and about topics not directly related to the criteria of due care, such as the quality of the physician's report (13%) and about other aspects (11%) such as whether the reporting physician was the same physician who had performed euthanasia and the reasons for the high number of independent consultations for one patient.

Table 3.5 Topics about which review committees asked for additional information. (as described in the verdicts of the review committees)

	n=75		
	%	(n)	%
The patient's request[1]	11	(8)	
Being well-considered			8
Voluntariness			9
The patient's suffering[1]	32	(24)	
Further specification of (unbearable) suffering			23
Course of disease			12
Patient was (sub) comatose			4
Other			4
Informing the patient about their situation and prognosis	-		
The presence of reasonable alternatives	1	(1)	
The consultation[1,2]	41	(31)	
Quality of consultant's report			12
Independency of consultant			19
Moment of consultation			9
Quality of consultation			1
Other			4
Performance of euthanasia and physician-assisted suicide[1]	17	(13)	
Type of medication			13
Physician's attendance			3
Other			3
Other topics[1]	21	(16)	
Decision-making of the physician			1
Quality of physician's report			13
Other			11

[1] More than one answer could be given.

[2] In 70% of the cases, the reporting physician was also involved in the question for additional information from the review committees.

3.4 Discussion

This study demonstrates that physicians report about cases in a variable way for most of the criteria for due care. Some criteria are hardly substantiated (voluntariness of the request, patient being well informed) and others are substantiated mainly by mentioning physical aspects (unbearable suffering). This study demonstrates that *if* review committees asked the reporting physician to provide further information, it primarily concerned the 'unbearableness' of the patient's suffering and the consultation of an independent physician.

The patient's request

In virtually all cases, physicians reported that the request had been voluntary and well-considered. A previous study showed that not granting a request for euthanasia or physician-assisted suicide is frequently due to the request not being well-considered according to the physician.[22] A voluntary and well-considered request is considered a condition sine qua non for euthanasia. However, physicians did not uniformly argue *why* they thought the request was well-considered and review committees rarely asked for additional information about this requirement. Possibly, the information was convincing enough for review committees to guarantee that the patient's request was voluntary and well-considered if the file did not contain information suggesting otherwise. This finding is consistent with an interview study among review committee members that showed that committee members virtually never experience problems with judging the patient's request.[26] On the other hand, elsewhere we found that physicians frequently report to experience difficulties in determining whether the request was voluntary and well-considered.[27] Such difficulties, however, do not seem to be present in the reporting discourse, nor in the requests for additional information of the committees.

The patient's suffering

Various arguments for the patient's suffering being 'unbearable' were given. Physicians often mentioned physical symptoms like pain, but function loss and other aspects related to the patient's suffering were mentioned as well. As reported previously, physicians who receive requests for euthanasia or physician-assisted suicide frequently experience problems with assessing the 'unbearableness' of the patient's suffering.[27] Whether or not a patient's situation is unbearable is to a large extent a matter of the patient's subjective experience and perspective, which can comprise more than physical symptoms alone.[28] A questionnaire study among physicians showed that pain had been among the reasons to perform euthanasia in 47% of cases nearly always in combination with other reasons. Other reasons, such as the lack of prospects of improvement (85%) or the patient's loss of dignity (60%) were more common than pain.[26] In addition, patients' *requests* for euthanasia are also often reported to be grounded in fear of losing dignity or autonomy and to a lesser extent by pain.[22 29] In their report to review committees however, physicians seldom reported loss of dignity but they relatively often mentioned physical aspects, such as pain and dyspnea. Probably, physicians attach much value to physical symptoms in their report because these can be more easily and objectively judged within their own medical-professional domain. Furthermore, based on a court decision of the Dutch Supreme Court (2002) that stated that in case of euthanasia the suffering should predominantly result from a medically classifiable disease or disorder[30], some physicians may assume that review committees consider physical symptoms as an important

prerequisite for euthanasia. However, review committees relatively often asked for additional information about the 'unbearableness' of the patient's suffering. This suggests that besides physical symptoms other factors are important for their judgment.

The information provided to patients about their situation and prognosis
In general, physicians briefly addressed the requirement that the patient should be well-informed about his situation and prospects.
In the cases studied, the review committees never asked for additional information about this requirement. The general Dutch law on patient-physician relationships, the Act on the Medical treatment agreement (In Dutch: WGBO), that states that every patient should be well-informed about his situation and prospects before deciding about treatment, is widely known and included in many checklists and guides by the Royal Dutch Medical Association.[31] Possibly, both physicians and review committees assume that informing the patient is a part of normal medical practice that has to be elaborated on in the review process only in case of clear indications of problems.

The absence of 'reasonable' alternatives
In 35% of all cases, physicians reported that at the time of the decision-making about euthanasia there had been (other) possibilities to relieve the patient's suffering that had not been applied. The majority of patients had refused these alternatives. The Euthanasia Act states that there should be no 'reasonable' alternative available to relieve the patient's suffering. However, the question in the standard form with regard to the presence of possibilities to relieve the patient's suffering does not include the adjective 'reasonable'. Physicians may thus not fully address this criterion in their reports as it is formulated in the Euthanasia Act. According to parliamentary proceedings, a patient may refuse treatment or palliative care; however, if the intervention proposed is not very invasive the physician may conclude that there is a reasonable alternative and that euthanasia or assistance in suicide is therefore not justified. However, our data show that a negative attitude of the patient plays an important role in deciding whether or not an alternative is 'reasonable', for both physicians and review committees. An interview study with committee members[26] showed that committees frequently have discussions about this requirement but often choose to go along with the patient's refusal. In their annual accounts, review committees virtually always address this topic; they stress the importance of obtaining information from the reporting physician about *why* they thought the proposed alternatives were considered to be unreasonable for a particular patient. Nevertheless, despite the fact that the Dutch euthanasia policy is based on the principle that euthanasia and physician-assisted suicide are only acceptable when the patient's suffering cannot otherwise be relieved, review committees virtually never ask the reporting physician to substantiate the lack of alternatives.

The consultation
Whether or not physicians consulted a totally independent second physician was not made fully clear in every report. In more than 80% of all cases, physicians reported that the consultant was a SCEN-physician and 6% used the word 'SCEN-physician' to describe their relationship with the consultant. SCEN-physicians have received training on medical, ethical and legal aspects of euthanasia and end-of-life care and participate in a formal network to provide independent and high-quality consultations in cases of requests for euthanasia or physician-assisted suicide. Implementation of SCEN-consultations

contribute to the quality of the consultation for euthanasia or physician-assisted suicide as has been shown in another study[32] partly because it stands for the independence of the consultant. The fact that the independent consultation most frequently received review committees' attention either suggests insufficient substantiation of this requirement or relatively high importance that review committees attach to this specific requirement.

Performance of euthanasia or physician-assisted suicide

In general, physicians reported to act according to the guideline of the Royal Dutch Association for the Advancement of Pharmacy that recommends the use of a barbiturate to induce a coma, followed by a muscle relaxant to induce the patient's death.[33] It seems likely that the physicians' report about *euthanasia* was incomplete in cases where only muscle relaxants were mentioned. The requirement that the termination of life should be performed with due medical care and attention especially led to additional questions from the review committees with regard to the type of medication. The use of muscle relaxants without sedatives for instance, may be very distressing for the patient.

Some limitations need to be taken into account. First, we analyzed the files with a checklist. Although we piloted the checklist and discussed possible interpretation problems during the data collection, we cannot preclude that the investigators' interpretation of certain information has influenced the results. Second, we did not investigate the consultant's report or other information in the files of reported cases and this study therefore does not provide a complete picture of the review process. Our main aim was to provide insight in the discourse between reporting physicians and review committees, not to review the reporting system as a whole. This study provides information about what physicians *report* about cases of euthanasia or physician-assisted suicide. Therefore, this study should not be seen as a description of practice but as a description of how physicians describe and interpret their acts.

Conclusions and suggestions for policy

The reported cases in 2005 represent a substantial amount (80%) of all euthanasia cases in the Netherlands in that year; studying the files therefore gives important insight in the practice of euthanasia.[34] Physicians substantiate the information provided to the patient and the performance of euthanasia in a rather straightforward and uniform way, but their substantiation is more variable for the patient's request, the patient's suffering, the absence of reasonable alternatives and the consultation. The variation we found is firstly due to variation in clinical situations, in particular with regard to the patient's suffering and the absence of reasonable alternatives. However, what physicians report may also be influenced by differences in knowledge of and viewpoints on euthanasia and the Euthanasia Act, and by uncertainty about how to deal with these criteria. It should be stressed that problems with the interpretation of some criteria of due care are not necessarily a negative finding. In the Act, criteria related to the patient's request, the patient's suffering, and the absence of reasonable alternatives are purposefully framed in open general terms. As such, the Act allows physicians and review committees to newly interpret the criteria in every new case, taking into account the specific circumstances of that case. Furthermore, the questions in the standard form concern both specific closed questions that call for straightforward answers, and open questions that often result in more variable answers. The standard form may thus also influence physicians' reports on the criteria of due care. It seems that there is room for improvement of this form,

especially for questions concerning the reasonableness of the alternatives, and the independence of the consultation. For treatment alternatives for instance, the question should be formulated more clearly to be able to assess whether these alternatives were considered 'reasonable' by the physician him- or herself. Recently, (June 2009), a new report form has become available[35]; the impact of these changes (which are partly in accordance with our recommendations) need to be awaited and studied.

For review committees, the standard form that is filled out by the reporting physician generally gives sufficient information to form their judgment; review committees asked for additional information in only 6% of all reported cases. We found elsewhere that review committees basically trust the reporting physicians[26], which may indicate that those 6% involve cases with clear inconsistencies or missing information. Possibly, the committees assume that reporting a case already reflects physicians' intention to act according to the legal criteria. A certain level of trust between review committees and reporting physicians is a prerequisite for an adequate reporting procedure, as this would stimulate physicians to report their acts. Review committees seem to mainly verify that the physician acted with due care, rather than trying to falsify this by looking for incongruent information. They concentrate their additional inquiries on two specific criteria; a subjective one (the patient's suffering) and a procedural one (the consultation), but hardly ask questions about the physical condition of the patient and the presence of possible alternatives. Possibly, their basic attitude of trust in the reporting physician is primarily related to criteria that physicians can assess within their own medical professional domain. Unbearable suffering is the most debated requirement, being subjectively and openly framed. Review committees possibly view their role as more relevant for this specific criterion than for criteria that mainly ask for profound medical knowledge.

Our results show that the Dutch review procedure seems to concentrate on the criterion of (unbearable) suffering and on procedural issues. US legislations do not contain criteria concerning the patients' degree of suffering: the patient's medical situation is addressed in the criterion concerning the patient's life expectancy which should be six months or less. In actual medical practice, the characteristics of patients who died as a result of euthanasia are rather similar in the Netherlands and Oregon and in both countries reported cases are rarely not approved. Differences in the formulation of due care criteria concerning the patient's medical situation apparently only have a limited impact in the practice of physician-assisted dying.

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4

The reporting rate of euthanasia and physician-assisted suicide: A study of the trends

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Abstract

Objectives To study trends in reporting rates of euthanasia from 1990 to 2005 in relation to whether recommended or non-recommended drugs were used, and the most important differences between reported and unreported cases in 2005.

Research design Questionnaires were sent to a sample of 6860 physicians who had reported a death in 2005 (response 78%). Previously, 3 similar studies were done at 5-year intervals. The total number of euthanasia and physician-assisted suicide cases was estimated using a 'gold standard' definition: death was –according to the physician– the result of the use of drugs at the explicit request of the patient with the explicit goal of hastening death (denominator). The Euthanasia Review Committees provided the number of reported cases (numerator).

Results The reporting rate of euthanasia and physician-assisted suicide increased from 18% in 1990, 41% in 1995, and 54% in 2001 to 80% in 2005. The reporting rate in the subgroup of euthanasia with recommended drugs (barbiturates and muscle relaxants) was 73% in 1995, 71% in 2001 and 99% in 2005. The reporting rate of euthanasia with non-recommended drugs (e.g. opioids) was below 3% in 1995, 2001 and 2005. Unreported euthanasia differed also from reported euthanasia in the fact that physicians less often labeled their act as euthanasia.

Conclusions Euthanasia with non-recommended drugs is almost never reported. The total reporting rate increased because of an increase in the use of recommended drugs for euthanasia between 1995 and 2001, and an increase in the reporting rate for euthanasia with recommended drugs between 2001 and 2005.

4.1 Introduction

In the Netherlands, euthanasia is defined as the act where a physician grants the explicit request of a patient for euthanasia, by actively ending his or her life by administering drugs. If a patient ends his or her own life by using drugs that were provided by a physician at the explicit request of the patient, this is physician-assisted suicide.

In the Netherlands, there have been procedures that sanctioned euthanasia and physician-assisted suicide since 1991. In 2001 a law was accepted (enacted in 2002) that provides legal security for physicians who perform euthanasia or physician-assisted suicide if they follow 'the requirements of due care'. The requirements of due care are as follows:
a) The physician is convinced that the patient's request for euthanasia was voluntary and well considered;
b) The physician is convinced that the patient's suffering was unbearable and hopeless;
c) The physician informed the patient about his/her situation and prospects;
d) The physician and the patient were both convinced that there was no other reasonable solution;
e) The physician consulted at least one other, independent physician, who saw the patient and made a written report on the requirements of due care listed in a. to d. above;
f) the physician terminated the patient's life or provided assistance with suicide with due medical care and attention.

These requirements are abstract, but have become more comprehensive through their use in practice, in guidelines and in case law. Requirement 'f' about the actual performance of euthanasia and physician-assisted suicide is now understood to include adhering to guidelines by 'The Royal Dutch Society for the Advancement of Pharmacy' (KNMP), who recommend the use of specific drugs for euthanasia and physician-assisted suicide.[1] For euthanasia, it recommends the administration of a barbiturate to induce coma, followed by a muscle relaxant that causes the death of the patient.

The law further stipulates that the physician who has performed euthanasia or assisted suicide then has to report it as such to the Coroner, who then sends the case to 1 of the 5 Regional Review Committees for Euthanasia. The review committee judges whether the requirements of due care were met by the physician, and thereby whether the actions of the physician fall within the exemption of prosecution this law provides. If they judge that one of the requirements was not (fully) met, they send the case to the Board of Procurators General and the relevant health inspector. This happened 14 times (in 0.3% of the reported cases) between the enactment of the euthanasia legislation in 2002 and 2005. In all of these cases the Board of Procurators General decided not to prosecute the physician, sometimes after preliminary hearings, and sometimes the nonprosecution was conditional (a probation period was set). The Health Inspectorate started procedures in 2 cases; in both cases the physician received an official reprimand from the medical disciplinary tribunal.

If a physician does not report a case of euthanasia or physician-assisted suicide as such to the Coroner, the physician cannot use the exemption provided by the law and is liable to prosecution and punishment even if the requirements of due care were met. The odds are

however, that such an unreported case will not come to the attention of the authorities, and the physician will go undisciplined. Another consequence of the fact that unreported cases are likely to pass unnoticed, is that it is unknown how often physicians perform euthanasia or physician-assisted suicide without reporting this and what the reasons are that they do not report these cases. In what way are these cases different from reported cases of euthanasia and assisted suicide?

An important basis for the euthanasia law was the idea that the practice of euthanasia should be controllable, therefore it is very important for the justification of the existence of a law that cases of euthanasia and physician-assisted suicide are indeed reported by physicians. To fill in this gap in knowledge, there have been 4 large studies (in 1990, 1995, 2001 and 2005) to monitor the occurrence of euthanasia and assisted suicide and the reporting rate of these acts. In a recent publication we presented the data from these studies about the incidence of euthanasia and physician-assisted suicide. The incidence of euthanasia in the Netherlands in 2005 had decreased to the level of 1990 (1.7% of the deaths), after a period in which the incidence was higher (2.4% in 1995 and 2.6% in 2001).[2] This decrease was mainly attributed to an improvement of palliative care and an increased occurrence of palliative sedation. The incidence of physician-assisted suicide remained relatively low at 0.1% of the deaths in 2005 (0.2% in 1990-2001).

This article will show the trend in reporting rates of euthanasia from 1990 to 2005 in relation to the type of drugs that were used (recommended vs. non-recommended), and the most important differences between reported and unreported cases in 2005.

4.2 Methods

Definitions
To calculate the reporting rate of euthanasia and physician-assisted suicide 2 numbers are required:
(a) the number of reported cases of euthanasia and physician-assisted suicide to the Regional review committees for euthanasia (numerator);
(b) an estimate of the total number of cases of euthanasia and physician-assisted suicide (denominator).

The number of reported cases *(a)* can be obtained from the regional review committees, the total number *(b)* is an estimate. To estimate the total number, questionnaires were sent to physicians. Physicians were asked to label their own act, but this was not used for the estimate of the total number of cases of euthanasia or physician-assisted suicide. Instead we used a 'gold standard', a combination of the answers to several questions led to the classification of a case as euthanasia or physician-assisted suicide, or another or no end-of-life decision. We classified a case as euthanasia if death was -according to the physician- the result of drugs that were given at the explicit request of the patient with the explicit goal of hastening death. If death was -according to the physician- the result of drugs that were given at the explicit request of the patient with the explicit intention to enable the patient to end his or her life, and the patient self-administered the drugs, cases were classified as physician-assisted suicide.

Physicians were also asked what type of drug(s) was administered or provided for this purpose: neuromuscular relaxants, barbiturates, benzodiazepines, morphine or a morphine-derivative, benzodiazepines or other drugs. Euthanasia with barbiturates and neuromuscular relaxants was defined as "euthanasia with recommended drugs", physician-assisted suicide with barbiturates was considered to be done with "recommended drugs". Euthanasia and physician-assisted suicide with other drugs were defined as performed with "non-recommended drugs". Physicians were also asked whether or not they reported the case, for the purpose of **Table 4.2** (see Analysis).

Design

Questionnaires were sent to a sample of physicians who attended the death of a patient from August to November in each of the study years (1990, 1995, 2001, 2005).[2-6] Statistics Netherlands receives death certificates for all deaths that occur in the Netherlands. To increase the reliability of the estimate of the total number of cases of euthanasia and physician-assisted suicide, we oversampled cases where an end-of-life decision was more likely. Based on the cause of death that was reported, the death was assigned to one of 5 strata. If it was clear from the death certificate that the person had died suddenly e.g. acute death from a car accident, the case was assigned to stratum 1, and no questionnaire was sent to the reporting physician. Other cases were assigned to stratum 2-5, with stratum 5 consisting of cases where the death certificate contained indications that the patient died from euthanasia or physician-assisted suicide. The sample of physicians who received a questionnaire was drawn in each stratum: cases that were assigned to stratum 2 received a questionnaire in 8.3% of the cases, stratum 3 in 12.5%, stratum 4 in 25% and stratum 5 in 50%. If the physician who received the questionnaire was not the main treating physician, he or she was asked to give the questionnaire to the main treating physician. Anonymity was guaranteed by Statistics Netherlands, who sent the questionnaires.

Response rates

To optimize the response rates the questionnaire was mailed with a letter signed by the Chief Inspector for Health Care and the president of the Royal Dutch Medical Association. In 2005, 6860 deaths were sampled (response rate 78%). In 2001, 7011 deaths were sampled (response rate 74%). In 1995, 5748 deaths were sampled (response rate 77%). In 1990, 6942 deaths were sampled (response rate 76%).

Analysis

In **Table 4.1**, the reporting rate was calculated by dividing *(a)* the number of reports of euthanasia and physician-assisted suicide (according to the Regional Review Committees for euthanasia) over *(b)* the total number of cases of euthanasia or physician-assisted suicide (which is estimated in this study using questionnaires). The total number was estimated by weighting each sample to the stratified sample fraction and, to correct for nonresponse, each death was weighted to the characteristics of all deaths in the study year, thereby enabling comparisons between the different study years and making the numbers representative for all deaths in the Netherlands in the study year.

In **Table 4.2**, the classification reported/unreported was made based on self-report, in combination with a more objective measure. Physicians were asked in each particular case whether or not they reported the death to the Coroner as being euthanasia or

physician-assisted suicide, as is required by law. The death-certificates provided a check if the physician claimed to have reported the case. Two cases of euthanasia which the physician said to have reported as euthanasia were considered to be unreported in the analysis, because the death certificate was completed by the physician without a report to the Coroner. The Regional Review Committees had not received any reports directly from physicians in the past years.

4.3 Results

In cases of euthanasia physicians most commonly used the drugs as recommended (63% in 1995; 76% in 2001; 78% in 2005). Opioids (incl. opioids in combination with other non-recommended drugs) were used in 47% in 1995, 23% in 2001 and 16% in 2005. Using only benzodiazepines for the purpose of euthanasia was a new phenomenon in 2005, and occurred in 6% of the cases of euthanasia.
Table 4.1 shows that the overall reporting rate of euthanasia and physician-assisted suicide had increased from 18% in 1990, 41% in 1995, and 54% in 2001 to 80% in 2005. The reporting rate of euthanasia with the drugs recommended for euthanasia (barbiturates and muscle relaxants) was 73% in 1995, 71% in 2001 and 99% in 2005. The reporting rate of euthanasia with other, non-recommended drugs (mostly opioids or benzodiazepines) was below 3% in 1995, 2001 and 2005.

Table 4.1 Reporting rates for euthanasia and physician-assisted suicide in the Netherlands in 1990, 1995, 2001 and 2005 for recommended and non-recommended drugs.

	1990	1995	2001	2005
No. of reported cases of euthanasia / assisted suicide	n=486	n=1463	n=2054	n=1933
Estimated total no. of euthanasia / assisted suicide[1]	n=2700	n=3600	n=3800	n=2410
Total reporting rate[2]	18.0%[3]	40.6%[3]	54.1%[3]	80.2%[3]
Reporting rate physician-assisted suicide	[4]	23.6%	53.7%	100%
Reporting rate for euthanasia with recommended drugs[5]	[4]	73.3%	70.8%	98.7%
Reporting rate for euthanasia with non-recommended drugs[6]	[4]	2.4%	1.3%	2.8%

[1] The total number was estimated by weighting to the stratified sample fraction and to the characteristics of all deaths in the study year. The original number of cases of euthanasia / assisted suicide in the sample were 159 in 1990, 282 in 1995, 335 in 2001 and 311 in 2005.
[2] No. of reports / estimated total no of euthanasia and assisted suicide.
[3] 95% confidence intervals 1990, 16-23%; 1995, 35-49%; 2001, 50-67%; 2005, 72-90%.
[4] This information is not available for 1990.
[5] Barbiturates / muscle relaxants.
[6] Mostly opioids and benzodiazepines.

Table 4.2 shows that clinical specialists (e.g. cardiologists, surgeons, specialists in internal medicine, pulmonology, and neurology) relatively often did not report euthanasia, when compared to general practitioners and nursing home physicians. Physicians who did not report euthanasia most often said (26 out of 30) that they did not report it because they thought it was not required in this case (data not shown). Only 2 out of 30 non-reporting physicians labeled their act as euthanasia, and these were the only nonreporting physicians who used muscle relaxants. Twenty-two of the non-reporting physicians labeled their act as sedation. Two of them thought it should have been reported but had not done so, one because the requirements for due care were not met and the physician feared judicial consequences, and the other because he or she considered it a matter between physician and patient.

Table 4.2 Cases of reported and unreported euthanasia (excl. physician-assisted suicide).

	Reported euthanasia n=260[1]		**Unreported euthanasia** n=30	
	n (%)	(95% CI)	n (%)	(95% CI)
Type of physician				
General Practitioner	197 (91.6)	(87-95)	23 (76.7)	(58-90)
Clinical specialist	8 (3.7)	(2-7)	6 (20.0)	(8-39)
Nursinghome physician	10 (4.7)	(2-8)	1 (3.3)	(0-17)
Drugs				
Recommended euthanasia drugs	205 (99.0)	(97-100)	2 (6.7)	(1-22)
Opioids[2]	1 (0.5)	(0-3)	21 (70.0)	(51-85)
Benzodiazepines	0	(0-2)	7 (23.3)	(10-42)
Other / unknown	1 (0.5)	(0-3)	0	(0-12)
Labeling of the act by the physician				
Euthanasia / assisted suicide / ending life	211 (99.1)	(97-100)	2 (6.7)	(1-22)
Pain-symptom management	2 (0.9)	(0-3)	5 (16.7)	(6-35)
Palliative / terminal sedation	0 (0)	(0-2)	22 (73.3)	(54-88)
Other	0 (0)	(0-2)	1 (3.3)	(0-17)

[1] In 45 cases the questionnaire was completed by the Coroner, in spite of our request to forward it to the physician. Because the Coroner was only involved after the death of the patient these cases were excluded from this table.

[2] Opioids (including opioids in combination with other non-recommended drugs).

4.4 Discussion

In 1995 and 2001, the reporting rates for euthanasia per drug (recommended vs. non-recommended) were similar: 71-73% for recommended drugs and 1-2% for non-recommended drugs. The overall reporting rate was higher in 2001 than in 1995, nonetheless because there was a relative shift in the type of drugs used in cases of euthanasia; physicians who performed euthanasia more often used recommended drugs. In 1995 and 2001, non-reporting occurred in each of the following 3 subgroups 1) physician-assisted suicide 2) euthanasia with recommended drugs 3) euthanasia with non-recommended drugs. In 2005, the nature of non-reporting had changed: the

reporting rate in group 1 and 2 had increased to almost 100%. The only remaining cause of non-reporting is to be found in the third subgroup; euthanasia with non-recommended drugs. This third subgroup is of a different nature than group 1 and 2 because -as we have found in the present study- physicians who perform euthanasia with non-recommended drugs are usually not aware that it should be reported. Physicians who performed euthanasia with recommended drugs or physician-assisted suicide (subgroup 1 and 2) are presumably always aware that it should be reported.

Why do physicians perform euthanasia with non-recommended drugs? Most of these physicians did not label their act as euthanasia themselves. The question then remains of whether they used non-recommended drugs to hasten the end of life because they think that they can avoid reporting in that way, or whether they prefer to use non-recommended drugs because they consider this a good means to hasten the end of life of the patient. The latter may be particularly applicable to clinical specialists who were found to perform euthanasia relatively more frequently with non-recommended drugs. A study we did on attitudes of physicians showed that 27% of the clinical specialists consider opioids a good means to perform euthanasia.[7]

Studies have shown that when opioids and sedatives are given to treat pain or other symptoms, this will hardly ever result in the death of the patient.[8-14] To what extent these results are applicable to these cases in which opioids and sedatives were used with the explicit intention to hasten the end of life is unknown. Nevertheless, the use of overdoses of opioids and sedatives with the intention to end life is advised against by the KNMP because the actual effect on the end of life is uncertain, and because higher dosages of morphine than is required for pain- and symptom treatment can have very unpleasant side-effects, such as nausea and hallucinations.[1] Our results show that in 16% of the euthanasia cases in 2005, opioids were used to perform euthanasia. Although we do not have data about the dying process of these patients, it is possible that these patients will have suffered from the side-effects that can be a result of using large doses of opioids. Physicians should be further educated on the effects and side effects of opioids and sedatives so that they can select the correct drugs if life termination is the envisaged objective and use drugs to alleviate pain and symptoms proportionally without fear of hastening death.

Limitations of this study include that it is based on the reports of the physicians. It is possible that physicians did not remember all characteristics of a case correctly, although they received a questionnaire within 1-6 weeks after the death of the patient. The reliability of the trends found in this study is assured by using identical questions in each of the study years. Our findings cannot be generalized beyond the Netherlands. Nevertheless, it seems likely from the limited data that has been collected abroad about physicians' knowledge of definitions of end-of-life decisions, that physicians in other countries are not more aware of the distinction between intentional and unintentional effects on the end of life than physicians in the Netherlands.[15 16]

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5

Physicians' labeling of end-of-life practices: Hypothetical case study

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Submitted

Abstract

Objectives To investigate why physicians label end-of-life acts as either 'euthanasia / ending of life' or 'alleviation of symptoms / palliative or terminal sedation', and to study the association of such labeling with intended reporting of these acts.
Methods Questionnaires were sent to a random, stratified sample of 2100 Dutch physicians (response: 55%). They were asked to label six hypothetical end-of-life cases: three 'standard' cases and three cases randomly selected out of 47), that varied according to (1) type of medication (2) physician's intention, (3) kind of patient request, (4) patient's life expectancy and (5) time until death. We identified the extent to which characteristics of cases are associated with physician's labeling, with multilevel multivariable logistic regression.
Results The characteristics that contributed most to labeling cases as 'euthanasia / ending of life' were the administration of muscle relaxants (99% of these cases were labeled as 'euthanasia / ending of life') or disproportional morphine (63% of these cases were labeled accordingly). Other important factors were an intention to hasten death (54%) and a life expectancy of several months (46%). Physicians were much more willing to report cases labeled as 'euthanasia' (87%) or 'ending of life' (56%) than other cases.
Conclusions Similar cases are not uniformly labeled. However, labeling is determinative in physicians' willingness to report their acts. Differences in how physicians label similar acts impede complete societal control. Further education and debate could enhance the level of agreement about what is physician-assisted dying, and thus should be reported, and what not.

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5.1 Introduction

In the Netherlands, euthanasia is defined as deliberately ending a person's life at the person's explicit request. It embraced 1.7% of all deaths in 2005.[1] In physician-assisted suicide, the patient self-administers medication that is prescribed by a physician. This practice is less common than euthanasia and embraced 0.2% of all deaths. In 2002, the Netherlands passed the 'Euthanasia Act' and so provided a legal ground for euthanasia and physician-assisted suicide. Physicians are required to report euthanasia and assisted suicide to the municipal coroner as an unnatural death to enable review by a multidisciplinary review committee, to guarantee transparency and public control. Since the early nineties, reporting rates increased gradually: from an estimated 18% of all cases in 1990, to 41% in 1995 and 54% in 2001, up to 80% in 2005.[1-3] However, non-reporting of physician-assistance in dying, which is a criminal offence, subsisted. Cases in which physicians had used opioids to deliberately end life were rarely reported.[1 4]

Opioid use at the end of life has been extensively discussed in the literature. In general, two situations can be distinguished. In the first situation, physicians alleviate the suffering of terminally ill patients by titrating the dosage of opioids against symptoms. This practice is generally considered to be part of normal medical practice. Yet, physicians have frequently expressed concerns about shortening these patients' lives, for example by causing respiratory depression.[5] The principle of proportionality states that in such situations practices may be justified if the probable harms are outweighed by the benefits for the patient (e.g. death could be a negative consequence of a beneficial action).[6] However, as there is increasing evidence that the potential life-shortening effects of opioids are limited, the benefits probably predominate in such cases.[7-9] In the second situation, physicians intentionally administer opioids in high or rapidly increasing dosages to shorten life: such cases should be regarded as a form of physician-assisted dying. In actual medical practice a grey zone emerges in which it may be difficult to distinguish between these two types of situations.

Correct labeling of end-of-life acts, including those where opioids are used, is important in countries where euthanasia is illegal because morphine and other potentially life-shortening drugs are often indispensable in end-of-life care. In countries that tolerate physician assistance in dying, there is an additional relevance due to the requirement to report cases where opioids are used in disproportional high dosages. In this paper we explore the determinants of labeling acts as 'euthanasia / ending of life' and the extent to which such labeling is associated with physician's intended reporting. We used hypothetical cases and studied the type and mode of medication, the physician's intention, the type of request, the patient's life expectancy and the time until death after the administration of medication.

5.2 Methods

Population

This study was a national questionnaire survey among 2100 Dutch physicians; 1300 clinical specialists (200 cardiologists, surgeons, lung specialists, ICU-specialists and neurologists and 300 specialists in internal medicine), 500 general practitioners and 300 nursing home physicians. The sample sizes were based on the frequency with which physicians have medical responsibility for dying patients, and on the total number of physicians working in a specific discipline. Respondents were selected according to the following criteria: (1) they were clinically active at the time they completed the questionnaire, (2) they had actively practiced the registered specialty for at least one year, (3) and they had to be living in the Netherlands. All addresses were taken from the professional registries of the relevant specialties. Over a 10-month period (February 2006 till November 2006) questionnaires were sent out and returned. We applied strict rules to ensure the physicians' anonymity. Physicians were requested to return a pre-printed card with their contact details, separately from the questionnaire. In such a way we were able to identify the physicians who responded without linking physicians to the questionnaire itself. Reminders were only sent to physicians from whom we did not receive the card. The questionnaire response rate, adjusted for physicians who were untraceable, was 55% (n=1032). In this paper we used data of 1004 physicians; 28 physicians did not fill out any question about the hypothetical cases. Of all respondents, 72% were male and 28% were female. 82% of the physicians were older than 40 years; 60% were general practitioners, 31% medical specialists and 9% nursing home physicians. Non-responders did not differ from responders in age, sex or place of residence.

Measurement instruments

Physicians received a 10-page written questionnaire that focused on experiences with and attitudes towards the Dutch Euthanasia Act. The questionnaire had been tested in a pilot study among 16 respondents, who had little or no problems with the interpretation of the questions.[10] Physicians were presented six hypothetical cases of elderly patients in the terminal stage of a lethal disease, who severely suffered from pain and fatigue. For each case, we applied small variations in patient-characteristics that were considered not relevant (e.g. patient's age varied from 71 to 76). The attributes that systematically varied between cases were based on earlier studies on end-of-life decision-making: [10 11 12] (1) the type of medication that was used, (2) the physician's intention while using this medication, (3) the kind of patient request, (4) the patient's life expectancy and (5) the time until death after administration of the medication (**Box 5.1**). We excluded clinically unrealistic combinations such as a life expectancy of a couple of months in combination with administration of proportional morphine and a time till death after the administration of morphine of a few minutes or hours. The total number of realistic combinations of these attributes was 50. Each physician was presented three 'standard cases' (**Table 5.1**). The definition of these standard cases was based on the legal definition of euthanasia and on large scale studies that describe the characteristics of patients who died from euthanasia (case 1), palliative or terminal sedation (case 2) and symptom alleviation (case 3). [10 13 14] Physicians were further presented three cases randomly selected out of the other 47. We ensured that all 47 cases were presented in similar frequencies but gave each physician a unique combination to avoid order effects. For all cases, physicians were asked which term would, in their opinion, describe the act in the presented case best:

alleviation of symptoms, palliative or terminal sedation, ending of life, euthanasia, or another term. They were further asked whether they would (probably) report the case as an unnatural death to the municipal coroner.

Box 5.1. Construction of hypothetical cases.

Attributes:	**1**	**2**	**3**	**4**	**5**
Type of medication	Morphine, proportional[1]	Morphine, disproportional[2]	Sedatives, no ANH[3]	Sedatives, ANH[3]	Muscular relaxant
Physician's intention	Relief of suffering	Hastening of death			
Type of request	No request	Request to end suffering	Request to end life		
Life expectancy	Couple of days	Couple of months			
Time till death	Minutes	Hours	Days		

[1] The physician decides to use a morphine drip and the dose is increased twice.

[2] The physician decides to use a morphine drip and the dose is doubled every 3 hours.

[3] ANH; artificial nutrition or hydration.

Statistical analyses

For all statistical analyses we weighted the data for different sampling fractions and response rates to make the results representative for all physicians in the relevant disciplines. Missing values were excluded when these comprised less than 5% of all cases assuming that this would not influence the representativeness of the data. We reported absolute frequencies and weighted percentages using the Statistical Package for Social Sciences 11.0 (SPSS Inc, Chicago, Ill).

We determined the relative importance of factors that may be related to the assignment of labels to the 47 other, non-standard hypothetical cases. The fact that each respondent evaluated three cases was accounted for by including respondent as a random effect in a multilevel multivariable logistic regression analysis. The model also included the 5 attributes (**Box 5.1**) that systematically varied between the cases. The outcome variable was the dichotomy 'Euthanasia / ending of life' vs. 'Alleviation of symptoms / palliative or terminal sedation'. This dichotomy was used because 'euthanasia' and 'ending of life' both represent acts of physician-assisted dying that should be reported as an unnatural death, whereas alleviation of symptoms and palliative or terminal sedation are considered to involve a natural death. We present adjusted odds ratios and overall p-values. Models were fitted with the June 2006 release of the experimental Glimmix procedure for generalized linear mixed models in SAS version 9.1. The 47 non-standard hypothetical cases were further analyzed to test univariate associations between physicians' labeling of cases and their willingness to report, using the Chi-square test for statistical significance. In total 3012 cases were presented (1004 respondents multiplied by 3 cases). In this paper we used 2976 cases because we excluded 36 cases where information about labeling or reporting was missing.

5.3 Results

A full description of the three 'standard' cases (A, B and C) is presented in **Table 5.1**. Most physicians labeled case A, where the attending physician administered a sedative followed by a muscle relaxant upon an explicit patient request to end life, as 'euthanasia' (87%) or 'ending of life' (12%). In case B, the patient received midazolam until death; the large majority of physicians labeled this case as 'palliative or terminal sedation' (93%). In case C, the patient received morphine by a morphine drip that was increased twice. This case was mostly labeled as 'symptom alleviation' (85%) but in a minority of cases (13%) as 'palliative or terminal sedation'.

Table 5.1 Labeling and willingness to report 3 'standard' cases that were presented to all physicians.[1]

Presented cases:	**Practice was labeled as:**	N=1004[2]
A		%
Patient *A* is a female of 74 years old with an inoperable ovarian carcinoma. She suffers from severe pain. Patient is expected to die within a couple of months. Patient has requested her physician several times to end her life. The attending physician decides to grant the patient's request. At an arranged moment in time, the physician administers a sedative and subsequently, a muscle relaxant. Patient dies a few minutes after the administration of the muscle relaxant.	Euthanasia	87
	Ending of life	12
	Palliative or terminal sedation	1.0
	Symptom alleviation	0.1
	Other	0.1
B		
Patient *B* is a female of 72 years old with terminal heart failure. She is short of breath and suffers from chest pain. She is fatigued and bedridden. Patient has a life expectancy of a few days. A morphine drip is insufficient to relieve her symptoms. Patient asks her physician to end her suffering. The decision is taken to relieve the patient's suffering in the best way possible by administering midazolam until death. The patient quickly becomes unconscious and dies 3 days after the administration of midazolam.	Euthanasia	1.1
	Ending of life	0.9
	Palliative or terminal sedation	93
	Symptom alleviation	5.2
	Other	0.2
C		
Patient *C* is a female of 73 years old with an oesophagus carcinoma and severe metastases. She is fatigued and suffers from severe pain in her whole body. Patient has a life expectancy of a few days. Patient's symptoms are treated with morphine patches but relief is insufficient. The decision is taken to use a morphine drip. The dose is increased twice to relieve the patient's suffering in the best way possible. The patient dies three days after the start of the morphine drip.	Euthanasia	0.4
	Ending of life	1.7
	Palliative or terminal sedation	13
	Symptom alleviation	85
	Other	0.2

[1] Data are given as percentages, weighted for different sampling fractions and response rates.
[2] 'N' concerns the number of physicians.

Determinants associated with labeling hypothetical end-of-life cases as 'euthanasia / ending of life'

The type of medication was significantly associated with physicians' labeling of end-of-life cases, also when taking into account the other attributes in a multivariate logistic regression analysis ($p<0.01$): 99% of all 292 cases in which muscle relaxants had been administered were labeled as 'euthanasia / ending of life'. **Table 5.2** further shows that 63% of all 720 cases in which disproportional morphine was administered and 11% of the 625 cases in which proportional morphine was administered were labeled as 'euthanasia / ending of life'. Further, 15% of the 316 cases in which a sedative was administered, were labeled as 'euthanasia / ending of life'. An intention to hasten death (54% of the 1614 cases) as compared to an intention to relieve suffering (12% of the 1322 cases) also contributed to the likelihood that cases were labeled as 'euthanasia / ending of life' ($p<0.01$). Further, physicians were more inclined to label cases as 'euthanasia / ending of life' when the patient was expected to die within several months (46% of the 1177 cases) as compared to a few days (28% of the 1759 cases) ($p<0.01$).

Table 5.2 Univariate percentages and adjusted odds ratios from a multilevel multivariable logistic regression analysis to investigate the association between labeling end-of-life cases as 'euthanasia' or 'ending of life' and its determinants.[1]

N=2936[2]	n/N[3,4]	%[5]	Odds ratio[6] (95% CI)	p-value[7]
Type of medication				<0.01
Morphine, proportional	67/625	11	1	
Morphine, disproportional	437/720	63	5.4 (3.3-8.8)	
Sedatives	49/316	15	1.5 (1.0-2.3)	
Sedatives and no ANH[8]	209/983	19	1.3 (0.9-2.0)	
Neuromuscular relaxant	288/292	99	338 (110-1037)	
Physician's intention				<0.01
Relief of suffering	165/1322	12	1	
Hastening death	885/1614	54	2.4 (1.6-3.6)	
Type of request				0.83
No request	380/1164	32	1	
Request to end suffering	397/1258	31	0.99 (0.8-1.3)	
Request to end life	273/514	52	1.1 (0.8-1.5)	
Life expectancy				<0.01
A couple of days	490/1759	28	1	
A couple of months	560/1177	46	3.4 (2.7-4.2)	
Time till death				0.56
Minutes, hours	586/1345	43	1	
Days	464/1591	29	0.93 (0.7-1.2)	

[1] Labels were dichotomized into either 'euthanasia/ending of life' or 'palliative or terminal sedation/alleviation of symptoms'. The 40 cases labeled as 'otherwise' (see Table 5.3), were excluded for this analysis.

[2] The total number of studied cases, concerning the 47 'other' hypothetical cases.

[3] Unweighted, absolute numbers.

[4] 'n' includes the number of cases labeled as 'euthanasia' or 'ending of life'. 'N' includes the number of hypothetical cases in which proportional morphine was administered (625 cases), disproportional morphine was administered (720 cases) etcetera.

[5] Percentages weighted for different sampling fractions and response rates.

[6] Odds ratio, calculated in a multi-level multivariate logistic regression analysis: corrected for the fact that each respondent could answer questions about three hypothetical cases and adjusted for type of medication, physician's intention, type of request, life expectancy and time till death.

[7] Overall p-value, calculated in a multilevel multivariable logistic regression analysis.

[8] ANH = artificial nutrition or hydration.

Physicians' labeling and willingness to report hypothetical end-of-life cases

Physicians were much more willing to report cases that they labeled as 'euthanasia' (87%) or 'ending of life' (56%) (**Table 5.3**). The willingness to report cases labeled as 'palliative or terminal sedation' (9.6%) and cases labeled as 'symptom alleviation' (2.2%) was much lower (p<0.01).

Table 5.3 Association between labeling and willingness[1] to report 'other' hypothetical end-of-life cases.

N=2976[2]	n/N[3,4]	%[5]	p-value[6]
Act was labeled as:			<0.01
Euthanasia	380/441	87	
Ending of life	345/609	56	
Palliative or terminal sedation	114/1201	9.6	
Other	10/40	17	
Alleviation of symptoms	21/685	2.2	

[1] Willingness to report hypothetical potentially life-shortening practices in which the physician's intention, the types of drugs used, the time until death, the patient's life expectancy prior to the act, and the type of request systematically varied.

[2] The total number of studied cases, concerning the 47 'other' hypothetical cases.

[3] Unweighted, absolute numbers.

[4] 'n' includes the number of cases that would (probably) be reported by physicians. 'N' includes the number of hypothetical cases labeled as euthanasia (441 cases), ending of life (609 cases) etcetera.

[5] Percentages weighted for different sampling fractions and response rates.

[6] Chi-square test to test univariate associations between physicians' willingness to report and their labeling of cases.

5.4 Discussion

This study on hypothetical cases shows that labeling is strongly associated with medical (the type of medication), physician (their intention) and patient (life expectancy) related factors. Our study further shows that physicians' labeling of similar acts varied. These labels are strongly associated with physician's intended reporting behaviour.

The large random sample and the complete anonymity of the physicians are strengths of the study. We approached clinical reality by using hypothetical cases. Such cases enable us to standardize the characteristics and to confront all physicians with similar situations. However, concise hypothetical case descriptions may lead to different interpretation of the respondents, which is a common weakness of hypothetical case studies.[15 16] Yet, our pilot study showed that most physicians found the cases realistic and could answer the questions adequately, although they sometimes expressed a need for more detailed information. Further, the willingness to report the acts presented in these end-of-life cases may not be identical to actual practice: real behaviour is known to be also influenced by cultural and situational factors.[17 18]

The existence of a grey zone between euthanasia and highly dosed alleviation of pain and symptoms was firstly described in 1990 in the first Dutch nationwide study on end-of-life decision-making.[11] It was then estimated to concern around 2% of all deaths. Our assessment of the grey zone identifies which characteristics clearly distinguish between

different end-of-life acts and which characteristics are less distinctive and consequently may contribute to the existence of a grey zone.

The use of a muscle relaxant was a strong discriminating factor related to physicians' label of 'euthanasia / ending of life' as almost all cases were labeled as such, also when taking into account the other attributes. For euthanasia, the Royal Dutch Society for the Advancement of Pharmacy (KNMP) recommends the use of a barbiturate to induce a coma, followed by a muscle relaxant to induce the patient's death. In contrast to the use of a muscle relaxant, the use of morphine and to a lesser extent the use of sedatives was more ambivalent in their association with labeling the act as 'euthanasia / ending of life'. On the one hand, in 11% of the cases in which morphine was administered in proportional dosages, physicians thought that the label 'euthanasia / ending of life' described the act best. Further, 15% of the cases in which a sedative was administered were labeled as 'euthanasia / ending of life'. This is a remarkable finding as these cases are generally considered as normal medical practice because of the unlikeliness that life is actually shortened when administering morphine or sedatives in proportional dosages, as is suggested in other studies.[7 8] On the other hand, cases in which morphine had been administered in disproportional dosages were labeled as either 'symptom alleviation / palliative or terminal sedation' in 37% of cases. Thus, an even greater proportion of physicians do not always perceive the use of disproportional morphine as some form of physician-assisted dying. As such, our data show that with respect to the type of medication that is administered, the grey zone is the result of difficulties in the classification of end-of-life practices in two directions.

Apart from the type of medication, the physician's intention and patient's life expectancy play an important role in how physicians distinguish different end-of-life acts, even after correction for the other attributes. An intention to hasten death, which is generally included in the definition of euthanasia[19 20], was significantly associated with labeling acts as 'euthanasia / ending of life'. However, only 54% of all cases with an intention to hasten death were labeled as such. Intentions are difficult to verify.[21] More is necessary than just intention and it is often argued that acts should be morally evaluated in connection with the characteristics of the actual medical act, such as the type of medication. The association of a longer life expectancy (i.e. a couple of months) with labeling cases as 'euthanasia / ending of life' corresponds with results from another study that suggested that euthanasia is often (but not always) performed at an earlier stage in the disease process than palliative or terminal sedation.[22] The fact that an intention of hastening death and a longer life expectancy significantly but not unanimously contributed to how physicians distinguish end-of-life acts, suggests that these factors also contribute to the existence of a grey zone. The type of request and the time till death on the other hand, were not significantly associated with labeling the act as 'euthanasia / ending of life'. Apparently, these characteristics have virtually no influence in how physicians distinguish different end-of-life acts.

In a European study performed in 17 countries in ICU-units, the authors also reported a grey zone between treatments administered to relieve pain and suffering and treatments intended to actively shorten the patient's life.[23] Physicians had the intent to shorten the dying process by administering an overdose of morphine or diazepam in 2.2% of death cases. However, the distinction between acts intended to relieve suffering and acts

intended to cause death appeared to not always be clear. Apparently, physicians in many countries encounter difficulties in drawing sharp lines between their acts and labeling is part of that discussion.[24]

Our study further shows that labeling is of key importance in whether or not physicians are willing to let their acts be reviewed. Most of the physicians were willing to report cases that they labeled as 'euthanasia'. However, physicians were less inclined to report cases that were labeled as 'ending of life' than cases that were labeled as 'euthanasia'. Possibly, physicians believe that cases of 'ending of life' represent acts that do not fullfill the definition of euthanasia in the Euthanasia Act, or acts in which some characteristics do not correspond with the criteria of careful practice. Some physicians would report cases labeled as 'palliative or terminal sedation' as well. At first, this seems a remarkable finding as palliative or terminal sedation is generally considered as a normal medical practice. However, if sedation involves cases with a longer life expectancy where physicians prefer to use sedatives instead of muscular relaxants, these cases indeed need to be reported. Figures from the Netherlands have shown that physicians sometimes use sedatives when they have the explicit intention of hastening death, or when the patient's life expectancy is more than one month.[1 25]

The grey zone as identified in our study reflects physicians' varying ideas about whether or not the type of medication, the patient's life expectancy, and their intention are determinative in whether the act should be regarded as a normal medical practice or not. It is likely that the strong association between labeling and reporting is the result of the fact that physicians base their willingness to report on their labeling of their acts. However, the grey zone is a social phenomenon as well: physicians might prefer not to label acts as euthanasia and thus refrain from reporting them in order to preserve some medical freedom. Accordingly, physicians may use highly dosed morphine instead of barbiturates and neuromuscular relaxants, while having the intention to end or to shorten the patient's life. In the Netherlands, fear of legal consequences of reporting has been mentioned as a reason not to report by some physicians and some of them think that reporting hampers the privacy of the relationship between patient and physician.[1] Further, through labeling acts within the domain of normal medical practice it may be easier to justify their act to themselves and others. The same probably holds for countries where euthanasia is not allowed; it cannot be precluded that physicians are tempted to label the administration of drugs with the explicit intention of hastening death as alleviation of symptoms.[26-28]

In conclusion, this hypothetical case-study shows that there are three main characteristics that contribute to the existence of a grey zone between euthanasia and highly dosed alleviation of pain and symptoms: medication other than muscle relaxants, physician's intention, and patient's life expectancy. This grey zone is expressed in variance in how physicians label their acts. Physician's choice to label the case as either an act within the domain of normal medical practice or not is determinative in physicians' attitudes towards public review of their act. The existence of a grey zone will therefore impede complete societal control and transparency.

Unanswered questions and future research

Our empirical assessment of the grey zone gives rise to several questions. To what extent is this grey zone based on insufficient knowledge and to what extent is it created on purpose? How large and to which end-of-life acts is the grey zone in countries where euthanasia is not allowed restricted? Future studies should focus on physician's knowledge and their personal reasons for labeling acts as practices within the domain of normal medical practice or not. International studies in countries with different legislation regarding euthanasia or other medical decisions at the end of life would also increase our understanding. Further education and debates with physicians, ethicists, legal experts and politicians, should enhance the level of agreement about what is considered physician-assisted dying, and thus should be reported, and what is not.

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6

Dutch experience of active ending a newborns' life

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Submitted

After the enactment of a national review committee in the Netherlands in 2007 that would investigate cases in which an infants' life was actively ended, no cases have been reported. We argue that there may be several explanations for this lack of reporting.

6.1 Introduction

The Netherlands has a long tradition of publicly discussing the acceptability of end of life decision-making by physicians.[1] Much of this debate has been devoted to euthanasia, which in the Netherlands is defined as deliberate ending a person's life at the person's request. Due to the incompetence of the patients and the special position of parents, there have been separate discussions about end-of-life decisions for infants. A cornerstone publication was the 1992 guideline of the Dutch Paediatric Association.[2] Apart from decisions to refrain from potentially life-sustaining treatment and decisions to alleviate suffering with possibly life-shortening effect, the guideline also allowed for decisions to actively end the life of newborns in extreme and exceptional circumstances that included an obligation to report their case. The 1990's saw two court cases;[3 4] both physicians were acquitted. Jurisprudence had started with these two cases.

6.2 Acceptability of active ending of life for newborns

Consecutive ministers of Health focussed on the passing of the euthanasia law, which finally occurred in 2001, and were reluctant to legally formalize active ending of life of newborns. This passive stance was left in 2005 when the 'Groningen protocol' attracted a lot of international attention.[5] This protocol prompted the government to take a next step. It was decided to keep active ending of life of newborns illegal but to set up a national review committee that would investigate cases in which an infants' life was actively ended.[6] This committee consists of a legal expert, an ethicist and three physicians. The committee evaluates whether physicians adhere to due care criteria, which are: 1) the suffering of the child has to be unbearable and without any prospect of improvement, 2) an independent physician has to be consulted, 3) the parents have to agree with the decision, and 4) physician assistance in dying has to be provided with due care. The committee's report serves as an important advice to the public prosecutor who always retains the final decision about prosecution.

The committee started its work in March 2007. Based on our earlier reports[7 8] and other studies[5 9] it was estimated that about 15 to 20 cases would be reported annually. However, till now (September 2009) none have been.

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6.3 Study

We explored possible explanations for the lack of reporting by scrutinizing data on end-of-life decision-making for infants from three Dutch nation-wide studies that we performed in 1995, 2001 and 2005, prior to the instalment of the committee.[8 10 11] In these studies, physicians were asked to fill in a four-page questionnaire about their medical decision-making for stratified samples of deceased infants that were drawn from the central death registry of Statistics Netherlands. Response rates were 88% (1995), 84% (2001) and 88% (2005).[8 10 11] In 2005, three cases were removed from the database because they appeared to involve induced abortions. For all studies, results were made representative of all infant deaths by weighting the data for stratification and response by the patients' sex and the cause and place of death.

Key-questions in the questionnaire were whether:
a) the physician had withheld or withdrawn life-sustaining treatments while taking into account or explicitly intending (potential) hastening of death;
b) the physician had intensified the alleviation of pain or other symptoms by the use of drugs, while taking into account or appreciating a possible life-shortening effect;
c) death had been the result of drugs that had been administered, supplied or prescribed drugs with the explicit intention of hastening death. If this question was answered affirmatively, the act was classified as active ending of life.

Other questions concerned the type of medication used, the estimated shortening of life, the most important reason for the decision, and the involvement of physicians, parents and others in the decision-making. The 2005 questionnaire contained a new question about the use of continuous deep sedation until death. Physicians were also for the first time asked whether they would report the act as a non-natural death and which term would, in their opinion, describe their act best.

6.4 Trends in end-of-life practices: 1995-2005

In 2005, 58% of all deaths were preceded by an end-of-life decision, as compared with 68% in 2001 and 62% in 1995 (**Table 6.1**). Forgoing potentially life-sustaining treatment remained with 55% the most frequent decision. In 21%, forgoing treatment was followed by the use of drugs with a possible life-shortening effect and in 6% by the use of drugs with the explicit intention to hasten death. The use of drugs with a possible life-shortening effect tended to be lower in 2005. In the 2005 study, no cases were found in which physicians had administered drugs with the explicit intention to hasten death without a preceding decision to forgo treatment. In 2005, 20% of all deceased infants were continuously and deeply sedated before death; in 2%, sedation was provided without artificial hydration or nutrition.

Table 6.1 End-of-life practices for deceased infants aged younger than 1 year.

	2005 n=119		**2001** n=233		**1995** n=299		**p-value**[1]
	n	%	n	%	n	%	
Sudden and unexpected death	37	19	52	20	74	24	0.07
Expected death, no end-of-life decision	21	23	27	12	41	14	
End-of-life decision[2,3]	61	58	154	68	184	62	
Life-sustaining treatment withheld and / or withdrawn	**n=57**		**n=143**		**n=168**		
No drugs given	26	28	60	26	76	26	0.84
Use of drugs with a possible life-shortening effect	27	21	65	29	68	23	
Use of drugs with the explicit intention to hasten death	4	6	18	8	24	8	
No life-sustaining treatment withheld and / or withdrawn	**n=4**		**n=11**		**n=16**		
Use of drugs with a possible life-shortening effect	4	3	7	3	12	4	
Use of drugs with the explicit intention to hasten death	0	0	4	1	4	1	
	n=119						
Continuous deep sedation[4]	20	19	NA[5]		NA[5]		
With artificial hydration and nutrition	19	17					
No hydration and nutrition	1	2					

[1] Chi-square test.
[2] End-of-life decisions include: forgoing potentially life-sustaining treatment and the administration of drugs while taking into account or explicitly intending a life-shortening effect.
[3] In this study continuous deep sedation was not included as an end-of-life decision.
[4] Continuous deep sedation may have been performed in conjunction with an end-of-life decision.
[5] NA = not available

6.5 Characteristics of 2005 cases in which life was actively ended

Active ending of life was in all 2005 cases preceded by a decision to forgo potentially life-sustaining treatment, because the infant had a limited chance of survival and an extremely poor prognosis regarding quality of life. In most cases it was expected that the infant would die shortly after forgoing life-sustaining treatment. In these cases, the decision to actively end the infant's life was made because of a longer than expected survival with severe suffering. Occasionally, life expectancy after forgoing of life-sustaining treatment was estimated to be relatively long. In these cases, active ending of life was an anticipatory decision to prevent future suffering or a protracted dying process. The boxes contain two fictional illustrative cases where physicians had administered drugs with the explicit intention to hasten death: an infant with a limited life-expectancy after forgoing treatment (**Case 1**) and an infant with a longer life-expectancy (**Case 2**). For these cases, we combined the information from all 2005 cases in which life was actively ended.

Case 1.

After 27 weeks of pregnancy an infant was born with a birth weight of 800 gram. His premature status, which involved IRDS (Infant Respiratory Distress Syndrome), required artificial respiration. A few days later an intracranial hemorrhage occurred, which resulted in an obstructive hydrocephalus. Because of severe suffering morphine and benzodiazepines were administered. The only possible additional treatment for the hydrocephalus would have been surgery. A multi-disciplinary team of physicians and the parents agreed on the very slight chance of survival for this child. Therefore and because of the severe suffering of the infant, they decided, on the explicit request of the parents, to forgo surgery and to withdraw artificial respiration. The terminal phase took longer than expected and involved severe gasping of the infant, which was a horrible sight for the parents. Therefore the physician decided to add neuromuscular relaxants to the morphine and benzodiazepines, with the explicit intention to hasten death. The estimated shortening of life by this last action was less than 24 hours. According to the physician, 'terminal sedation' was the most appropriate term for his actions. He also indicated that he did not report this case as an unnatural death to the coroner because the parents' stress, that had been caused by the severe gasping, necessitated a quick decision that could not wait for initiation of a proper procedure. Further, the physician was aware of the legal consequences when reporting this case without having used the proper procedure.

Case 2.

After 30 weeks of pregnancy an infant with spina bifida was born with a birth weight of 1000 gram. Operations were needed to close the meningohydrocele, and to relieve the hydrocephalus by placing a ventriculo-peritoneal shunt. However, the parents together with a multidisciplinary team decided not to start these operations in this preterm infant. Another reason was the expected poor prognosis for later life despite the operations. Life expectancy at this point was more than six months if only few complications would occur as a result of prematurity, but would be predominated by great suffering and a low quality of life. Because the expected low quality of life and the explicit request of the parents, the team decided to explicitly hasten death by administering neuromuscular relaxants. In advance, continuous deep sedation was started. The infant's death followed shortly after a neuromuscular relaxant was administered. The attending physician labeled his action as 'ending of life'. According to the same physician this case would normally be reported to a Coroner as an unnatural death, in correspondence with the Groningen protocol. Extensive discussions within the team finally resulted in the decision not to report this case as a non-natural death.

6.6 Explanations for the lack of reporting

This analysis of available data suggests several possible explanations for the lack of reporting.

First of all, the practice of neonatal end-of-life decision-making seems to have changed after 2001. The percentage of deaths of infants that had been preceded by an end-of-life decision decreased. The decrease was partly due to the lower frequency of the use of drugs with a possible life-shortening effect. It cannot be precluded that this decrease is at least partly the result of a decreasing tendency among physicians to attribute life-shortening effects to opioids. Previous studies have suggested that when opioids and sedatives are proportionally given to treat pain or other symptoms, this will hardly ever result in the hastening of the death of the patient.[12 13] Many of the cases of active ending of life in 1995 and 2001 involved the use of opioids.[14] Physicians may have been more inclined to expect life-shortening effects and use morphine with the intention of hastening death in these years, which resulted in a higher reported number of cases of active ending of life in our studies.

Secondly, and probably partly related to the opioid discussion, physicians in 2005 who administered drugs with the explicit intention to hasten death, sometimes described ('labeled') their act as some form of 'symptom alleviation'. Possibly, if physicians were unsure whether the drugs shortened the patient's life, they decided not to label their act as 'ending of life'.

Thirdly, the 2005 data show that a substantial number of infant deaths were preceded by the use of sedatives. Among adults, the use of continuous deep sedation significantly increased in the last couple of years.[15] Although the practice differs from adults, as continuous deep sedation in infants was mostly provided together with artificial hydration or nutrition, a similar trend of increased use of sedatives among infants is likely. It could be that continuous deep sedation has taken away, at least in some cases, the need to actively hasten the end of life of infants.

The introduction of ultrasound examination in 2006 at 20 weeks' gestation as part of the routine prenatal screening in the Netherlands is another relevant development in medical practice. Although our data provide no explanations, ultrasound examination is expected to result in higher detection rates of structural congenital abnormalities, as shown in other countries where routine ultrasound examination has been an integral part of prenatal care much longer.[16] This increased prenatal detection rate may result in more induced abortions before 24 weeks of pregnancy, less infants born with a congenital abnormality, and less post-natal deaths due to congenital abnormalities.[17] Such developments will probably result in a decrease of the frequency of end-of-life decisions in infants in the Netherlands as well.

The number of 15 to 20 cases of ending of life in newborns that the national review committee was expected to receive was thus probably an overestimation, due to recent changes in neonatal end-of-life practice. Some characteristics of the previous studies may have enlarged such overestimation. All three studies included infants who had died in their first year of life. The regulation however concerns newborns only. It is nowhere stated at what age an infant stops being a newborn, but this will certainly be before reaching the age of one. Some of the cases in our study are thus not subject to the regulation for newborns and cannot be reported to the committees. Furthermore, a careful check of the original files in the 2005 study revealed that some cases that were reported to Statistics Netherlands as infant deaths actually were cases of termination of pregnancy.

Whereas the expected number of 15 to 20 cases may thus have been an overestimation, it is likely that at least some cases of active ending of life occurred during the past years. Physicians' reluctance to report these cases may have several causes. First of all, a committee that can only advise the public prosecutor but lacks legal power may not inspire physicians with sufficient confidence to report their act. For euthanasia, numbers of reported cases significantly increased after the enactment of the euthanasia law (to 80% in 2005), which gave the committees the power to decide on cases.[11] Furthermore, it may be useful to look separately at cases where life was ended because foregoing treatment unexpectedly resulted in severe suffering during a protracted dying phase (as in Case 1), and cases where ending of life was an anticipatory decision to prevent expected future suffering (as in Case 2). In case 1 situations, physicians appeared not to label their act as 'actively ending of life', but as adequate terminal care. Labeling this form of terminal care as 'active ending of life' would require both physicians and parents in a very short timeframe to drastically adapt their mindset, because the infant is no longer dying from a natural cause while receiving the best possible comfort care. Probably, most physicians consider this (consciously or unconsciously) as too burdensome for the parents and therefore decide to label and report their case as a natural death. An additional factor that may hamper physicians from reporting cases like these, is that the fact that decisions need to be made quickly to do any good to the infant could stand in the way of adequate fulfilment of the consultation requirement. A recent Dutch study also showed that similar situations as described in case 1 were reported as a natural death.[18] Physicians were more inclined to label their decision as 'actively ending of life' in case 2 situations, where life is ended to prevent expected future suffering. Physicians may be reluctant to report cases like these because of the requirement that ending of life is only permissible for an infant

that is presently suffering unbearably, whereas in these cases the ending of life is predominantly aimed at preventing future suffering, as in spina bifida.

Concluding remarks

We identified several changes in the practice of end of life decision-making for infants that may explain the lack of reporting of cases of active ending of life. Furthermore, it seems virtually impossible to comply with the requirements in the current regulation, due to either time constraints or the nature of the suffering that is addressed. If societal control of active ending of life in newborns is considered useful, a different regulation is needed. Attention should be paid to the requirements for careful practice in the current regulation, to physicians' awareness of when they should report their act, and to a safe legal environment for reporting.

6.7 References

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PART II

CULTURAL ASPECTS

7

A comparison of physicians' end-of-life decision-making for non-western migrants and Dutch natives in the Netherlands

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Abstract

Background Non-western migrants have a different cultural background that influences their attitudes towards health care. As the first wave of this relatively young group is growing older, we investigated, for the first time, whether end-of-life decision-making practices for non-western migrants differ from Dutch natives.
Methods In 2005, we sent questionnaires to physicians who attended deaths identified from the central death registry of Statistics Netherlands (n=9651; non-western migrants: n=627, total response: 78%). We performed multivariate logistic regression analyses adjusted for age, sex and cause of death.
Results Of all deaths of non-western origin, 54% were non-sudden, whereas 67% of all deaths with a Dutch origin were non-sudden (p=0.00). A relatively large number of non-suddenly deceased persons of non-western origin had died under the age of 65 (53%) as compared to Dutch natives (15%). Euthanasia was performed in 2.4% of all non-suddenly deceased persons in the non-western migrant group as compared to 2.7% in the native Dutch group (adjusted odds ratio=0.82, p=0.63). Alleviation of symptoms with a potential life-shortening effect was somewhat lower for non-western migrants (30% vs. 38%; adjusted odds ratio=0.78, p=0.07). Physicians decided to forgo potentially life-prolonging treatment in comparable rates (26% vs. 23%; adjusted odds ratio=1.1, p=0.73). Yet, the type of treatments forgone and underlying reasons differed.
Conclusion Euthanasia was not less common among non-suddenly deceased non-western migrants as compared to Dutch natives. However, intensive symptom alleviation was used less frequently and forgoing potentially life-prolonging treatment involved different characteristics. These findings suggest that cultural factors may affect end-of-life decision-making.

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7.1 Introduction

Today, many European countries have a multiethnic society with a rising proportion of people who originate from non-western countries. In the Netherlands, 10% of the population is from non-western origin.[1] This ethnically diverse group predominately originates from Turkey (20%) and Morocco (20%). Another 30% comes from (former) Dutch colonies and 30% comes from other African or Asian countries. Their arrival was the result of several migration waves starting in 1946 and mainly related to better work opportunities in the Netherlands or political developments in the countries of origin.[2] In the Netherlands, at least half of the non-western migrants are Muslim.[1] Most of them live in larger cities, in densely concentrated neighbourhoods.[3 4]

The health of non-western migrants is on average worse compared to the Dutch natives, especially in migrants who recently arrived in the Netherlands.[3 5] A different social and economic position, substandard housing, and limited access to health care services might be explanatory factors.[6] As compared to the native Dutch population, death rates among non-western migrants are higher (especially at young age) and cause-specific mortality varies.[7] The higher susceptibility to illness is in line with the lower self-reported health of non-western migrants and the more frequent visits to general practitioners. Yet, the use of specialized hospital care is often lower indicating possible cultural differences in attitudes towards health and health care.[8-10] It has further been shown that such cultural differences and migrant's illiteracy or inadequate control of the language might complicate effective communication between patient and physician.[11]

As the first wave of non-western migrants is growing older, medical care and medical decision-making at the end of life increases in importance. End-of-life decisions, e.g. decisions to withhold or withdraw potentially life-prolonging treatment or to alleviate pain or symptoms with opioids in potentially life-shortening dosages, are known to be an aspect of end-of-life care in a substantial proportion of all deaths. Such decisions are based upon a balanced consideration of medical, ethical, psychosocial, societal and cultural/ethnic aspects.[12 13] In most Western countries, terminally ill patients generally consider quality of life as highly important and hastening of death can sometimes be an accepted result of end-of-life care.[14 15] For migrants from non-western countries, their original religion or culture, in which sanctity of life is often highly valued while explicitly hastening death is considered unacceptable, is probably often important.[16 17] As a result, the frequency and characteristics of end-of-life decision making practices might differ for this group. However, few empirical data are available on end-of-life practices in different ethnic groups. In this empirical study we investigated, for the first time, whether the frequency and characteristics of end-of-life practices of non-western migrants differed from Dutch natives. This study provides partial results of a larger study aimed at evaluating the Dutch Euthanasia Act.[18]

7.2 Methods

Death certificates
We obtained a stratified sample of death certificates of deceased persons from the central death registry of Statistics Netherlands. This sample was drawn between August and November 2005 (n=9965). In this paper we used data about 9651 persons aged 17 years or older at their time of death; 627 of them concerned non-western migrants. Further details about the sampling procedure have been published elsewhere.[18]

Data on the deceased persons' country of origin, age, sex, marital status, cause- and place of death were derived from the death certificate and municipal administration registers without breaking their anonymity. The following definition of non-western migrants was used: the person had lived in the Netherlands and had at least one parent who was born in Africa, Latin America or Asia (excluding Indonesia and Japan). Thus, this group included both first generation migrants (persons migrated to the Netherlands themselves) and second-generation migrants (persons born in the Netherlands but with at least one parent born abroad). Migrants from other western countries, such as Germany and Belgium, were included in the native Dutch group.

Questionnaire
Physicians who signed the death certificate for a non-sudden death received a four-page written questionnaire about their medical decision-making prior to the patient's death. We guaranteed strict anonymity for the responding physicians; the questionnaires were only opened after all identifying information had been removed. Of the 6860 questionnaires sent out, 5342 were sent back (total response: 78%). According to Dutch policy, the study did not require review by an ethics committee because the data collection was anonymous with regard to the deceased patient and the attending physician.

The questionnaire consisted of 25 questions. Key questions were whether the physician:
(1) had withheld or withdrawn medical treatments while taking into account or explicitly intending (potential) hastening of death;
(2) had intensified the alleviation of pain or other symptoms while taking into account or appreciating possible hastening of death; and
(3) had administered, supplied or prescribed drugs with the explicit intention of hastening death, which act resulted in the patient's death.

If the third question was answered affirmatively and if this act was performed upon the explicit request of the patient, the act was classified as euthanasia or physician-assisted suicide. For deaths in which more than one of the three key questions were answered with yes, the decision with the most explicit intention concerning hastening death was determinative, whereas in case of similar intentions, questions 2 and 3 prevailed over question 1.

If one of these acts had been performed, questions about the decision making followed. The physician was further asked to estimate the patient's competence, that is, the patient's ability to assess his or her situation and to decide adequately. Further, additional information was gathered on the type of treatment forgone, the type of drugs used, the

most important reasons for the decision, and the estimated degree of life shortening. We also asked whether the patient had been deeply and continuously sedated prior to death.

Analyses
The results were made representative of all deaths in 2005 by weighting the data for stratification and response by the patients' age, sex, marital status, and cause and place of death. Further, χ^2-tests were applied to assess the significance of differences in background characteristics between non-western migrants and Dutch natives. Univariate and multivariate logistic regression analyses were conducted to assess the association between the patients' origin and the occurrence of different end-of-life practices; we calculated odds ratios adjusted for age, sex and cause of death. P-values < 0.05 were considered to indicate statistical significance. Percentages were corrected for missing values when these comprised < 5% of all cases. Statistical analyses were performed using the Statistical Package for Social Sciences 11.0 (SPSS Inc, Chicago, Ill).

7.3 Results

Population characteristics
Of all deceased persons with a non-western origin, 46% died suddenly and unexpectedly; this percentage was significantly lower for persons with a Dutch origin (33%) (**Table 7.1**). Among non-western migrants, the majority concerned people from Turkey (16%), Suriname (38%), or people from other non-western countries (26%). This group most frequently involved first generation migrants (93%). In the relatively young non-western migrant population, 53% of all non-sudden deaths concerned persons under the age of 65 as compared to 15% in the native Dutch population. Non-western migrants less frequently died due to cancer (31% vs. 36%) or pulmonary diseases (6.5% vs. 12%) than Dutch natives. They more often died in a hospital than Dutch natives (59% and 32%, respectively). Physicians reported that patients had suffered from severe pain and dyspnoea during the last 24 hours of their lives in comparable frequencies.

End-of-life practices
Euthanasia was performed in 2.4% and 2.7% of all non-sudden deaths in non-western migrants and Dutch natives respectively (adjusted odds ratio=0.82, p=0.63) (**Table 7.2**). The percentage of euthanasia cases among all deaths was 1.3% and 1.8%. Ending of life without an explicit patient request occurred less frequently, these percentages were 0.2% (one case observed) and 0.5% (15 cases observed). The proportion in which potentially life-prolonging treatment had been forgone did not substantially vary between the two groups (26% vs. 23%; adjusted odds ratio=1.1, p=0.73). Yet, the percentage in which the alleviation of symptoms was intensified with hastening of death as a potential result was lower in non-western migrants (30% vs. 38%; adjusted odds ratio=0.78, p=0.07). Continuous deep sedation was provided in 14% of all non-sudden deaths in non-western migrants and in 12% of all non-sudden deaths in the native Dutch population (adjusted odds ratio=0.93, p=0.67).

Table 7.1 Characteristics of deceased persons with a non-western origin or Dutch origin.[1]

	Non-western migrants n=627 %	**Dutch natives**[2] n=9024 %	
All deaths studied (%)	2	98	100
	%	%	p-value[3]
Sudden and unexpected death			
Yes	46	33	0.00
No	54	67	
Non-sudden deaths	n=307	n=3476	
	%	%	
Country of origin			
Turkey	16	NA[5]	
Morocco	8.3	NA[5]	
Suriname[4]	38	NA[5]	
Dutch Antilles or Aruba	12	NA[5]	
Other countries in Africa or Asia	26	NA[5]	
Generation			
First	93	NA[5]	
Second	7	NA[5]	
Age			
18-64	53	15	0.00
65-79	27	33	
80+	20	52	
Sex			
Male	54	47	0.02
Female	46	53	
Marital status			
Married	48	42	0.06
Unmarried	52	58	
Cause of death			
Cancer	31	36	0.00
Circulatory disease	25	25	
Pulmonary disease	6.5	12	
Diseases of the nervous system	1.5	3.0	
Other / unknown	35	23	
Place of death			
Hospital	59	32	0.00
Nursing home	18	30	
Home for the elderly	3.7	11	
Home	16	23	
Other	2.7	3.4	
Presence of symptoms			
Severe pain[6]	19	21	0.44
Severe dyspnoea[6]	28	32	0.17

[1] Weighted percentages, unweighted absolute numbers.
[2] Western migrants were included in the native Dutch group.
[3] χ^2-test.
[4] Persons from Surinam are diverse in itself and originate from West Africa, India, Java, China and persons of mixed origin.
[5] NA = not applicable.
[6] Score 4 or 5 on a scale of 1 (symptom not present) to 5 (symptom strongly present despite treatment) during the last 24 hours before death. Symptoms were missing from 7.4% up to 8.1% of all non-sudden deaths.

Table 7.2. End-of-life practices among non-sudden deaths: non-western migrants versus Dutch natives.[1]

Number of studied deaths	**Non-western migrants** n=307		**Dutch natives**[2] n=3476		**Unadjusted**		**Adjusted**	
	%	n	%	n	Odds ratio[3]	p-value	Odds ratio[4]	p-value
End-of life practices:								
Euthanasia and physician-assisted suicide	2.4	9	2.7	301	0.89	0.76	0.82	0.63
Ending of life without an explicit patient request	0.2	1	0.5	15	0.47	0.52	0.20	0.18
Forgoing potentially life-prolonging treatment	26	71	23	642	1.2	0.23	1.1	0.73
Alleviation of symptoms with a potentially life-shortening effect	30	99	38	1351	0.70	0.01	0.78	0.07
Continuous deep sedation[5]	14	42	12	449	1.2	0.26	0.93	0.67

[1] Weighted percentages, unweighted absolute numbers.
[2] Western migrants were included in the native Dutch group.
[3] Univariate regression analysis, likelihood that an end-of-life decision concerned non-western migrants.
[4] Multivariate logistic regression analysis, likelihood that an end-of-life decision concerned non-western migrants after adjusting for differences in age, sex, and cause of death.
[5] Continuous deep sedation may have been provided together with end-of-life decisions.

Decision-making characteristics

Treatments were less frequently withheld in non-western migrants (12%) than in the native Dutch (15%), but more frequently withdrawn (20% vs. 12%) (data not in table). The types of treatment forgone varied between the two groups (**Table 7.3**). Artificial respiration (38% vs. 16%, adjusted odds ratio=1.8, p=0.04) and cardiovascular medication (30% vs. 11%, adjusted odds ratio=2.8, p=0.00) were more often forgone in the non-western migrant group. Artificial nutrition or hydration on the other hand, were less often forgone in non-western migrants (12% vs. 28%, adjusted odds ratio=0.40, p=0.02).

Table 7.3 Type of treatment withheld or withdrawn: non-western migrants versus Dutch natives.[1]

Number of studied deaths	**Non-western migrant** n=71		**Dutch natives**[2] n=642		**Unadjusted**		**Adjusted**	
	%	n	%	n	Odds ratio[3]	p-value	Odds ratio[4]	p-value
Artificial respiration	38	26	16	86	3.3	0.00	1.8	0.04
Cardiopulmonary resuscitation	5.6	4	4.4	23	1.3	0.66	1.5	0.52
Cardiovascular medication	30	21	11	59	3.5	0.00	2.8	0.00
Antibiotics	7.9	6	15	80	0.49	0.12	0.78	0.61
Other medication	18	13	18	124	0.97	0.92	1.4	0.36
Surgery	6.3	4	7.4	45	0.86	0.77	0.67	0.46
Oncotherapy	0	0	3.1	35	-	-	-	-
Renal dialysis	11	7	3.6	20	3.2	0.01	1.9	0.20
Hospital admission /diagnostics	5.2	4	11	71	0.43	0.13	0.59	0.36
Artificial nutrition or hydration	12	10	28	181	0.36	0.01	0.40	0.02

[1] Weighted percentages, unweighted absolute numbers.
[2] Western migrants were included in the native Dutch group.
[3] Univariate regression analysis, likelihood that the decision to forgo potentially life-prolonging treatment concerned non-western migrants.
[4] Multivariate logistic regression analysis, likelihood that the decision to forgo potentially life-prolonging treatment concerned non-western migrants after adjusting for differences in age, sex, and cause of death.

In both groups, the most important reason to forgo treatment was the absence of perspectives of improvement. This percentage was, however, significantly higher in the non-western migrant group (83% vs. 71%) (**Table 7.4**). Physicians less frequently indicated that the patient's or family's request were the most important reasons for their decision for non-western migrants (3.4% and 3.8%) than for Dutch natives (25% and 18%). These differences were found for both competent and incompetent patients. An estimated shortening of life due to the forgoing of treatment of > week was reported less often for non-western migrants than for Dutch natives (5.9% vs. 14%). Alleviation of symptoms that potentially hastened death had the same characteristics in both groups: physicians had usually administered morphine, sometimes combined with benzodiazepines (data not in table). Physicians' most important reasons for their decision were in both groups the presence of severe pain (52% and 48% in non-western migrants and Dutch natives, respectively) and severe other symptoms of the patient (42% vs. 42%) (Table 7.4). The estimated shortening of life due to the alleviation of symptoms did not significantly differ between the two groups: life shortening of > week occurred in 4.6% (non-western migrants) and 3.0% (Dutch natives) of all cases.

Table 7.4 Physician's most important reason to make an end-of-life decision and the estimated life shortening: non-western migrants versus Dutch natives.[1,2]

	FORGOING TREATMENT		ALLEVIATION OF PAIN AND SYMPTOMS	
	Non-western migrants n=71 %	**Dutch natives**[3] n=642 %	**Non-western migrants** n=99 %	**Dutch natives**[3] n=1351 %
Most important reasons for the decision[5]				
Severe pain	7.4	10	52	48
Severe symptoms	21	23	42	42
Loss of dignity	9.3	11	4.2	7.7
Patient's request	3.4[4]	25[4]	7.8	13
Family's request	3.8[4]	18[4]	8.6	9.9
Expected suffering of the patient	19	28	18	19
No perspectives of improvement	83[4]	71[4]	43	41
Other treatment too burdensome	12[4]	23[4]	10.6	9.3
Estimated life shortening				
< week	83	73	84	81
> week	5.9	14	4.6	3.0
Unknown	11	14	12	16
	χ^2 (p=0.04)		χ^2 (p=0.63)	

[1] Weighted percentages, unweighted absolute numbers.
[2] The most important reasons to perform euthanasia are not included because of the small number of cases.
[3] Western migrants were included in the native Dutch group.
[4] χ^2-test ($p<0.05$).
[5] More than one answer possible.

Competence

In general, non-western migrants for whom an end-of-life decision was made were siginificantly more often considered incompetent than Dutch natives (60% vs. 45%) (**Table 7.5**). If patients were competent, physicians frequently discussed the decision with patients themselves in both non-western migrants (85%) and Dutch natives (83%). For non-western migrants, physicians more often mentioned that decisions were not discussed with the competent patient because they thought that the decision was evidently the best choice (39% vs. 25%). If patients were incompetent, 4.5% of the non-western migrants and 17% of the Dutch natives had expressed a wish to hasten their end of life in an earlier stage of their disease. For non-western migrants, incompetent patients more frequently died in hospital (67% vs. 37%) where an estimated life shortening of < week was reported for > 90% of the cases.

In general, physicians more frequently discussed decisions with other physicians when non-western migrants (57%) instead of Dutch natives (37%) were involved.

Table 7.5 Competence of patients for whom an end-of-life decision had been made and physician's discussion: non-western migrants versus Dutch natives.[1]

	Non-western migrants n=180 %	**Dutch natives**[2] n=2309 %
Patient was competent (95% CI)	27 (22-34)	35 (33-36)
Patient ever expressed wish to hasten death[3]	-	8.0
Discussed with patient[3]	85	83
Discussed with relatives[3]	63	65
Not discussed with patient nor relatives	11	12
Patient was incompetent (95% CI)	60 (52-66)	45 (43-48)
Patient ever expressed wish to hasten death[3]	4.5	17
Discussed with patient[3]	31	22
Discussed with relatives[3]	71	71
Not discussed with patient nor relatives	17	24
Competence unknown (95% CI)	13 (8.9-18)	20 (18-22)
Discussion with other caregivers[3]		
Other physician	57	37
Nursing staff	39	34
No discussion with other caregivers	24	33

[1] Weighted percentages, unweighted absolute numbers.
[2] Western migrants were included in the native Dutch group.
[3] More than one answer possible.

7.4 Discussion

Medical end-of-life decisions were made for a substantial percentage of deceased persons of both non-western and Dutch origin. Euthanasia, continuous deep sedation and forgoing potentially life-prolonging treatment were practiced in comparable rates, whereas the incidence of intensive symptom alleviation tended to be lower in people of non-western origin.

The high response rate, the endorsement of the study by authoritative medical bodies, and the guarantee of anonymity of patients and physicians strengthen the validity and reliability of our results. However, our study has some restrictions too. First, we only studied the physician perspective. Second, we were not able to distinguish in migrants' religions. As a result, it is likely that we missed some additional differentiation given the variety in attitudes in end-of-life practices across religious and non-religious groups.[19] Another potential restriction has to do with the absence of information on duration of residence. Migrants who have lived in the Netherlands for a long time may be more comparable with the native Dutch population than migrants who arrived more recently. However, it is probable that most migrants for whom end-of-life decisions were made had

lived in the Netherlands for quite a period, because end-of-life decisions are generally taken in the elderly, first-generation population. Finally, the absolute number of end-of-life practices and decision-making characteristics for non-western migrants was too small to be able to give the percentages for each country separately. This study on end-of-life practices provides a good starting point for discussion on migrant's attitudes and wishes towards the end of life. Future studies, reflecting the views of other health care providers and/or family would increase our understanding of end-of-life decision-making in the non-western migrant population.

The different age structure of the non-western migrant population is the main cause of the relatively high number of deaths at a young age in this group.[1] The younger age at death is a reasonable explanatory factor for the higher prevalence of sudden deaths, which probably mainly included deaths caused by traffic accidents. The variety in incidence rates for specific diseases might be explained by the younger age as well, or, by different genetic or life style factors in people from non-western origin.[7 20]

Euthanasia

In this study we found no significant differences in the occurrence of euthanasia between non-western migrants and Dutch natives, although euthanasia is deemed unacceptable in different religious doctrines[16 17] and euthanasia acceptance is quite low in the countries of origin of non-western migrants (e.g. Turkey).[19] Apparently, non-western migrants in the Netherlands are relatively open towards euthanasia, possibly as a result of the continuous medical and public discussions that eventually resulted in the adoption of the Euthanasia Act (2002). Legalization of euthanasia is a topic of debate in many countries[21 22] and secularization still proceeds in many western European countries.[23 24] Such developments might be correlated with an increased acceptance of euthanasia among non-western migrants as well.

Intensified alleviation of symptoms

The percentage of the alleviation of symptoms with a potential life-shortening effect was significantly lower in non-western migrants. A previous study showed that percentages of the alleviation of pain and symptoms were rather similar across six European countries with various cultural backgrounds.[13] The lower frequency of the alleviation of symptoms with a potential life-shortening effect seems to be in conflict with the finding that physicians reported equal rates of severe pain and dyspnoea in the two groups. One explanation for the lower rate of alleviation of symptoms might be related to the possibility that patients' needs at the end of life are different due to cultural variances: many Turkish people for example believe that a certain extent of suffering should be part of life.[25] The relative importance of physical health as compared to eternal salvation plays an important role in several religions. Another possibility is that physicians themselves did not understand the patients' needs due to cultural misunderstandings or language barriers.[26] Intuitively, physicians might have avoided decisions that possibly hastened death, assuming that non-western migrants prefer less medical involvement in the dying process. However, the fact that euthanasia was performed in comparable rates suggests that this assumption may not always be true. It is not likely that financial motives are related to the observed differences, because nearly all health care costs are covered by either mandatory private health insurance or public financing in the Netherlands. Whether the disparities reflect some form of undertreatment cannot be shown with these data.

However, there are no indications that this is related to some explicit form of discrimination.

Forgoing potentially life-prolonging treatment

The frequency of forgoing potentially life-prolonging treatment did not significantly differ between the two groups. However, among non-western migrants treatments were less frequently withheld than withdrawn (12% and 20%) and the estimated degree to which life was shortened was clearly less, which might indicate that non-western migrants were treated later in the course of their disease. Possibly, physicians were more hesitant to stop life-prolonging treatment unless death was clearly inevitable and/or treating would be medically futile. The significantly higher frequency of 'no perspectives of improvement' as physicians' most important reason to forgo treatment supports this assumption. Further, in non-western migrants the type of treatments forgone more frequently concerned high- instead of low-technology interventions: artificial respiration, renal dialysis and cardiovascular medication were more frequently forgone, whereas the frequency of forgoing artificial nutrition or hydration was much lower. These findings are in line with the traditional religious viewpoints that exist in the migrant's countries of origin: high technology treatment is easier perceived as disproportionate and therefore forgoing them is sometimes permitted, whereas administering food and fluids is often considered as a form of basic care that should not be denied to anyone. This perspective is deeply rooted in cultural beliefs.[16 17 27]

Cultural aspects in end-of-life decision-making

In our study, non-western migrants were relatively often considered to be incompetent. Non-western migrants most frequently died in hospital, where the number of incompetent patients is relatively high in general. Probably, patients dying in hospital are more often incompetent to participate in the decision-making due to the fact that the attending clinical specialists have their first encounter with patients relatively late in the course of illness. General practitioners, typically know their patients much longer and have much more opportunity to discuss issues concerning end-of-life care and end-of-life decision-making. Language barriers and not understanding patients' preferences might be an explanatory factor as well.[26] As compared to native Dutch patients, end-of-life decisions for non-western migrants were rarely the result of the patient's or the family's expressed wishes. Possibly, non-western migrants are not used to or do not want to express such wishes, either because they just prefer a more natural death or because they trust their physician to make the right decisions. Dutch physicians sometimes seem to have a more paternalistic attitude towards non-western migrants; since they more frequently said not to have discussed their decision with competent non-western patients because it was 'simply the best for the patient'. A couple of studies performed in Turkey found comparable reasons for not disclosing a severe diagnosis to the patient.[25 28] However, although we have no insight in the quality of the communication, decisions were discussed with the large majority of both competent non-western migrants and Dutch natives, which is typical for the Dutch open culture towards end-of-life decision-making.[29]

The comparable incidence rates and the differences in the decision-making characteristics, could be the result of acculturation. This is in line with the results of a cross-cultural survey in which the attitudes and desires concerning end-of-life issues of Japanese Americans, Japanese-speaking Americans and Japanese living in Japan were

compared. It showed that attitudes of Japanese Americans shifted toward western values while at the same time some traditional Japanese values retained that influenced the end-of-life decision-making.[30]

Conclusion

The incidence rates of medical end-of-life decisions for non-western migrants and Dutch natives were rather similar, even in case of euthanasia. Yet, compared to Dutch natives, non-western migrants somewhat less often received intensive symptom alleviation with hastening of death as a potential result, and forgoing potentially life-prolonging treatment involved different underlying characteristics. On the one hand, it seems that migrants' confrontation with western individualistic thinking and life style could have resulted in a more liberal attitude towards end-of life decision making as compared to their country of origin. On the other hand, our results indicate that cultural issues may indeed play a role in medical end-of-life decision-making, and that adequate patient-centred end-of-life care should include the consideration of cultural aspects.

KEY POINTS

What is already known on this subject?

- Non-western migrants' actual and perceived health is generally worse as compared to the native Dutch.
- Qualitative studies examining aspects of end-of-life care describe the importance of the original religion or culture held by patients and families from different ethnic backgrounds.

What this study adds?

- This is a first quantitative overview of end-of-life practices in the Netherlands for non-western migrants and Dutch natives.
- Incidence rates of end-of-life practices are largely similar in both groups implying that migrants' confrontation with western individualistic thinking and life style may result in a more liberal attitude towards end-of life decision making.
- The underlying characteristics of end-of-life practices varied, which points out that adequate patient-centred end-of-life care should include the consideration of cultural aspects.

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8

Forgoing artificial nutrition or hydration in six European countries

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Abstract

Whether or not artificial nutrition or hydration (ANH) may be forgone in terminally ill patients has been the subject of medical and ethical discussions. Information about the frequency and background characteristics of making decisions to forgo ANH is generally limited to specific clinical settings. The aim of this study was to compare the practice of forgoing ANH in six European countries: Belgium, Denmark, Italy, the Netherlands, Sweden, and Switzerland. In each country, random samples were drawn from death registries. Subsequently, the reporting physician received a questionnaire about the medical decisions that preceded the patient's death. The total number of deaths studied was 20,480. The percentage of all deaths that were preceded by a decision to forgo ANH varied from 2.6% in Italy to 10.9% in the Netherlands. In most countries, decisions to forgo ANH were more frequently made for female patients, patients aged 80 years or older, and for patients who died of a malignancy or disease of the nervous system (including dementia). Of patients in whom ANH was forgone, 67-93% were incompetent. Patients in whom ANH was forgone did not receive more potentially life-shortening drugs to relieve symptoms than other patients for whom other end-of-life decisions had been made. Decisions to forgo ANH are made in a substantial percentage of terminally ill patients. Providing all patients who are in the terminal stage of a lethal disease with ANH does not seem to be a widely accepted standard among physicians in Western Europe.

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8.1 Introduction

In patients nearing death, decisions to withhold or withdraw potentially life-prolonging treatments are frequently made.[1-4] If possible, such decisions are often discussed with the patient concerned, but they also frequently relate to incompetent patients. The treatments that are withheld or withdrawn may include high technology interventions such as dialysis or surgery, but may also concern more basal treatments such as the artificial administration of nutrition or hydration (ANH).[5]

The question of whether stopping such basal care is ever justifiable has induced stirring medical and ethical discussions within several countries.[6-10] Several arguments are given. One argument for providing ANH in every case of possible dehydration or malnutrition is that it is a form of basic care that should not be denied to anyone. This perspective is deeply rooted in cultural and religious beliefs.[11 12] On the other hand it is argued that even basic care can become disproportional under special circumstances, such as in terminally ill patients with severe dementia.[13-15] At present, it is not clear what these circumstances are and whether physicians in different European countries agree on when ANH becomes disproportional care.

It has also been claimed that forgoing ANH is wrong because dying from thirst and hunger is inhumane. However, no clear evidence has been found that forgoing ANH causes discomfort in patients who are in their last phase of life and have no more feelings of hunger or thirst.[16 17] Additionally, several studies have shown, that in both terminally ill patients and patients with advanced dementia ANH not only failed to provide any benefit, but also brought along complications, such as infections, aspiration and fluid overload.[18-20]

Empirical studies on the practice of forgoing ANH in terminally ill patients are often limited to specific clinical settings or countries.[16 17 21] More insight in this practice in different settings and cultures would contribute to the debate on whether and when providing ANH to severely ill patients should be regarded as disproportionate care. This article aims to provide insight in the practice of forgoing ANH, and whether or not there are indications of extra suffering of these patients compared to other patients, in six countries in Western Europe: Belgium, Denmark, Italy, the Netherlands, Sweden, and Switzerland. We tried to answer the following questions: (1) In these countries, what is the percentage of people in whom death is preceded by a decision to forgo ANH?, (2) What are the characteristics of these patients and what is the decision-making process?, and (3) Do these patients receive more drugs to relieve symptoms in potentially life-shortening dosages during the dying phase as compared to other patients?

8.2 Methods

Study design and data collection

In Belgium (Flanders), Denmark, the Netherlands, Sweden, and Switzerland (German speaking part) we obtained random samples of death certificates of deceased persons aged one year or older from death registries to which all deaths are reported. In Italy

(Emilia-Romagna, Trento, Tuscany, and Veneto), only deaths of persons older than 18 years were included. More details about the sampling procedure for this study have been published elsewhere.[2] All deaths occurred between June 2001 and February 2002.
We guaranteed strict anonymity for the responding physicians; the questionnaires were only opened after all identifying information had been removed. Ethics committees in Belgium, Italy and Sweden approved this study. In Denmark such approval was not necessary for observational research; in Switzerland, the cantonal authority for data security confirmed anonymity of the data used in the study, and in the Netherlands the Royal Dutch Medical Association and the Health Inspectorate approved the study.

Questionnaire
Physicians, who had signed one of the death certificates in the samples, were asked to fill out a four-page questionnaire about the medical decisions that had preceded the patient's death. The questionnaire consisted of 26 questions. Key questions were whether the physician had made end-of-life decisions (ELDs), such as withholding or withdrawing possible life-prolonging medical treatments, or administering possibly life-shortening drugs to alleviate symptoms. If such ELDs had been made, the physician was asked to specify which treatment was forgone or which drugs had been given.

The physician was also asked to detail the decision-making process and to judge the patient's competence, that is, the patient's ability to assess his or her situation and to decide adequately. When more than one ELD had been made, these answers were given with respect to the decision that had been made with the most explicit intention concerning hastening of death.

Analyses
Questionnaire response percentages were 59% for Belgium, 62% for Denmark, 44% for Italy, 61% for Sweden, 67% for Switzerland and 75% for the Netherlands. The total number of deaths studied was 20,480 (2). The results were made representative of all deaths in each country during the period studied by weighting the data for stratification (if applicable) and (where possible) for response by sex, age, place and cause of death.

We calculated 95% confidence intervals to assess the accuracy of the estimates of the occurrence of decisions to forgo ANH. Furthermore, χ^2tests were applied to assess the significance of differences in the use of symptom-alleviating drugs in potentially life-shortening dosages between two groups of patients in whom death was preceded by end-of-life decision-making: patients in whom ANH was forgone (possibly in combination with other ELDs) and patients for whom other ELDs had been made. A multiple logistic regression analysis was conducted to assess the association between the patients' age, sex, place- and cause of death with the occurrence of decisions to forgo ANH for each country separately and for all countries together. In the analysis for all countries together, we used an additional country-specific weighting factor to ensure that all countries were equally weighted. Statistical analyses were performed using the Statistical Package for Social Sciences 11.0 (SPSS Inc, Chigago, III).

Role of the funding sources
The sponsors approved the study design but were not involved in the collection, analysis, or interpretation of the data or in the decision to submit the manuscript for publication.

8.3 Results

The percentage of deaths that were preceded by decisions to withhold or withdraw possibly life-prolonging treatments varied between 6.3% in Italy and 41% in Switzerland (**Table 8.1**). A decision to forgo ANH was made least often in Italy (2.6% of all deaths) and most often in Switzerland (9.9%) and the Netherlands (10.9%). In all countries, ANH was more frequently withheld than withdrawn; this held especially for Switzerland (8.5% and 1.7%, respectively).

Table 8.1 Frequencies of the decision to forgo artificial nutrition or hydration (ANH) in 6 European countries.

	COUNTRY					
	Belgium	**Denmark**	**Italy**	**Netherlands**	**Sweden**	**Switzerland**
Number of studied deaths	n=2950 %[1]	n=2939 %[1]	n=2604 %[1]	n= 5384 %[1]	n=3248 %[1]	n=3355 %[1]
Sudden death	34	33	29	33	30	32
Non sudden death, no ELD[2]	27	26	48	23	34	17
Non sudden death, ELD	38	41	23	44	36	51
Treatment forgone [3,4]	27	23	6.3	30	22	41
ANH forgone[3]	7.2	4.7	2.6	10.9	7.0	9.9
(95 % CI)	(6.4 8.2)	(4.0-5.6)	(2.1-3.3)	(10.1-11.8)	(6.2-8.0)	(8.9-10.9)
ANH withheld[3]	5.6	3.2	1.6	8.1	5.5	8.5
(95 % CI)	(4.8-6.5)	(2.6-3.9)	(1.2-2.2)	(7.4-8.8)	(4.8-6.4)	(7.6-9.5)
ANH withdrawn[3]	2.3	1.7	1.2	3.4	2.3	1.7
(95 % CI)	(1.8-2.9)	(1.3-2.2)	(0.8-1.7)	(2.9-3.9)	(1.8-2.9)	(1.3-2.2)

[1] Weighted percentages.

[2] End-of-life decisions (ELDs) include: Forgoing treatment and use of drugs in (potentially) life-shortening dosages.

[3] Whether or not combined with other ELDs.

[4] 'Forgone' indicates withheld or withdrawn.

ANH had been forgone in patients in all age groups, but most often in patients who were 80 years or older; percentages for this age group ranged from 1.5% in Italy up to 6.7% in the Netherlands (**Table 8.2**).

Table 8.2 Determinants of forgoing artificial nutrition or hydration (ANH) in 6 European countries.

	COUNTRY											
	Belgium		**Denmark**		**Italy**		**Netherlands**		**Sweden**		**Switzerland**	
Studied deaths	n=2950		n=2939		n=2604		n=5384		n=3248		n= 3355	
	%[1]	OR (95% CI)[2]	%[1]	OR (95% CI)[2]	%[1]	OR (95% CI)[2]	%[1]	OR (95% CI)[2]	%[1]	OR (95% CI)[2]	%[1]	OR (95% CI)[2]
Age range[3]												
1-64	0.9	1	0.5	1	0.3	1	0.9	1	0.6	1	1.0	1
65-79	2.2	1.1 (0.7-1.8)	1.5	1.6 (0.9-2.9)	0.8	1.2 (0.5-2.7)	3.3	2.4 (1.7-3.3)	2.0	1.5 (0.9-2.6)	2.3	1.4 (0.9-2.1)
80+	4.2	1.5 (1.0-2.4)	2.7	2.2 (1.2-3.9)	1.5	1.6 (0.7-3.6)	6.7	3.1 (2.2-4.2)	4.5	2.0 (1.2-3.4)	6.6	2.3 (1.6-3.5)
Sex[4]												
Male	2.8	1	1.9	1	1.2	1	3.9	1	2.9	1	4.0	1
Female	4.5	1.6 (1.2-2.2)	2.9	1.3 (0.9-1.9)	1.4	1.1 (0.7-1.8)	7.1	1.4 (1.2-1.7)	4.2	1.3 (1.0-1.8)	5.9	1.2 (1.0-1.6)
Place of death[5]												
Hospital	2.7	1	1.6	1	1.0	1	2.4	1	3.5	1	2.9	1
Other places	4.5	1.8 (1.3-2.4)	3.1	1.1 (0.8-1.7)	1.6	1.4 (0.9-2.4)	8.6	1.7 (1.4-2.1)	3.5	0.7 (0.5-0.9)	6.9	1.5 (1.2-2.0)
Cause of death[6,7]												
Cardiovascular	1.0	1	1.0	1	0.4	1	0.8	1	2.6	1	2.1	1
Malignancy	2.7	4.3 (2.8-6.7)	1.6	1.8 (1.1-2.8)	1.4	4.4 (2.2-8.9)	2.5	3.7 (2.5-5.3)	2.2	1.9 (1.3-2.6)	2.9	2.9 (2.1-4.0)
Respiratory	0.6	2.2 (1.2-3.9)	0.3	0.7 (0.3-1.4)	0.1	1.0 (0.2-4.6)	1.0	4.0 (2.6-6.1)	0.3	1.3 (0.6-2.7)	0.7	1.6 (1.0-2.7)
Nervous system[8]	1.7	5.5 (3.4-8.8)	0.9	2.2 (1.3-3.8)	0.2	9.2 (2.9-29.2)	2.1	8.0 (5.5-11.7)	0.2	5.2 (2.0-13.9)	2.6	5.1 (3.6-7.3)
Other	1.2	1.7 (1.0-2.9)	0.9	1.0 (0.6-1.7)	0.6	3.1 (1.4-6.8)	4.5	6.4 (4.5-9.0)	1.8	2.3 (1.6-3.4)	1.6	1.6 (1.1-2.3)

[1] Weighted percentages; percentage of patients in whom ANH had been forgone.
[2] Odds ratio, determined using multiple logistic regression analysis.
[3] In 132 cases, information on age was missing.
[4] In 133 cases, information on sex was missing.
[5] In 73 cases, information on place of death was missing.
[6] In 38 cases, information on cause of death was missing.
[7] Cerebrovascular disease is included in cardiovascular diseases for Italy and Sweden and in diseases of the nervous system for Belgium, Denmark, the Netherlands, and Switzerland.
[8] Including dementia.

In all countries, percentages of forgoing ANH were higher among female patients compared to male patients. This was particularly the case in Belgium (4.5%), Switzerland (5.9%) and the Netherlands (7.1%). A decision to forgo ANH was most frequently made for patients who died in other places than the hospital, except for Sweden. In Denmark, the Netherlands, Sweden and Switzerland where place of death could be further distinguished, ANH was most often forgone in nursing homes or homes for the elderly (2.1% in Denmark up to 5.6% of all deaths in the Netherlands). Decisions to forgo ANH were made relatively often for patients who died from a malignancy or a disease of the nervous system. Further, multiple logistic regression showed that older age (odds ratio (OR) = 1.54 to 3.06), being female (OR = 1.08 to 1.79) and death from a disease of the nervous system (OR = 2.18 to 9.24) all significantly contributed to the likelihood of forgoing ANH. Multiple logistic regression analysis for all countries together showed that country as a separate determinant was also significantly associated with forgoing ANH, with relatively high ORs for Sweden (OR=3.03, with Italy as reference country), Switzerland (OR = 3.71) and the Netherlands (OR = 3.88). Physicians estimated that the decision to forgo ANH (possibly in combination with other types of treatments) had shortened patient's life with less than one week in 72% (the Netherlands) to 91% (Italy) of the cases (**Table 8.3**). The estimated degree of life shortening was rarely more than one month, except for the Netherlands (10%) where shortening of life by more than one month mainly concerned patients in nursing homes or homes for the elderly (76%).

Table 8.3 Estimated life shortening in patients in whom artificial nutrition or hydration (ANH) was forgone in 6 European countries.

	COUNTRY					
	Belgium	**Denmark**	**Italy**	**Netherlands**	**Sweden**	**Switzerland**
Number of studied deaths[1]	n=131 %[2]	n=88 %[2]	n=48 %[2]	n=465 %[2]	n=189 %[2]	n=233 %[2]
Estimated life shortening[3]						
Less than 1 week	78	87	91	72	91	83
1 week to 1 month	18	9.0	7.2	18	9.1	11
More than 1 month	3.6	3.6	1.3	10	0.3	5.6

[1] Only concerns patients for whom a decision to forgo ANH had been made (possibly combined with other treatments forgone).

[2] Weighted percentages.

[3] In 46 cases, information on estimated life shortening was missing.

Decisions to forgo ANH most frequently involved incompetent patients: percentages ranged from about 67% of all cases in Denmark and Switzerland, to 73% in the Netherlands, and 84% or over in Sweden, Belgium and Italy (**Table 8.4**).

Table 8.4 Competence of patients and physician's discussion about the decision to forgo artificial nutrition or hydration (ANH).

	COUNTRY					
	Belgium	**Denmark**	**Italy**	**Netherlands**	**Sweden**	**Switzerland**
Studied deaths[1]	n=131	n=88	n=48	n=465	n=189	n=233
	%[2]	%[2]	%[2]	%[2]	%[2]	%[2]
DISCUSSION WITH PATIENT AND RELATIVES						
Patient was competent	16	33	7.3	27	15	33
(95% CI)[3]	(10-23)	(24-45)	(3.2-21)	(23-31)	(10-21)	(27-39)
Discussed with patient	4.0	31	-	17	17	19
Discussed with patient and relatives	55	60	100	79	50	69
Not discussed with patient, but with relatives	21	2.5	-	3.4	12	9.1
Not discussed with patient or relatives	20	6.3	-	0.6	21	2.7
Patient was incompetent	84	67	93	73	85	67
(95% CI)[3]	(77-90)	(55-76)	(79-97)	(69-77)	(79-90)	(61-73)
Discussed with patient	-	2.5	1.4	2.1	1	0.9
Discussed with patient and relatives	9.4	7.8	9.4	20	7	13
Not discussed with patient, but with relatives	74	64	67	71	56	61
Not discussed with patient or relatives	17	25	22	7.0	36	25
Discussion with other caregivers[4, 5]						
Other physician	29	33	37	43	28	30
Nursing staff	76	64	22	59	60	73
No discussion	18	19	49	19	34	14

[1] It only concerns patients for whom a decision to forgo ANH had been made (possibly combined with other treatments forgone).
[2] Weighted percentages.
[3] In 46 cases, information about the patients' competence was missing.
[4] Both competent and incompetent patients.
[5] One or more answers are possible.

If patients were competent, physicians had discussed the possible hastening of death as a result of the decision to forgo ANH most frequently with the patients themselves in Sweden, Denmark and the Netherlands, and least frequently in Belgium. In Belgium however, a relatively large number of competent patients with whom the decision was not discussed had, at an earlier stage expressed a wish to hasten their end of life (8%). The decision to forgo ANH was rarely discussed with incompetent patients themselves, except for the Netherlands. Of all incompetent patients with whom the decision was not discussed, 10% (Sweden) to 22% (Denmark, Switzerland) had, at an earlier stage expressed a wish to hasten their end of life. For incompetent patients, relatives were frequently involved in the decision-making process: percentages varied from 63% in Sweden to 83% in Belgium and 91% in the Netherlands. If patients were competent, discussion with relatives occurred in more than 62% the cases.

In all countries except Italy, nursing staff was more often involved in the decision-making process than other physicians. This held for both competent and incompetent patients. The percentage of patients for whom nursing staff was involved varied from 22% (Italy) to 76% (Belgium). In most countries the decision to forgo ANH was discussed with other physicians in about 30% of the patients, except for Italy (37%) and the Netherlands (43%). There was no discussion with nursing staff or other physicians in 14% of the patients in Switzerland up to 49% of the patients in Italy.

Forgoing ANH was combined with the administration of drugs to relieve symptoms in possibly life-shortening dosages in 52% (Italy) up to 67% (Belgium) of all cases (**Table 8.5**). Physicians had usually administered opioids (whether or not combined with other types of drugs) in these cases. In all countries, except Belgium, patients in whom ANH was forgone received significantly less drugs to relieve symptoms than other patients for whom other ELDs had been made.

Table 8.5. Decisions to forgo artificial nutrition or hydration (ANH) and use of drugs to relieve symptoms in potentially life-shortening dosages in 6 European countries.

	COUNTRY					
	Belgium	**Denmark**	**Italy**	**Netherlands**	**Sweden**	**Switzerland**
Number of studied deaths	n=2950 %[1]	n=2939 %[1]	n=2604 %[1]	n= 5384 %[1]	n=3248 %[1]	n=3355 %[1]
ANH forgone	**7.2** (n=252)	**4.7** (n=149)	**2.6** (n=89)	**11** (n=712)	**7.0** (n=264)	**9.9** (n=331)
Drug administered (95% CI)[2]	67 (61-73)	61[3] (53-69)	52[3] (41-62)	58[3] (55-62)	55[3] (48-61)	62[3] (57-68)
No drug administered (95% CI)	33 (27-39)	39 (31-47)	48 (38-59)	42 (38-46)	45 (39-52)	38 (32-43)
Other ELD[4]	**31** (n=1099	**36** (n=1206)	**21** (n=725)	**33** (n=2051	**29** (n=1063	**41** (n=1373)
Drug administered[5] (95% CI)	73 (70-75)	72[3] (69-75)	88[3] (85-91)	73[3] (70-75)	70[3] (67-73)	69[3] (67-72)
No drug administered (95% CI)	28 (25-30)	28 (25-31)	12 (9-15)	27 (25-30)	30 (27-33)	31 (28-33)
No ELD[4]	**62** (n=1599)	**59** (n=1584)	**77** (n=1790)	**57** (n=2542)	**65** (n= 1921)	**49** (n=1651)

[1] Weighted percentages.
[2] In 73 cases, information concerning the type of drug administered was missing (3.1% up to 7.8%).
[3] Difference in the administration of drugs between patients in whom ANH was forgone (whether or not combined with other ELDs) and other patients for whom another ELD had been made, χ^2 test, $p<0.05$.
[4] End-of-life decisions (ELDs) include: Forgoing treatment and use of drugs in (potentially) life-shortening dosages.
[5] In 1368 cases, information concerning the type of drug administered was missing (13% up to 33%).

8.4 Discussion

Our results show that decisions to forgo ANH were made in all countries that were included in this study, but that frequencies varied from 2.6% of all death cases in Italy to 11% in the Netherlands. In all countries ANH was more often withheld than withdrawn. This may in part be due to the fact that forgoing ANH may not always be perceived as explicitly refraining from potentially life-prolonging treatment. The frequency of withholding ANH is more likely to be affected by differences in physicians' awareness of their end-of-life decision making practices than the frequency of withdrawing ANH, since the latter is easier perceived as causing death.[22] However, the difference between all countries in the appreciation of withholding and withdrawing treatment could also be indicative of a real difference in occurrence, which would be consistent with other studies.[23 24]

The variation among countries in the occurrence of decisions to forgo ANH is in line with another study on end-of-life practices.[25] This variety could be reflective both of true differences in practice patterns among the six countries and of differences in reporting or self-perception from the same act. Here, we should bear in mind that the ideas about whether or not forgoing ANH had a potentially life-shortening effect may have varied between the countries as well. The independent effect of country in our study suggests that cultural factors may explain at least part of the variation. The relatively high

frequency in the Netherlands may be related to the Dutch open culture toward end-of-life decision-making. In the Netherlands, providing ANH to dying patients is often seen as disproportionate care; it is frequently considered to only prolong the dying phase and to postpone death.[7] Such a consideration might also explain the relatively high frequencies in the Netherlands of nursing home patients in whom the estimated degree of life shortening was more than one month. The particularly low percentage of forgoing ANH (2.6%) in Italy is in accordance with the low percentage of decisions to forgo any type of life-prolonging treatment in this country (6.3%). This could be related to the fact that Italy in particular has a strong Catholic tradition and a widespread acceptance of the idea that life is sacred and should be preserved at all costs. Pope John Paul II has pronounced the moral duty to administer ANH at all times in a speech at a congress in March 2004.[12]

Older age, being female, and death due to malignancies or diseases from the nervous system appeared to be the most important patient-related predictors of decisions to forgo ANH. Apparently providing ANH was, in all countries, more often regarded as disproportionate when patients were elderly. Higher frequencies of forgoing ANH in elderly patients may be explained by the fact that the patients involved were more seriously ill or had a relatively poor prognosis, and not by age discrimination per se, which has been reported for other end-of-life decisions also.[26] It is difficult to explain why the frequency of forgoing ANH (especially in Belgium and the Netherlands) was higher among deceased women, even after taking the effect of differences in age and cause of death between men and women into account. A potential explanatory factor might be that female patients have been found to be more inclined to strive for quality of life compared to male patients[27], and, therefore, might prefer to refrain from more weighty treatments like the provision of ANH. Another factor might be related to the fact that, at least in nursing homes, ANH is often provided at the request of the patient's family and spouse, and that women more often then men survive their partners.[28] In general, the most frequently reported causes of death in all countries for patients in whom ANH had been forgone were malignancies or diseases of the nervous system (including dementia). Apparently, life-prolonging treatments such as the provision of ANH are more often regarded as disproportionate in patients who suffer from such degenerating diseases. Literature shows that physicians frequently have to decide whether or not to administer ANH in patients with dementia who have difficulties with eating.[29 30] In this study, we could only use general disease categories, and as a result, we could not identify patients with dementia in particular.

Decisions not to administer ANH usually concerned incompetent patients (67% or higher), which has also been found in other studies.[21 31] In general, forgoing ANH typically involved a limited degree of life shortening and thus was predominantly decided in the very last phase of life. Consequently, it seems plausible that patients were often incompetent due to the progression of their disease. For incompetent patients, the attending physicians frequently involved both relatives and, to a somewhat less extent, other caregivers in the decision to forgo ANH. Thus, our results suggest that decisions to forgo ANH are typically based upon ideas and values about medical management in the last phase of life of incompetent patients that are discussed between caregivers and family. Forgoing ANH when there is dissention from family members, such as in a recent case in the US, are probably the exception to the rule.[32]

Only a minority of the patients was competent (8% - 33%) It is possible that in most of these patients feelings of hunger and thirst had disappeared partly or fully, which is a well-known phenomenon in case of serious illness or advanced age. However, a number of these patients may have intentionally refused to eat and drink, or to receive ANH, as a means to control their own process of dying.[33] Few patients have been reported to have made such a choice, but empirical research on this topic is rare.[34]

The percentage of patients who received drugs to relieve symptoms in possibly life-shortening dosages were not higher for patients in whom ANH was forgone as compared to patients in whom other ELD's had been made. This finding may be seen as an indication that forgoing ANH did not induce extra suffering. As such, it confirms the outcomes of other studies that specifically focused on the suffering of patients in whom ANH was forgone. For example, in a prospective, longitudinal observational study of 178 patients in Dutch nursing homes, Pasman *et al* found no difference in the level of discomfort of patients with dementia who barely ate or drank.[17] A prospective study in a comfort care unit showed similar results: terminally ill patients did not experience hunger and thirst and the administration of ANH played a minor role in the patient's comfort.[16]

Our study has some limitations. Non-response may have influenced our results, especially in Italy (response percentage: 44%). Furthermore, although the anonymity of the respondents was guaranteed, social desirable answers may have been given (that might vary from one country to the other). Finally, in case ANH was not the only type of treatment forgone, we were not able to distinguish characteristics of the decision-making between the different types of treatments that were forgone. However, it is probable that in many cases, decisions to refrain from several life-prolonging treatments were made simultaneously.[21]

In conclusion, a substantial number of deaths in six countries in Europe are preceded by decisions to forgo ANH. Such decisions usually involve a limited degree of shortening of life and are not likely to involve extra suffering for dying patients. Providing all patients who are in the terminal stage of a lethal or degenerating disease with ANH does not seem to be a widely accepted standard among physicians in Western Europe.

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9

Artificial nutrition and hydration for patients with advanced dementia: Perspectives from medical practitioners in the Netherlands and Australia

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Submitted

Abstract

It is sometimes difficult to decide about the use of artificial nutrition or hydration (ANH) for patients suffering from advanced dementia. A study in six European countries showed that the rate of forgoing ANH in patients nearing death is high, but significantly varies between countries. We investigated opinions of Dutch and Australian doctors about the use of ANH in patients with advanced dementia in a qualitative semi-structured interview design. We interviewed 15 Dutch doctors (14 nursing home physicians and one geriatrician) and 15 Australian doctors (9 general practitioners, 5 geriatricians and one palliative care specialist) who care for patients with advanced dementia in nursing homes, hospitals, and palliative care units (Australia only). We transcribed and analyzed the interviews with qualitative methodologies and held consensus meetings about the interpretation. Dutch and Australian doctors use similar medical considerations when they decide about the use of ANH. Their default approach is not to start ANH but both are willing to administer ANH in specific situations. Disparities between the Dutch and Australian doctors are related to the process of decision-making: Dutch doctors seem to put more emphasis on a comprehensive assessment of the patient's actual situation, whereas Australian doctors are more inclined to use scientific evidence and advance directives. Furthermore, Dutch doctors take the primary responsibility themselves whereas Australian general practitioners seem to be more inclined to leave the decision to the family. In conclusion, it seems that Dutch and Australian doctors use somewhat different care approaches for patients with advanced dementia. Combining the Dutch comprehensive approach and the Australian analytic approach may serve the interest of patients with advanced dementia and their families best.

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9.1 Introduction

The prevalence of dementia - a progressive illness with cognitive, functional, and physical decline – will increase substantially worldwide in the near future.[1] In the Netherlands, one in nine people die of dementia but this number is expected to grow in future.[2] Patients with advanced dementia commonly develop eating difficulties[3], and decreased feelings of hunger and thirst are often part of the dementia process.[4] Furthermore, they frequently develop acute diseases, such as pneumonia, which can be a terminal event for patients with advanced dementia.[5] With progressive dementia, patients become incompetent to make decisions.[6] In such situations, physicians and families may discuss whether artificial nutrition or hydration (ANH) is likely to be of any benefit for the patient.[7 8]

The artificial provision of artificial nutrition or hydration (ANH) is now widely accepted as medical treatment. However, some argue for ANH at all times because it is regarded as a form of basic care and not as a medical intervention.[9] Percutaneous endoscopic gastrostomy (PEG) tube feeding for patients with advanced dementia has given rise to controversy in several western countries.[10] Clinical evidence of beneficial effects of tube feeding for patients with advanced dementia is not available. It has been shown that its use sometimes results in complications such as aspiration pneumonia and fluid overload.[11-13] There is no clear evidence either that forgoing of ANH in patients with advanced dementia causes discomfort.[4 14]

Nursing home patients with dementia in the US are more likely to receive intravenous antibiotics, rehydration therapy and feeding tubes than Dutch patients as reported by other studies.[15 16] Administering ANH or antibiotics often seems to be the norm in the US.[5] This is in contrast to what is considered standard care for patients with advanced dementia in the Netherlands,[17] and other western countries such as Canada, [18] Belgium [19] and Australia,[20] where guidelines suggest that administering ANH is disproportionate care in dying or severely demented patients. A study in six European countries showed that the rate of forgoing ANH in patients nearing death is high, but significantly varies between countries.[21] Patient-related factors, such as age, gender and diagnosis appeared to be important predictors of forgoing ANH in all six countries. Each country has its own judicial system, social structure, history, religion and culture.[22] Differences between countries may thus be related to organizational, legal or cultural factors.

A deeper understanding of how physicians' perceptions affect their treatment choices will clarify whether decision-making in this area is culturally and / or medically determined. We conducted an exploratory study in two western countries: the Netherlands and Australia. We investigated how Dutch and Australian doctors decide about the use of ANH in patients with advanced dementia and under what circumstances its use is considered appropriate or inappropriate.

9.2 Methods

Participants
Eligible participants included medical practitioners who cared for patients with advanced dementia and who had at least three years of work experience. Initially, doctors were recruited through existing contacts in the field. A snowball technique was then used, in which contacted doctors were asked to identify doctors who had expertise in this area. Participants were purposively[23] sampled to represent a range in years of experience, gender, age, and setting (nursing home, hospital, palliative care unit). In the Netherlands, we recruited participants from smaller and larger cities; in Australia we recruited participants from smaller and larger cities in the state of New South Wales. In the Netherlands, we predominantly interviewed doctors trained in nursing home medicine (i.e. nursing home physicians), as they provide primary care for patients with advanced dementia. In Australia, such a specialty does not exist: general practitioners (GPs) and geriatricians take care of patients with advanced dementia and were the main target for recruitment. The ethics committees of the participating institutions had no objections to the study.

Data collection
Data for this study were collected between April to October 2008 through face-to-face interviews that lasted about 30 minutes (range: 20-60 minutes). We approached participants by telephone, mail or e-mail and the study aims and methods were explained by the principal investigator (HB). Further, every (potential) participant received an information sheet. If doctors were willing to participate an interview date was set. In total 15 Dutch and 16 Australian interviews were conducted by HB. We excluded one Australian interview because this doctor appeared to have insufficient experience with patients with advanced dementia.

Interview format
The interview guide consisted of two parts: (1) open-ended questions about doctors' general experiences with patients with advanced dementia, and (2) open-ended questions where doctors were asked to reflect on two actual cases of patients with advanced dementia, one in which ANH had been withheld and one in which ANH had been withdrawn. Each actual case needed to meet the following criteria at the time of the interview: the patient had died less than 5 years ago and had been incapable of expressing his or her own wishes (i.e. had been incompetent) at the time the decision about ANH was made. We did not use a specific definition of ANH but evaluated what the respondent actually meant when he or she spoke about ANH in each interview. We also obtained data about the doctor's background (demographics, religious beliefs, work experience).

Analysis
The interviews were conducted in Dutch in the Netherlands and in English in Australia. All interviews were audio-taped and transcribed verbatim. We removed information that could lead to identification of the doctor. After the third and sixth interview the content of the Dutch (HB, AH) and Australian (HB, PB, JC) interviews was discussed to see if any changes in the interview format were necessary. This appeared not to be the case. Data

analysis was informed by qualitative methodology.[24 25] We read through all the interviews to identify general themes and subsequently specific categories within the themes. We developed these categories further by comparing across transcripts. We met several times and reviewed the categories till consensus was reached. The themes were checked within and across transcripts and within and across countries. During meetings, the researchers worked towards consensus about the interpretation considering possible meanings. The primary researcher checked these interpretations with the existing data. All data were analyzed using qualitative research software (NVivo 8).[26]

9.3 Results

Participant characteristics

In the Netherlands, we interviewed 14 nursing-home physicians and one geriatrician (**Table 9.1**). Eight Dutch doctors declined to participate (all said they were too busy). In Australia we interviewed 5 geriatricians, 9 general practitioners and one palliative care specialist. One Australian doctor declined to participate because she did not want the interview to be recorded. The Dutch sample comprised doctors with an average age of 45 years; 7 were women. In the Australian sample the average age was 49; 6 doctors were women. Work experience of Dutch doctors varied, with 7 having less than 15 years experience and 6 having 15 to 20 years experience. Of the Australian doctors, 10 had more than 20 years of work experience. In both samples, about half of the doctors had a specific religious affiliation; most of these doctors said that their religious beliefs were important to them in their work.

Table 9.1 Physician characteristics.

	Netherlands n=15	**Australia** n=15
Mean age (+/- SD)	45 (10)	49 (6)
Sex		
Male	8	9
Female	7	6
Specialty		
Nursing home physician	14	-
Geriatrician	1	5
General practitioner	-	9
Palliative care specialist	-	1
Work experience		
< 15 years	7	2
15 -20 years	6	3
> 20 years	2	10
Working place		
Large city[1]	9	9
Small city[2]	6	6
Religion		
Christian	7	8
Other	3	1
Not religious	5	6

Table 9.1 Cont.	n=10	n=9
Importance of religious beliefs		
Important[3]	8	6
Less or not important	2	3

1. > 150.000 inhabitants.
2. < 150.000 inhabitants.
3. Religious beliefs were important in a sense that they indicated that these beliefs were part of who they were.

Our analysis of the interviews showed that the concept of (withholding and withdrawing) ANH was differently defined. Further, we identified 4 domains influencing doctors' decision-making for patients with advanced dementia: advance care planning, doctors' default position towards ANH, considerations concerning the use of ANH and doctors' responsibilities towards the patient.

What is artificial nutrition or hydration?

Artificial nutrition and hydration can have different meanings. For the Australian doctors, ANH was interpreted either broadly (including spoon feeding and hydration as well as tube feeding) or narrowly (tube feeding only). Australian doctors using the narrow definition associated artificial nutrition with burdensome interventions, whereas artificial hydration was regarded as an acceptable intervention that is often given together with antibiotics. Australian doctors (GPs) who applied the broad definition regarded all types of food and fluids that patients receive (because they are unable to take in adequate nutrition and hydration themselves) as some form of ANH. Most of the Dutch doctors regarded ANH as tube feeding and hydration that is administered subcutaneously or intravenously. Although Dutch doctors did not mention spoon feeding as a form of ANH, they indicated that spoon feeding is always offered if a patient with advanced dementia refuses to eat or drink.

But those [tube feeding] aren't the commonest forms of artificial feeding, that will be spoon feeding. […] Most families will say; we won't do it [tube feeding]. But if it's a question of just spoon feeding, they often say they will. Respondent 9, Australian GP.

So in the first instance we agreed we would no longer send in to the hospital, we'd offer food and drink and we'd see how it goes. Respondent 1, Dutch nursing home physician.

Australian doctors (mainly geriatricians) sometimes stated that they prefer not to speak about 'withholding or withdrawing ANH'. If, for instance, the patient's prospects of recovery are small and if the family agrees, it may be decided not to give ANH, in which case it is not regarded as 'withholding ANH' but as avoiding inappropriate care.

Quality of life and comfort is paramount. And so we may not institute tube feeding because it's inappropriate. It won't improve the patient's quality of life or prognosis, it won't do it. It's just not appropriate. That's not necessarily withholding treatment. That's not giving, that's not giving futile treatment. So I don't regard it as withholding treatment. Respondent 13, Australian geriatrician.

Advance planning of care

Doctors in both countries noted the benefits of advance care planning for ANH (and other medical treatment) but it was differently shaped for Australian and Dutch doctors. For the Australian doctors, advance care planning is often associated with written advance directives although these are not very often used in actual practice. Doctors who use such directives (mainly GPs) indicated that these directives bring up the discussion concerning ANH and that they guide the family and themselves in the decision-making, especially in difficult situations. Australian doctors in smaller cities had more experience regarding advance care planning than doctors in large cities, possibly because these doctors often work on an individual basis. Dutch doctors associated advance care planning with discussions with the family and (if possible) the patient. A few associated advance care planning with advance care directives, which they also seldom used. Although they said that they appreciated advance care directives in difficult situations, they generally found directives not specific enough, outdated and no replacement for the ongoing discussion and documentation of advance care planning.

I'm probably a little bit unusual that we actually do a lot of advance care planning with our patients and their families. I've actually been one of the GP's who is driving a big advance care planning project. Respondent 12, Australian GP (small city).

If people are admitted, people with dementia, fairly soon afterwards we have a talk, usually only with the family, sometimes with the people themselves present. And then artificial nutrition and hydration is always an item for discussion. Yes [….] it's always mentioned, yes. And it is actually more or less anticipated that it will be. Respondent 14, Dutch nursing home physician.

And then I think an advance directive, fine, that's OK up to a certain point, but if the family says yes but we are enjoying life with pa so much and I see that he's enjoying it too, then in that case I tend to be more active than the advance directive would seem to indicate. Yes. And I think that is totally justified. Respondent 4, Dutch nursing home physician.

Default position: not prescribing ANH to patients with advanced dementia

Dutch and Australian doctors were hesitant to provide ANH to patients with advanced dementia. Dementia is seen as a progressive deteriorating disease, and administering ANH as interfering with the dying process. Some of the Australian doctors referred to evidence in the literature indicating that ANH (especially PEG-feeding) for patients with advanced dementia does not contribute to the patient's quality of life. This argument was not used by Dutch doctors.

So I've explained to them [family] that many studies have shown that if we feed, PEG feed a person in poor condition we actually may create harm rather than good. Respondent 14, Australian GP.

Well, dementia in principle is a progressive deteriorating disease so for me that's often an argument for being cautious. Respondent 14, Dutch nursing home physician.

Dutch and Australian doctors further indicated that making decisions is often not that complicated, because in most patients with advanced dementia who are nearing death it is so obvious that ANH does not provide any benefit. Some Australian doctors said that the topic of ANH is sometimes not discussed with family because physicians do not consider it appropriate.

R: Did we discuss it as a topic? I: With the family? R: Not specifically, no. But her daughter said to me look, I know mum's dying; I just want her to be comfortable. That was really the discussion. Respondent 5, Australian GP.

Despite their reluctance to provide ANH, Dutch and Australian doctors indicated that they always try to interpret whether ANH may contribute to the patient's quality of life and whether it agrees with the patient's (presumed) wish. To arrive at a conclusion they also involve the family, other professional caregivers, and if possible the patient. Some Australian doctors commented that the involvement of nursing staff may complicate the decision in nursing homes, as nurses in Australian nursing homes are not always fluent in the English language (originating from Asian or other countries), or are more focussed on providing 'active' care.

I: Which factors generally influence your decision-making? R: I think particularly patient desire. But often with someone with severe dementia they can't actually speak for themselves. So it's only if they're voiced that to their families that we'll know what they thought. So it's actually the family or the Person Responsible that's making the decision on their behalf. Yeah and their comfort and quality of life I guess. Respondent 12, Australian GP.

Here there are quite a lot of nurses who can't accept not giving treatment. Respondent 9, Australian GP.

Australian GPs indicated they sometimes visit nursing home patients only occasionally and at nurses' request. As such, they do not always know their patients very well, and they cannot follow the patient's course of disease closely. Dutch nursing home physicians work in the nursing home at a daily base. They indicated that they have many opportunities to see their patients or to discuss patients' condition with nurses.

I went back a week or 10 days later. And unfortunately the nurses didn't call me at all and she was back to dehydrated again. Respondent 3, Australian GP.

The provision of ANH

In some situations Dutch and Australian doctors may be willing to provide ANH. For some doctors the distinction between active and palliative care was important. Providing antibiotics, intravenous fluids or nutrition is regarded as active care and palliative care is, in contrast, regarded as comfort care, which involves no provision of nutrition and fluids other than what patients spontaneously eat and drink, and administration of medications only when it is directed at comfort.

And there was initially an active policy because, of course, she was fairly young and had young children. And four or so years ago when the dementia had already advanced I agreed with the family that we would no longer pursue any active policy but a symptomatic one. And when it got to that stage, we would not resort to artificial nutrition and hydration. Respondent 12, Dutch nursing home physician.

Sometimes there is no need for discussion; if dehydration is the result of a sudden deterioration, and there is a reasonable prognosis (i.e. no end-stage dementia), Dutch and Australian doctors will provide ANH (mostly hydration) to improve the patient's condition.

We needed to feed her with a tube. There was no other option. And that's an acute treatment. It's not to prolong someone's life with advanced dementia, it was an acute intervention to save her life. Respondent 13, Australian geriatrician.

Sometimes Dutch and Australian doctors provide ANH as a means to sort things out. The patient's physical and emotional condition may go up and down or a very quick deterioration cannot be clearly explained. Doctors may then decide to support the patient for a short period of time to see whether the patient recovers and starts eating and drinking him- or herself again. Australian doctors seem to be more inclined to administer ANH in this particular situation than Dutch doctors.

I mean we're doing everything we can to see how much reversibility there is. And hopefully she will recover and return home. Respondent 1, Australian geriatrician.

But you might consider in the case of pneumonia, if it really is a short-term illness and you expect that someone can reasonably recover, it might be worth considering. But even then I'm very cautious. Respondent 6, Dutch nursing home physician.

Although doctors may have their own opinion on whether ANH is of likely medical benefit for the patient or not, Dutch and Australian doctors typically want to be sure that everyone involved is comfortable with the decision. Rejecting food or fluids, spitting it out, or pulling out tubes, are often considered as expressions of the patient being uncomfortable. Such behavior is sometimes also interpreted as expressions of a wish not to have such interventions anymore – especially by the Dutch doctors. Some doctors also indicated that they took into account the verbal expressions of the (incompetent) patient.

The thing is, if people actually say to me, doctor I want to go on living, I don't think its permissible not to treat them, that's impossible, you cannot do that, I mean they may be incompetent in the sense that they don't know that they have dementia, no longer have any grip on reality, but people often still know whether they want to live or not. Respondent 4, Dutch nursing home physician.

On the one hand, Dutch and Australian doctors indicated that the provision of ANH should not harm the patient. On the other hand, both Dutch and Australian doctors pointed out the important role of the family. They indicated that they are willing to administer ANH for a short period of time when families cannot cope with or accept not giving ANH.

So I try to explain all that [why it is unwise to give ANH] but then if they feel that it's [giving ANH] in line with the persons' wishes because they feel that it [not giving ANH] is euthanasia or physician assisted death or whatever… then we give them a trial of PEG feeding. Respondent 14, Australian GP.

That lasted about five days and on the sixth day pressure ulcers (bed sores) developed quite quickly and I thought, no now it's a complication and I'm going to stop. And the family agreed. Yes, in fact I did something that was not in my patient's interest, because in the end after all he got pressure sores, but anyway, I saw that I…. I encountered such resistance, so fierce, so emotional; I thought I can't manage with this. No. Respondent 12, Dutch nursing home physician.

Withholding and withdrawing ANH

Withholding and withdrawing ANH are sometimes seen as similar acts. This especially holds for the Australian doctors:

Well, really there is no difference. People perceive a difference but there is none. And what I say to people is, look even if you decide to go one way initially; you can change your mind. If you decide that we'll put down a naso-gastric tube or we'll ask the gastroenterologist to put a PEG-feed, feeding tube in…. they can be removed down the track. Respondent 1, Australian geriatrician.

Most of the Dutch and some of the Australian doctors saw important differences between withholding and withdrawing ANH: withdrawing ANH is emotionally much more burdensome. Some consider the withholding of ANH to be easier because they can be clear with the family about the patient's prospects. Some of them indicated that withholding is easier because the association with the patient's death is less concrete than in case of withdrawing treatment: it is emotionally more difficult to withdraw ANH, especially when it concerns nutrition administered via a PEG-tube or nasogastric tube. However, most doctors indicated that the latter is especially difficult for the family who often feel great responsibility for the patient and the patient's death. On the other hand, if it is explained to the family beforehand that the patient is to get ANH on a temporary basis, withdrawing ANH becomes less difficult.

Dr: Yes, withdrawing is emotionally more drastic. Yes. I: And why is that? Dr: Well, I suppose it's a bit like playing God. Yes. Yes. Respondent 12, Dutch nursing home physician.

Withholding or withdrawing – emotionally withdrawing is more burdensome, but since I myself always include the guarantee that if it doesn't work, we'll stop, I'm no so affected emotionally. Respondent 11, Dutch nursing home physician.

Doctors' (perceived) responsibilities across healthcare settings

Australian doctors seem to follow the family's wishes more than Dutch doctors: some of them indicated that their only role is to advise people and help the family make a decision. Others (geriatricians only) indicated that they are the ones ultimately responsible, which corresponds with the role most Dutch doctors ascribe to themselves.

I give people the options and then they can make their…own decisions. Respondent 5, Australian GP.

And that requires lots of talks, a lot of communication because I think as a doctor I am ultimately responsible and I don't want to carry out futile treatment. Respondent 1, Dutch nursing home physician.

In some cases patients with advanced dementia are referred to palliative care units in either private or public hospitals where palliative care specialists provide care. Palliative care specialists may also advise the GP or geriatrician, but these consultations mainly relate to pain and symptom management. GPs however seemed to be more inclined to consult a geriatrician than a palliative care specialist for patients with advanced dementia.

They are more in the nursing homes in consultation. There they would have dementia as a major factor. We'd probably get a um a dozen a year sort of seeing with patients in that setting. There's a lot of patients in the nursing home that have dementia but our role in the setting of that [i.e. if patients lie in a nursing home] is probably more about pain management or picking up heart failure problems or other health problems that are affecting them. Respondent 2, Australian palliative care specialist.

Furthermore, the doctor's responsibilities in large cities in Australia differ from those of doctors working in smaller cities. Whereas geriatricians in the large cities are responsible for patients with advanced dementia in hospitals it is the GP who takes care of patients with advanced dementia in the smaller cities, visiting patients in nursing homes as well as hospital settings. In these areas, it seems that GPs are more hesitant to consult a geriatrician or other specialist because the specialist may be inclined to provide active care, such as a PEG tube. Palliative care specialists do not seem to be consulted either, in smaller Australian cities, because of their perceived lack of experience with patients with advanced dementia.

Because traditionally in our hospital, you know, probably 89% of the geriatrics is done by the GP's anyway. […] Much more a picture for this area. In Sydney for example, it is very rare [for GPs] to look after patients in hospital. Respondent 6, Australian GP (small city).

If someone says, you know, I'm gonna go and see a specialist, perhaps I should see a specialist a, geriatrician, for this I'll say [..], well, let's think about it. You know, they're gonna say, 'put the PEG tube in", so let's think about this before you even go there. Respondent 9, Australian GP (small city).

You know, sometimes I consult the geriatrician for, ah, usually behaviour problems and dementia. But the palliative care team mostly has to do with patients with cancer in the community. Respondent 9, Australian GP (small city).

9.4 Discussion

In our study, Dutch and Australian doctors used similar medical considerations when they decide about the use of artificial nutrition or hydration (ANH) for patients with advanced dementia. Their default approach is not to start ANH. In some situations they consider the administration of ANH for a short period of time appropriate.

The circumstances in which Dutch and Australian doctors arrive at their conclusions vary. Dutch nursing home physicians are responsible for both active and palliative care approaches for patients with advanced dementia, whereas they often involve different specialties in Australia. Further, decision-making is predominantly based upon concurrently observing the patient and having many discussions about his/her presumed wishes with the family for Dutch doctors, whereas written advance care directives and scientific evidence seem more influential in the decision making of Australian doctors. In their final evaluation Australian GPs seem to follow the family's wishes somewhat more than Dutch nursing home physicians and Australian geriatricians, who tend to see the decision-making as their final responsibility. Finally, perceptions of what constitutes 'artificial' vary - with Australian general practitioners (GPs) using a broader definition than

Dutch doctors. Perceptions of whether withholding is different from withdrawing treatment also vary - with Australian doctors experiencing fewer differences.

A possible explanation for these differences may be related to differences in the health care system. In Australia, care for dementia patients seems somewhat more fragmented than in the Netherlands, especially in the large cities. GPs, geriatricians and neurologists may be involved in the initial diagnosis and work up of patients with dementia. Once the disease is advanced, dementia is generally managed in nursing homes by the GP, but the geriatrician participates in the ACATs (Aged Care Assessment Teams) that finally needs to give approval for referral to a nursing home.[20] When dementia patients require acute care in large cities in Australia they are admitted to a hospital where they are looked after by a hospital specialist (a geriatrician or other type of specialist depending on the nature of the underlying problem) and the GP often gets left out of the loop as far as decision-making is concerned. In the Netherlands, advanced dementia is generally managed by the nursing home physician, who provides care in the nursing home on a daily basis. Dutch nursing home physicians have followed a three year training in nursing home medicine and offer both active and palliative care to patients with advanced dementia. Dutch nursing homes not only employ nursing staff, but have their own medical, paramedical and psychosocial staff, which allows them to provide continuous long-term care, including end-of-life care.[27] In the Netherlands, patients with advanced dementia are seldom hospitalised and if so, it is always limited to a short time-frame. Our findings suggest that the Dutch care approach for dementia care is predominantly holistic with a comprehensive interpretation of the patient's actual situation and life story serving as the guide to decision-making.[28] The Australian approach, on the other hand, seems predominantly analytic, with objective factors and scientific evidence playing an important role in the decision-making.

The tendency of Australian doctors (mainly GPs from smaller cities) to attach more importance than Dutch doctors to written advance directives may also be the result of their inclination to be analytic and focus on patient autonomy for decision-making, since advance directives are often regarded as a useful instrument to structure communication processes prior to the patient loosing decision-making capacity. In a comprehensive, holistic care approach such instruments may get less emphasis, as found in previous studies from the Netherlands also.[8 29] The fact that Dutch nursing home physicians expressed serious concerns about whether advance directives should be followed, also underlines the importance they attach to the patient's current well-being rather than their prior wishes. The Dutch and Australian care approaches may also explain why some of the Australian GPs are more inclined to associate 'artificial' with all interventions that are provided by professional caregivers. In a comprehensive, holistic care approach 'artificial' is predominantly associated with clinical or technical aspects, while hand feeding is regarded as basic care.

A comprehensive, holistic care approach could also clarify why Dutch nursing home physicians tend to see the decision-making as their final responsibility more than Australian GPs, as the enduring relationship with their patients and their family enables them to concentrate on and have a pro-active role in the decision-making. The supportive role of Australian GPs to the family may be in line with the importance they attach to written advance directives. Our findings suggest that the Dutch care approach brings

about the risk that care is more emotionally driven. The emotional difficulties Dutch doctors experience with withdrawing ANH may be related to the relationship they have with their patients and the family, which is one of continuity and personal understanding. A more analytic approach may explain our finding that most Australian doctors tend not to experience the difference between withholding and withdrawing treatment.

Australian palliative care specialists seem to have a limited role in patients with advanced dementia. Our study as well as previous studies performed in Australia suggest that patients aged over 80 years, country residents and non-cancer patients often do not receive specialist palliative care support.[31 32] However, palliative care specialists aim to integrate medical and non-medical aspects of patient care and could therefore contribute to the holistic aspects in dementia care. In Australia, the development of palliative care was started in hospitals for patients with terminal cancer.[33] Currently, palliative aged care is developing as a specialty area in Australia as well.[34] In the Netherlands, the development of palliative care was started in nursing homes in the 1960's,[35] which included a continuous, active and integral care approach for dying patients, provided by nursing home physicians.[27]

There are potential limitations to our study. First, we restricted our Australian respondents to the state of New South Wales because legal regulations vary from state to state. Our sample therefore does not represent the whole of Australia. Performing a qualitative study, we did not intend to represent any population but to provide some in-depth exploration about a complex phenomenon. Second, Australian doctors were somewhat older and had more work experience than the Dutch doctors; this may have influenced the answers of the respondents. Finally, our results are based on the physician perspective only and do not address the patients', families' or nurses' viewpoint. Future studies are needed to better understand the perspectives of others involved.

In conclusion, the answers of the Dutch and Australian respondents suggest that the Netherlands and Australia seem to have developed different care models for patients with advanced dementia. Both a comprehensive, holistic approach that puts emphasis on the patient's actual situation and life story and an analytic approach that puts much emphasis on objective empirical evidence have benefits and drawbacks when making decisions about ANH. Striving to combine the two and providing patients with analytic care that takes into account the 'patient as a whole person' seems to serve the interest of patients with advanced dementia and their families best.

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10

General discussion

10.1 Introduction

In this thesis, a series of studies is presented that focus on the Dutch euthanasia review procedure and on cultural aspects of end-of-life decision-making in general. With these studies the following research aims were addressed:

1. To study how and to what extent societal control of euthanasia and physician-assisted suicide is achieved in the Netherlands.
2. To study variation in end-of-life decision-making between culturally diverse groups and between countries.

In this chapter the main study findings will be discussed. Some methodological considerations will be addressed (10.2), the findings related to the first and second research aim will be summarised and discussed (10.3), and implications for policy and practice and further research are considered (10.4).

10.2 Methodological considerations

In this thesis four different studies were used: a survey among physicians, a study of euthanasia reports, death certificate studies and qualitative in-depth interviews. For all studies, great care was taken to ensure the validity of the results. The quantitative studies were conducted nationwide and include data that are considered to be representative for the whole of the Netherlands. For the qualitative interviews, the systematic sampling method guaranteed a sample of physicians representing a wide range in years of experience, gender, age, and setting. Furthermore, the guaranteed anonymity for physicians contributes to the credibility and validity of the data used in this thesis. Finally, the validity of the death certificate studies has been previously shown in several studies.[1-4] Some potential sources of bias and limitations regarding generalizability should be taken into account.

Nation-wide physician survey

One limitation of the physician survey concerns the representativity of the physicians in our questionnaire survey: response rates varied from 75% for nursing home physicians, 56% for general practitioners to 46% for medical specialists.[5] Although a non-response analysis revealed that most physicians who had not responded indicated to be too busy, it cannot be precluded that physicians who are most interested in this research topic - and probably have a positive attitude towards euthanasia – are overrepresented in this sample of physicians.

The survey studied experiences with and attitudes towards the Dutch Euthanasia Act and end-of-life practices in general. Attitudes are generally considered to be a predictor of actual behaviour.[6] However, other factors, such as environmental and social factors may also influence how people eventually act. Thus, attitudes may only partly explain actual behaviour which is especially relevant for the hypothetical end-of-life cases that we presented to the physicians and where we asked whether they would be willing to report the cases, that is, for their intended behaviour.

Study of euthanasia reports

The initial sample of euthanasia files was stratified for the five review committees and comprised files with old and new versions of the standard form to report a case.[5] Our study was restricted to cases where physicians used the latest version of this standard form. The question may rise whether our results can still be extended to all reported euthanasia cases. On the other hand, the new version of the standard form provided more detailed information and therefore gives a more precise picture of the way Dutch physicians report their act.

The euthanasia files were analyzed with a checklist by eight researchers. If the reporting physicians elaborated on questions which were framed in an open way, the researcher eventually decided what information was the most important to note on the checklist. As such, researcher's interpretation of certain information may have influenced the results. However, the interrater reliability between researchers was high with an average agreement for 20 randomly chosen variables of 91%.

Nation-wide death certificate studies

Differences in the infant study were based on a small number of cases which reduces the power of this study. Another issue is that the EURELD study was only performed in parts of Italy (Emilia-Romagna, Trento, Tuscany, and Veneto), Belgium (Flanders) and Switzerland (German-speaking part). The retrospective design of the death certificate studies automatically implies that it is based on physicians' recall. As such, it could be that physicians do not remember the precise details of the deceased person and the precise details of their own acts. Our findings may be subject to recall bias. The time between the patient's death and the moment at which the physician received the questionnaire was kept as short as possible, and was on average 75 days in the 2005 death certificate study.

Qualitative interviews among Dutch and Australian medical practitioners

The Netherlands and Australia are completely different from a spatial point of view: a densely-populated versus a sparsely-populated country, which influenced our method of recruitment. In the Netherlands, we recruited physicians from all parts of the Netherlands. In Australia, we restricted ourselves to one state (New South Wales) and to two different cities (large and smaller) excluding remote areas where direct hospital care is virtually absent. However, the population is mainly concentrated in the state capitals, such as Sydney. Furthermore, physicians who work in larger cities may regularly fly to remote areas to assist the local health care workers.

During the interviews, respondents may have felt pressed to give socially acceptable answers and this pressure might have differed between countries. However, compared to euthanasia (which is legally allowed in the Netherlands and illegal in Australia), decisions about ANH for patients with advanced dementia are less controversial and are made on a regular basis: doctors in both countries freely spoke about the decisions they had taken. The fact that we ensured the anonymity of the physicians has probably minimized potential risks even further.

10.3 Interpretation of findings

PART I – SOCIETAL CONTROL

How to achieve a euthanasia review procedure that guarantees careful practice and that at the same time stimulates physicians to report their act to the legal monitoring system? Enhancing legal security and societal control – the main aim of the Euthanasia Act - is at least a challenging assignment. The Act has provided a legal basis for the review system that already existed. However, in doing so it also changed the Criminal Code by granting immunity to a physician who acts in accordance with the statutory due care criteria. In 2005, 74% of all physicians (nation-wide physician survey) believed that legal security had improved due to the enactment of the Euthanasia Act.[5] Possibly, physicians' confidence in the legal monitoring system stimulated them to report their act: the reported cases in 2005 represented a substantial amount (80%) of all euthanasia cases in the Netherlands.[4] Studying the files of reported cases therefore gives important insight in the quality and carefulness of reported euthanasia cases (chapter 3). Studying physicians' problems in the decision-making with regard to the due care criteria when considering a request for euthanasia reveals where potential problems are situated and whether these problems are reflected in the reporting discourse (chapter 2).

10.3.1 Carefulness of control

Dutch physicians who perform euthanasia have to comply with six criteria of due care (Box 1.1, page 11) and review committees should subsequently evaluate whether physicians actually complied with these criteria. The substantive criteria relate to the patient's request, the patient's suffering and the presence of reasonable alternatives and are openly framed. The consultation of another physician, the information provided to the patient and the applied method are criteria which are more procedural in nature. This thesis showed that each criterion is dealt with in a different way due to different interactions between and interpretations of review committee and physician (**Box 10.1**):

Box 10.1 Emphasis that is placed on the six criteria of due care by review committee and reporting physician.

Criterion:	Review committee[1]	Reporting physician[2]
1. The patient's voluntary and well-considered request.		+
2. The patient's unbearable and hopeless suffering.	+	+
3. The information provided to the patient.		
4. The absence of reasonable alternatives.		
5. The consultation of an independent physician.	+	
6. The performance of euthanasia.	+	

[1] Emphasis as in additional questions that were posed to the reporting physician and/or independent physician (chapter 3).
[2] Emphasis as in physician's problems with the interpretation of the due care criteria (chapter 2) and / or the way physicians substantiate the criteria in their report to the review committee (chapter 3).

1. With regard to the patient's request, we found a relatively high number of physicians who experienced problems with the interpretation (chapter 2). However, these difficulties were absent in the reporting discourse: in their reports, physicians provided straightforward answers and review committees paid no specific attention to this criterion either (chapter 3). Probably, the assessment of whether or not the patient's request was well-considered and voluntary is an important prerequisite for the physician, who refrains from performing euthanasia if any doubts are left. A previous study has shown that in 13% of all cases in which the patient's request was not granted, physicians had doubts about whether the request was voluntary and well-considered.[7] Probably, if physicians decide to go on with the procedure, the voluntary and well-considered request of the patient is rather clear-cut.

2. With regard to the patient's suffering, many physicians considered it difficult to assess whether the patient was suffering unbearably (chapter 2) and they often substantiated the unbearableness with aspects that can be relatively objectively determined, such as pain and other symptoms; they did not describe whether and on what grounds they themselves were convinced of the patient's unbearable suffering (chapter 3). Review committees put much emphasis on this criterion as they relatively often asked for a further specification of the patient's suffering (chapter 3); apparently review committees attach importance to the subjective aspects of the patient's suffering as well.
Suffering is influenced by the patient's personality, physical and mental perseverance, history and perceptions of the future.[8] Hence, what is still bearable for one person may be unbearable for another and it is therefore argued that it should mainly be left to the judgment of the patient.[9] Some claim this makes the unbearableness of suffering something a physician can hardly assess, but the RDMA and the review committees argue that suffering is at least partly open to objectification.[10 11] However, subjectivity probably remains an important aspect of the evaluation of the criterion of unbearable suffering, which is consistent with the legal system of euthanasia where the suffering criterion is purposefully framed in open terms.

3. With regard to the provision of information, physicians did not experience difficulties in the decision-making (chapter 2). Most physicians only briefly addressed this criterion in their report and review committees paid no specific attention to this criterion either (chapter 3). If the little attention that was paid to this criterion would result in acts that the patient would not have wished had he/she been fully informed, this could be interpreted as problematic. Our finding that in 35% of all reported cases alternative treatment had been present which in the large majority had been refused by the patient, suggests that such alternatives are rather often discussed. However, this provides no insight in the quality of the communication; end of life discussions are very difficult for both the physician and the patient[12] and it has been shown that physicians sometimes fail to recognize patient's misconceptions regarding their prognosis.[13] The little emphasis on this criterion by review committees and physician may also be related to the fact that they consider informing the patient as part of normal medical practice that has to be elaborated on in the review process only in case of clear indications of problems.

4. With regard to the presence of reasonable alternatives, it is remarkable that for physicians, this specific criterion was experienced to be the least difficult to assess of the three substantive criteria (i.e. patient's request, patient's suffering, presence of reasonable

alternatives) (chapter 2). Although physicians often described several treatment alternatives for the patient in their report, they also indicated that the majority of the patients had refused these alternatives. Review committees paid no specific attention to these alternatives and often chose to go along with the patient's refusal that was described in the physician's report (chapter 3).
The relatively little attention that is paid to the alternatives by the physicians and review committees brings up the question what 'reasonable alternatives' actually are and to what extent respect for patient's autonomy predominates over physician's responsibility to seriously consider less 'harmful' alternatives. In their annual reports, review committees provide some indications in how to judge the criterion of reasonable alternatives.[11 14] Discussions in parliament also contribute to the question to what extent a patient may refuse (palliative) care without consequences for his euthanasia request.[5] It has been argued that in some situations palliative options may take away the unbearableness of the patient's suffering and that physicians may subsequently conclude that euthanasia is therefore not justified. For review committees, it seems that the patient's refusal of the proposed alternatives to a large extent determines the unreasonableness of the alternatives. Committees probably consider the report of the independent consultant concerning this issue as well. For both physicians and independent consultants however, strong pressure from patient and family may complicate the decision-making (chapter 2, Table 2.3, page 30). This may result in following the patient's wish for euthanasia in the presence of non-burdening alternatives with few or no side effects. On the other hand, a previous study showed that doubts about the availability of treatment alternatives relatively often resulted in the decision not to grant the patient's request, which proves alternatives are seriously considered in a significant number of cases.[7] It can be concluded that further elaboration of this criterion is warranted.

5. With regard to the independent consultation, physicians indicated that they hardly experienced problems, but in their reports this criterion was often substantiated in vague terms (chapter 2). Such substantiation of the consultation requirement was not in all cases considered sufficient by the review committees and they relatively often asked additional questions about this issue (chapter 3).
The little attention physicians gave to the consultation requirement is possibly due to their misapprehension of this requirement: they might have felt that the substantiation of this requirement can be left to the independent consultant. The majority of physicians who intend to perform euthanasia consult a SCEN-physician.[15 11] SCEN-physicians are trained by the RDMA to advise physicians who have questions about the procedure or the performance of euthanasia and to give the required expert second opinions. Possibly, physicians did not know what they need to substantiate, namely whether the physician was a really independent physician.

6. With regard to the applied method of ending life, physicians hardly experienced difficulties in the decision-making (chapter 2). However, their report was sometimes somewhat inaccurate with regard to the type of medication and it relatively often attained review committees' attention (chapter 3).
For euthanasia, the guideline of the Royal Dutch Association for the Advancement of Pharmacy (RDAP) recommends the use of a barbiturate to induce a coma, followed by a muscle relaxant to induce the patient's death.[16] In actual practice, exceptions can be made with regard to the type of medication, but only for good reasons.[11] They use of

muscle relaxants without sufficient sedatives for instance, may be very distressing for the patient. Physicians possibly feel no need to substantiate such medical aspects as it belongs to the basic tasks of a physician. However, if physicians deviate from the guideline of the RDAP a more comprehensive substantiation of the type of medication is needed for review committees in order to carefully judge these cases.

The fact that the review committees rarely disapprove cases,[11] suggests that the practice of euthanasia in the Netherlands is largely careful. We conclude that the discourse between reporting physicians and review committees generally reflects a careful procedure for societal control. However, our findings also suggest some room for improvement with regard to the consideration of criteria of due care.

10.3.2 Transparency

Physicians are required to report cases of euthanasia or physician-assisted suicide and they will not be prosecuted if they act in accordance with the aforementioned criteria of due care. However, by compelling physicians to report their act, the law actually requires physicians to lay themselves open to potential prosecution. The annual reports of the review committees show that under the Euthanasia Act virtually all reported cases of euthanasia and physician-assisted suicide have been approved; in the period 2003 – 2008, 29 cases were not approved.[11 14 17-20] Not all cases of euthanasia and physician-assisted suicide are reported, but the proportion of reported cases substantially increased, from 18% in 1990, to 41% in 1995 and 54% in 2001, up to 80% in 2005.[4 21 22] By analyzing the results of chapter 4 and 5 we search for the reasons of non-reporting and see where transparency could be further increased.

In 1990, interviews with physicians showed that the most important reasons for non-reporting were 'avoiding the fuss of a judicial inquiry', 'to protect patient's relatives from a judicial inquiry', and 'fear of prosecution'.[21] The interview studies performed in 2001 also showed that physicians' reasons not to report a case were especially related to fear of prosecution.[23] The 2005 study for the first time addressed non-reporting in the death certificate study, so that actual practices could be related to physicians' considerations. For the 28 non-reported cases of euthanasia, most physicians stated that they had not reported their act because they had not perceived ('labeled') it as 'euthanasia' or 'ending the patient's life'. Fear for legal prosecution was not mentioned.[4] Although the research methodology was different from previous years, this finding suggests that nowadays, in the much smaller proportion of non-reported cases, other reasons for non reporting are predominant.

For many physicians, ending of life seems directly related to the use of muscle relaxants. Chapter 4 shows that the reporting rate of cases in which muscle relaxants were used, sharply increased to almost 100% in 2005; if they used other medication than muscle relaxants physicians reported only 2.8% of cases. Further, physicians labeled ending of life with other types of medication (i.e. sedatives and opioids) rarely as 'euthanasia' and mostly as 'palliative or terminal sedation' (73%) or 'symptom alleviation' (17%). Chapter 3 shows that reporting physicians rarely report the use of other medication than muscle relaxants in the standard form. Chapter 5 provides a more comprehensive picture of the characteristics of non-reporting based upon hypothetical end-of-life cases which confirms

the findings from the death certificate study. It shows that medication other than muscle relaxants, as well as physician's intention and the patient's life expectancy, contribute to a grey zone between euthanasia and highly dosed alleviation of pain and symptoms; in this grey zone labeling shortening of life as 'euthanasia' is not self-evident.

Why are euthanasia cases that fulfil the definition of euthanasia not perceived as ending the patient's life and accordingly not reported? If physicians indicate that the death of a patient was the result of opioids or sedatives that were administered with the explicit intention to hasten death on the patient's explicit request (chapter 3), they actually agree that it concerns a life-shortening practice. Possibly, the fact that patients in these cases typically had a limited life expectancy and the administration of drugs probably shortened the patient's life only little explains why they did not label it as 'euthanasia'. In fact, it may be difficult to conclude whether the patient died as a result of the medication administered or from natural causes in such cases.
In the Netherlands, the nation-wide study in 2001[3] sparked a debate about whether or not opioids can be used for euthanasia, because of their doubtful lethal potential and the likelihood of side effects.[24 25] Recently, some evidence has been published that the life-shortening potential of opioids is limited.[26-28] As a result, physicians may have become less inclined to attribute life-shortening effects to opioids.
For sedatives, the picture is somewhat different. The national guideline of palliative sedation prescribes that only patients with a limited life-expectancy (life-expectancy within one or two weeks) may be sedated.[29] In such cases, sedation is unlikely to result in shortening of life. There are no indications that a substantial number of the cases of continuous deep sedation in 2005 are in fact euthanasia in disguise[30-32] as there was no intended life-shortening effect in the majority of cases.[33] In some cases, however, continuous deep sedation was used with the explicit intention of shortening the patient's life: in such cases, continuous sedation is morally equivalent with euthanasia, especially if it is done on the patient's explicit request.

Fear of prosecution and evading regulation in order to preserve some medical freedom may still be other explanations of not labeling an act as 'euthanasia'. If physicians think that other medication than muscle relaxants is appropriate to perform euthanasia for a particular patient but at the same time assume that such cases will not be approved by the review committee, they might (consciously or unconsciously) prefer not to label the act as 'euthanasia' and refrain from reporting because they fear prosecution. The nation-wide physician survey showed that a substantial proportion of physicians consider the administration of high dosages of opioids a good way to perform euthanasia.[5] SCEN-physicians can have an important role by advising physicians how to perform euthanasia with due medical care and attention. Public debate about appropriate medication at the end of life might stimulate physicians to report their case also. However, it is plausible that this is a difficult area to further increase transparency.

10.3.3 Reporting of active ending of life of newborns

The review procedures for euthanasia and active ending of life in newborns correspond to a certain level, but for euthanasia only cases in which the due care criteria are not met are forwarded to the public prosecutor. For newborns, the act is illegal and the public prosecutor still retains the final decision.[34] The national review committee that investigates cases of active ending of life in newborns evaluates whether physicians adhere to the following criteria: 1) the suffering of the child has to be unbearable and without prospect of improvement, 2) an independent physician has to be consulted, 3) the parents have to agree with the decision, and 4) physician-assistance in dying has to be provided with due care. So, in contrast to euthanasia, the decision to end life does not originate from an explicit and well-considered request but is primarily based on quality and quantity of life considerations[35] in which the parents have an important role.[36] Whereas the suffering criterion is rather important among adults, it is often questioned whether suffering is a reasonable criterion in newborns as it is per definition a subjective matter.[37 38] However, although infants cannot express their feelings through speech, they do so through different types of crying, movements, and reactions to feeding which gives observers at least an impression of the infants' suffering.[39]

The national regulation is based on the committees' report (1997)[40] and the 'Groningen Protocol' (2002).[39] This protocol is meant for infants who are not dependent on intensive medical treatment but for whom a very poor quality of life associated with sustained suffering is predicted. The 22 cases of actively ending of life among newborns that were reported to the public prosecutor between 1997 and 2004 all concerned infants with spina bifida.[41] Although it was concluded that the criteria were met in these cases, a careful evaluation showed that the suffering predominantly concerned expected unbearable suffering in later life, rather than present suffering as addressed in the Groningen Protocol and as required under the current regulation.[37]

The national review committee that started its work on March 2007 had not received any reported case of actively ending a newborns' life up till September 2009, although it was estimated that 15 to 20 cases would be reported annually. It is likely that at least some cases of actively ending of life still occur. Chapter 6 gives possible causes for a lower number of reported cases.
Firstly, physicians may decide not to report their act as a non-natural death because the infant's situation stands in the way an adequate fulfilment of one or more criteria. For the suffering criterion quality of life considerations could have resulted in the administration of drugs with the explicit intention of hastening death in situations where present suffering was absent (as in Case 2, chapter 6, page 80). For the consultation criterion the need to do any good to the infant could have hampered sufficient time to ask a physician for independent advice (as in Case 1, chapter 6, page 79). Secondly, physicians may consider their act (consciously or unconsciously) a part of normal medical practice. If muscular relaxants are administered to prevent gasping when an infant with a limited life expectancy is disconnected from the ventilator, the fact that the infant was already dying and / or the forgoing of treatment was considered the most important decision, might result in not labeling the act as 'active ending of life' and accordingly reporting of the act.

A recent Dutch nation-wide study in 10 Dutch NICUs extracted information concerning end-of-life decisions from charts of 340 infants that died within the first two months of life

in hospital and interviewed the attending neonatologists who cared for newborns with a poor prognosis.[42] The majority of deaths (92%) were the result of withdrawing artificial ventilation; muscle relaxants were administered in 16% of cases after the end-of-life decision. The medical files revealed that the most important reasons to administer muscular relaxants after the end-of-life decision were to continue the medication that was already given as part of the treatment regimen and to stop or prevent gasping. In one case the muscle relaxant was administered to end life. None of the cases in which muscular relaxants had been used and / or physicians administered (other) medication with an intention of hastening death, were reported as a non-natural death, which is in accordance with our findings. It seems essential to know what physicians' underlying reasons are to administer medication such as muscle relaxants to be able to qualify their acts and to compare these acts with the requirements in the current regulation.

In cases where life is ended to prevent expected future suffering, physicians seem to perceive the act as 'active ending of life' although they neglected to report these acts. The suffering criterion is taken over from the due care criteria for euthanasia and the condition of present suffering could hamper adequate fulfilment of this requirement as it is established for newborns. Previous (national and international) studies have shown that decisions to withhold or withdraw treatment for infants are frequently made based on future quality of life considerations.[43-46] It has also been shown that such decisions are virtually always discussed with the parents and other physicians in multi-disciplinary teams; justifications to end the infants' life are never based on one single opinion.[36 46] Although decisions to forgo treatment belong to a different category than active ending of life, it at least shows that such future quality of life considerations often legitimize medical end-of-life decisions for physicians. To adapt the suffering criterion to newborns it could be argued to take into account expected suffering as well.

In actual practice however, it seems that the administration of life ending drugs is much more often a decision to prevent (unexpected) present suffering of the infant due to the forgoing of medical futile treatment. In such situations, the current review procedure may be a burdening experience for parents while they drastically have to adapt their mindset. In these cases, physicians themselves often (consciously or unconsciously) indicate that the purpose is alleviation of pain and symptoms, which is probably partly related to the fact that they consider reporting as a non-natural death as too burdensome for the parents. It has been argued that if no alternative treatment is available to stop the infant's gasping and if this might improve parental comfort and relieve their grieving, the administration of muscle relaxants may be seen as adequate palliative care, which suggests that reporting such cases as active ending of life would not be appropriate.[47] On the other hand, compelling physicians to report all cases in which they administered medication with the explicit intention to hasten death is in accordance with the aim to ensure that actively ending of life complies with the criteria of due care.

PART II – CULTURAL ASPECTS

Defining 'culture'

'Culture' is the system of shared beliefs, values, customs and behaviours acquired by a group of people in the course of generations through individual and group striving.[48] Since culture is continually transformed through the social actions of both individuals and groups, it is characterized as much by change and transformation as by continuity.[49] Cultural patterns can be expressed materially (i.e. peoples' diet or clothes) or non-materially (i.e. peoples' language, religion or rituals). Culture often shapes the way people make meaning out of illness, suffering, and dying.[50] There is no standard and agreed definition of culture which probably also explains why the term 'culture' is sometimes misused, also in the context of end-of-life decision-making: if 'culture' is simply reduced to a series of isolated beliefs or practices categorized by ethnic origin or religion it runs the risk of stereotyping, e.g. assuming that all Turkish patients in the Netherlands do not want to be told their diagnosis. In contrast, failure to take culture seriously can be a form of cultural imperialism, e.g. insisting that all Turkish patients in the Netherlands must be told their diagnosis.[51]

The influence of culture in end-of-life decision-making

Variation within countries

Chapter 7 showed that the frequencies of certain end-of-life practices substantially vary between Dutch natives and non-western migrants, even when adjusted for age, sex and cause of death. In addition, physicians far more often decided to forgo treatment because the patient or families requested to do so for Dutch natives than for non-western migrants. Whether the differences reflect different needs of non-western migrants or a different care approach of physicians towards non-western migrants cannot be said. However, the differences in the frequencies of end-of-life practices and decision-making suggest that cultural factors play a role in the end-of-life decision-making.

For people with a non-western cultural background some aspects in the decision-making may be more important than factors that are generally considered to be important in western countries.[52-54] Some ethnic or cultural groups may hold different approaches to decision-making at the end of life. The concept of patient autonomy that is so highly valued in western countries, and that is (together with the principle of beneficence)[55] the basis of many end-of-life decisions, may be not as important or may be differently shaped in other cultures. In the Netherlands, non-western migrants predominantly originate from Turkey and Morocco.[56] For Turkish and Moroccan communities the diagnosis of a terminal disease is often not discussed with the patient and it is often a family or group oriented care model that is followed instead of a decision-making model that purely focuses on the patient.[57 58] This contrasts with what most Dutch physicians believe about how the physician's relationship with the patient and family should be. Above that, the general Dutch law on patient-physician relationships, the Act on the Medical treatment agreement (In Dutch: WGBO), states that every patient should be well-informed about his situation and prospects before deciding about treatment.[59] Article 448 (III) however states that if this would seriously harm the patient, information does not need to be disclosed. For western physicians this actually means that they can have conflicting responsibilities. In order to provide 'culturally appropriate' care they need to integrate multiple cultures

when they communicate with their patients: their own culture, the culture of the patient and/or family, and the health care institution's culture. For migrants, every individual will have its own level of acculturation, which underlines the need for an individual assessment once more.[52]

If cultural differences in end-of-life decision-making would result in lower quality of care, this would be problematic. In some cases, physicians who try to provide culturally appropriate care unintentionally encourage stereotyping and thereby negatively influence the quality of care. [60 61] A recent Scottish study showed that most health care services had problems to deliver culturally appropriate care, due to health care professionals' uncertainty about how to adapt their usual care and occasionally because of personal racial and religious discrimination.[62] A recent Dutch study showed that general practitioners had problems to deliver adequate home care, due to difficulties in identifying the needs of Turkish and Moroccan patients.[63]
In case of end-of-life care, there may be different perceptions of death and dying, and culture can also influence the expectations patients have from healthcare systems. It has been shown that migrants often receive inadequate care because of their own misconceptions about specific health care services.[62 64] In the Netherlands, originating from a non-western country is often interrelated with a lower socio-economic status and an inadequate control of the Dutch language.[65 66] As such, increasing patient's ability to understand the language and the culture of the health care system may be as important as improving the skills of the physician to provide culturally appropriate care.

Variation across countries
In chapter 8 and 9 the end-of-life decision-making about (foregoing) artificial nutrition and hydration (ANH) between countries is analyzed in a quantitative and qualitative study. In chapter 8, the practice of ANH was studied among all deaths and in chapter 9 the practice of ANH was studied for patients with advanced dementia. Again, 'culture' is probably a factor in both studies that could explain our findings.

In chapter 8, culture seems to be manifest in the decision whether to forgo ANH or not. This chapter shows substantial differences in the occurrence of forgoing artificial nutrition and hydration (ANH) for dying patients between 6 West-European countries; frequencies varied from 2.6% in Italy up to 10.9% in the Netherlands. This variation in frequency could not be explained by medical factors (e.g. patient's age, diagnosis). Further, although ANH was most often discussed with the patient and relatives in the Netherlands, most decision-making characteristics were comparable in all six countries. In the past decades, northern and central European countries have become more secular, which placed life and death in a different perspective. Instead of leaving the responsibility to God or the medical profession, people started to prefer to make their own decisions about their lives.[67 68] It has been shown that in these countries patients and relatives are generally involved in medical decision-making and that the frequency of end-of-life decisions is higher.[69] Southern European countries, such as Italy, are much more shaped by a Catholic life stance in which sanctity of life is highly valued, which probably explains why ANH is less frequently forgone.[70] Other studies support our finding of different frequencies of specific end-of-life practices in northern and southern European countries.[71-73]
In chapter 9, culture is subtly manifested in the process of decision-making. This chapter showed that Dutch and Australian doctors when considering the use of ANH use the

same medical considerations. Although this study did not provide any insight in the occurrence of forgoing ANH, the answers of the Dutch and Australian respondents suggest that the Netherlands and Australia have developed different care approaches for dementia. The more comprehensive care approach for Dutch dementia patients possibly stems from the development of nursing homes in the 1960's,[74] which provide a continuous, active and integral care approach for chronically ill patients.[75] The more analytical care approach of the Australian doctors possibly stems from a health care system which is predominantly medically oriented, in which doctors try to incorporate scientific evidence and objective factors in the decision-making.

Chapter 8 and 9 suggest that medical aspects concerning ANH are weighed in a similar manner in western countries, but that countries seem to develop their own accents in end-of-life care and end-of-life decision-making. Such differences may influence the type and moment of decision-making, but also how end-of-life care in general is shaped. These developments are probably related to the physician-patient relationship which is often no more a hierarchical one but one in which the patient has much to say.[76 77]

10.4 Implications for policy, practice and further research

Policy and practice implications

The findings presented in this thesis indicate that societal control of euthanasia is to a large extent successful in the Netherlands. Cases of euthanasia and physician-assisted suicide are carefully reviewed and most physicians adequately collaborate in making such review possible.

The interpretation of the due care criteria for euthanasia deserves ongoing attention. Societal discussion and case law can stimulate the exploration of the evaluation and boundaries of unbearable suffering and the reasonableness of available alternatives for ending life, which might contribute to more uniform decision-making. In the new version of the standard form for reporting that has become available in June 2009, rephrased questions also serve to further explore current vaguely elaborated aspects of the review procedure.[78] With regard to the patient's suffering, there is an additional question about whether the physician him- or herself was convinced of the patient's unbearable suffering. With regard to the treatment alternatives, the advantages and disadvantages of available palliative and therapeutic treatment alternatives have to be explained, which serves to assess whether the treatment alternatives were 'reasonable' or not. The question concerning the reporting physician's relationship with the consultant is also more clearly formulated. The impact of these changes has to be awaited and needs to be studied.

This thesis reaffirms and clarifies the existence of a grey zone between euthanasia and alleviation of pain and symptoms, which hampers complete transparency. Further research, education and debate about the effects of opioids and sedatives in various clinical situations could enhance the level of agreement about what is 'euthanasia' and what is not. SCEN-physicians should advise physicians who consider euthanasia about the appropriate use of opioids and sedatives. Such advises may reassure physicians in their decision-making. If physicians consciously use other medication than what is advised by the RDAP, they should report and account for their choice. In their report of

2008[14], review committees indicate that they seriously consider the arguments and background of the use of atypical drugs but that they always ask the reporting physician for additional information in such cases.

In order to stimulate physicians to report cases of active ending of life of newborns the interpretation and conditions of the criterion of unbearable and hopeless suffering warrants further explanation and possibly some rephrasement. If expected suffering can be a ground for active ending of life as well, the present condition of the child should be clearly established and evaluated by another physician to ensure appropriate medical care. It should be clearly stated what measures should be taken beforehand (e.g. assessment of reasonable treatment alternatives, assessment of infant's pain or symptoms) and whether these measures differ in cases when expected (instead of present) suffering would be the most important reason to end the infant's life. Furthermore, under the current regulation it seems virtually impossible to obtain control of active ending of life of infants who suffered from severe suffering after the forgoing of treatment and at the same time guarantee careful practice. Whether and how the current regulation should be adapted to these specific situations is difficult to say and requires further discussions and input from physicians, jurists and ethicists. An important basis of careful practice for all cases where life is actively ended is probably a skilled and experienced physician, strong involvement of the multidisciplinary team, careful documentation in the medical files and continuous education about the use of medication after the forgoing of life-sustaining treatment for physicians.

Pressure from patient and family sometimes complicated the decision-making about euthanasia (chapter 2, Table 2.3, page 30). Such pressure could be reinforced by the idea that euthanasia is every patient's right, as it is sometimes presented in the media. Interest in patient autonomy is probably the result of increased knowledge of medicine and medical practice due to better education and to the information that is given by the media in the past decades. At the same time, increased knowledge has probably enhanced patient autonomy somewhat more as well.[76] Probably, with a growing population of people for whom patient's autonomy gains in importance other issues in the euthanasia debate will start to play a role. Currently, physicians seem to struggle with euthanasia requests of patients who suffer from early dementia. Although such a condition does not exclude a justification for euthanasia it seems logical that in such cases the chance that physicians' personal beliefs stand in the way to perform euthanasia is higher. Such difficulties however warrant continuous attention from the public, medical, ethical and political arena in how to judge these cases and / or where to draw the line between acceptable and unacceptable forms of euthanasia.

Cultural aspects influence end-of-life decision-making. Although these data did not provide clear insight in whether these differences reflected problems in the decision-making, physicians need to be aware of cultural differences when providing end-of-life care. Discussions among physicians and patients with various cultural backgrounds as well as medical and ethical debates will further contribute to the question how cultural differences should be interpreted and dealt with, on a national as well as an international level.

Suggestions for further research

The annual number of reported cases of euthanasia and physician-assisted suicide is increasing since 2003; in 2008, it has risen with approximately 10% as compared to 2007.[14] This could be due to an absolute increase in the actual number of cases, a relative increase in the use of recommended medication, an increase of physicians' willingness to report cases in which other than the recommended medication was used, or to a combination of these factors. The increased number of reported cases definitely warrants further monitoring of end-of-life decision-making in the Netherlands. In addition, the absence of reported cases of actively ending a newborns' life till September 2009 is another important reason to continue such monitoring over time. Regional differences within the Netherlands should be taken into account in such monitoring because different religious or cultural beliefs across the Netherlands might result in different attitudes towards end-of-life decision-making.

This thesis suggests that the language physicians and review committees use could influence medical practice. It is important in how physicians substantiate their acts to a review committee (chapter 3) and in how they account for their end-of-life practices (Chapter 4, 5 and 9). Critical discourse analysis (CDA) analyzes the way in which different interlocutors (e.g. physicians or review committees) employ critical terms (e.g. 'euthanasia', 'unbearable suffering' or 'artificial nutrition or hydration') and explore the ways in which this usage relates back to society. Such a language-based approach enables the terms to be utilized with greater precision; critical discourse analysis could for instance further increase our understanding of how the euthanasia review procedure works in the Netherlands.

The studies described in this thesis only used a few variables to explore the impact of culture on end-of-life decision making: the variables 'ethnic origin' and 'duration of residence' in chapter 7, and the variable 'country' in chapter 8 and 9. Future studies should carefully conceptualize culture by using various objective measures. Furthermore, subjective measures that study the impact of culture towards end-of-life care and end-of-life decision-making, need to take into account the different meaning certain concepts can have in different cultures (e.g. pain can carry different nuances[79]). Apart from the physician perspective, nurses', relatives' and patients' perspectives need to be studied to explore where the differences in end-of-life decision-making are situated (e.g. communication, different cultural beliefs, miscomprehension, language barriers, etcetera). Although cultural aspects are applicable to everyone in society, migrants – especially from non-western countries – deserve particular attention. The fact that the non-western migrant population in the Netherlands is growing older underlines the importance of future studies. Although some research has been done [80] [63] the information of migrants' needs with regard to end-of-life care and especially end-of-life decisions is sparse, whereas such information is a prerequisite for health care services to meet migrants' needs. Studies should also focus on the migrants' perspective; qualitative and quantitative research will further contribute to our understanding how attitudes and preferences regarding end-of-life care are distributed among the migrant population.

10.5 References

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11

Summary

The studies that are described in this thesis had two main aims:

1. To study how and to what extent societal control of euthanasia and physician-assisted suicide is achieved in the Netherlands (part 1 of this thesis).
2. To study variation in end-of-life decision-making between culturally diverse groups and between countries (part 2 of this thesis).

In part 1, the due care criteria are addressed from a physician and review committee perspective and the trends in the reporting rates of euthanasia are investigated. Furthermore, characteristics of reported and unreported cases of euthanasia are compared and related to how physicians perceive ('label') these cases. This part also examines possible explanations for the lack of reports of active ending of life in infants under the current review procedure. In part 2 is investigated whether end-of-life decision-making practices for Dutch natives differed from practices for non-western migrants in the Netherlands. This part also compared the practice of forgoing artificial nutrition and hydration (ANH) in six European countries and the opinions of Dutch and Australian doctors about the use of ANH in patients with advanced dementia.

Four different studies were used: a nation-wide physician survey about physicians' experiences with and attitudes towards the Dutch Euthanasia Act, a study of euthanasia reports, nation-wide death certificate studies and qualitative interviews among Dutch and Australian medical practitioners.

Chapter 1 contains an introduction of the research questions, the study designs and the content of this thesis.

PART 1 – SOCIETAL CONTROL

In April 2002, the Euthanasia Act (Termination of Life on Request and Assisted Suicide (Review Procedure) Act) came into force. The Act requires physicians to assess that (1) the patient's request is voluntary and well-considered, (2) the patient's suffering is unbearable and hopeless, (3) the patient is informed about his situation and prospects and (4) there are no reasonable alternatives. Further, (5) another, independent physician should be consulted and (6) the termination of life should be performed with due medical care and attention. In **chapter 2** was studied whether physicians experienced problems with these criteria in medical practice. For each criterion, physicians could indicate what specific aspects had caused their problems in pre-structured answer categories. Problems were mostly related to the assessment of whether the patient's suffering was unbearable and hopeless (79%) and whether the patient's request was voluntary and well-considered (58%). This means that they especially experienced problems with the criteria that are related to subjective patient experiences.

In order to find out whether physicians' problems with the criteria are reflected in physicians' reporting, **chapter 3** investigated how physicians substantiate the criteria of due care when they report a case. In this chapter it was further assessed which criteria attain most attention of the review committees. We studied the physician's reports and the verdicts of the review committees in 158 files of euthanasia or physician-assisted suicide cases that were performed in 2005. Physicians substantiated their adherence to the

criteria with an emphasis on physical aspects. Unbearable suffering for instance was often substantiated by describing the presence of physical symptoms (62%), function loss (33%), dependency (28%) or deterioration (15%). In 35%, physicians reported that there had been alternatives to relieve patients' suffering which were refused by the majority. Review committees relatively often scrutinized the consultation (41% of all cases in which additional information was asked) and the patient's suffering (32%); they had few questions about possible alternatives (1%). We conclude that physicians substantiate the information provided to the patient and the performance of euthanasia in a rather straightforward and uniform way, but that their substantiation is more variable for the patient's request, the patient's suffering, the absence of reasonable alternatives and the consultation. *If* review committees asked for additional information they concentrated on the most debated requirement, i.e. (unbearable) suffering, and on the requirement that serves to a priori guarantee careful decision-making, i.e. the consultation.

Chapter 4 and 5 aimed to further increase our understanding of physicians' reporting behaviour in case of euthanasia or physician-assisted suicide. In **chapter 4**, we reported the trends in the reporting rate (i.e. the number of reported cases divided by the total number of euthanasia cases) in relation to the type of medication administered by the physician. Euthanasia was defined as the administration of drugs that was given at the explicit request of the patient with the explicit intention of hastening death as indicated by the physician. This study showed that the reporting rate of euthanasia with muscle relaxants (as recommended by the Royal Dutch Association of the Advancement of Pharmacy) had sharply increased to almost 100% in 2005 whereas the reporting rate of euthanasia with atypical drugs (i.e. opioids and sedatives) was below 3% in 1995, 2001 and 2005. The increase in the reporting rate (i.e. from 18% in 1990, to 41% in 1995 and 54% in 2001, up to 80% in 2005) was related to an increased use of muscle relaxants for euthanasia. Euthanasia cases that were not reported were often not labeled as 'euthanasia'. In **chapter 5**, we investigated *why* physicians perceive ('label') end-of-life acts as either 'euthanasia / ending of life' or 'alleviation of symptoms / palliative or terminal sedation', and studied the association of such labeling with intended reporting of these acts. We presented hypothetical end-of-life cases of elderly patients in the terminal stage of a lethal disease. The use of a muscle relaxant was a strong discriminating factor related to physicians' label of 'euthanasia / ending of life'. Physicians' intention and patients' life-expectancy were important factors as well. Labeling was strongly associated with physician's intended reporting behaviour. These findings suggest that differences in how physicians label similar acts impede complete societal control

Actively ending a newborns' life also needs to be reported to a review committee. Till September 2009, the review committee that started its work in 2007 had not received any case. In **chapter 6**, possible explanations for the lack of reporting were explored by scrutinizing data on end-of-life decision making for infants from three Dutch nation-wide studies that were performed in 1995, 2001 and 2005. We conclude that the lack of reporting could be related to several changes in medical practice. The number of cases of active ending of life may have decreased, but it is likely that at least some cases during the past years occurred. Cases in which life is ended as a 'last resort' option to address severe current suffering may not be reported because they are not labeled as 'ending of life' but as adequate terminal care. Time constraints may also play a role in such cases,

because extreme suffering of the child could have hampered an independent advice of another physician. Cases in which life is ended to prevent expected severe suffering in the future may not be reported because the regulation seems to be focussed on current suffering.

PART 2 – CULTURAL ASPECTS

By comparing end-of-life decision-making practices within and across western countries we explored the impact cultural aspects can have. In **chapter 7** we investigated whether end-of-life decision-making practices for Dutch natives differed from practices for non-western migrants in the Netherlands. A non-western migrant was defined as a person who had lived in the Netherlands and of whom at least one parent was born in Africa, Latin America or Asia (excluding Indonesia and Japan). Euthanasia was not less common among non-suddenly deceased non-western migrants (2.4%) as compared to Dutch natives (2.7%). Intensive symptom alleviation however was used less frequently (30% versus 38%). Forgoing potentially life-prolonging treatment occurred at comparable rates but involved different characteristics: artificial nutrition and hydration was significantly less often forgone for non-western migrants than for Dutch natives (12% versus 28%) whereas artificial respiration was far more often forgone (38% versus 16%). These differences suggest that cultural issues play a role in medical end-of-life decision-making.

In **chapter 8** the practice of forgoing artificial nutrition or hydration (ANH) was compared between six European countries: Belgium, Denmark, Italy, Sweden, Switzerland and the Netherlands. The percentage of all deaths that were preceded by a decision to forgo ANH varied from 2.6% in Italy to 11.0% in the Netherlands. In most countries decisions to forgo ANH were more frequently made for female patients, patients aged 80 years or older, and for patients who died of a malignancy or disease of the nervous system (including dementia). Furthermore, patients in whom ANH was forgone received significantly less drugs to relieve symptoms than other patients for whom other end-of-life decisions had been made. These findings suggest that the practice of ANH does not involve extra suffering for dying patients. **Chapter 9** subsequently explored the use of ANH for patients with advanced dementia by interviewing Dutch and Australian doctors. The interview guide consisted of two parts: (1) open-ended questions about doctors' general experiences with patients with advanced dementia, and (2) open-ended questions where doctors were asked to reflect on actual cases of patients with advanced dementia. Dutch and Australian doctors use similar medical considerations when they decide about the use of ANH: their default approach is not to start ANH for patients with advanced dementia, but both are willing to administer ANH in specific situations. Disparities between the Dutch and Australian doctors were related to the process of decision-making. The Dutch care approach for dementia care is predominantly holistic with a comprehensive interpretation of the patient's current situation and life story serving as the guide to decision-making. The Australian care approach, on the other hand, seems predominantly analytical, with objective factors and scientific evidence playing an important role in the decision-making.

Discussion

In **chapter 10** of this thesis, the main findings are summarized and discussed and some implications of our studies for policy and practice are given.

The Dutch review procedure seems to reflect a predominantly careful procedure for societal control although there remains some room for improvement for every requirement. The interpretation of the due care criteria for euthanasia for instance is not obvious in all cases and deserves ongoing attention. The same holds for the regulation of active ending a newborns' life; rephrasing the current guidelines for actively ending a newborns' life may contribute to physicians' willingness to report. Furthermore, the use of opioids and sedatives in various clinical situations deserves ongoing attention with education, debate and further research.

Further monitoring of end-of-life decision-making in the Netherlands is recommended, also because of the increasing number of reported cases since 2003. Regional differences within the Netherlands should be taken into account in such monitoring. The findings that are presented in this thesis suggest that the language physicians use could influence medical practice. Methods in which language-based approaches are used, such as critical discourse analysis, could further increase our understanding of how the review procedure works. Lastly, in future studies that investigate the influence of culture in end-of-life decision-making, the concept of culture should be carefully conceptualized. Apart from the physicians' perspective, nurses', relatives' and patients' perspectives need to be studied.

Samenvatting
&
Dankwoord

Samenvatting

Het onderzoek dat in dit proefschrift wordt beschreven heeft een tweetal doelstellingen:
1. Nagaan hoe en in welke mate maatschappelijke controle van de praktijk van euthanasie en hulp bij zelfdoding plaatsvindt in Nederland (deel 1 van dit proefschrift).
2. Nagaan welke verschillen in medische besluitvorming in de laatste levensfase bestaan tussen verschillende culturele groepen en landen (deel 2 van dit proefschrift).

In deel 1 komen de zorgvuldigheidseisen voor euthanasie aan de orde vanuit het perspectief van artsen en het perspectief van regionale toetsingscommissies euthanasie. Daarnaast worden trends in het meldingspercentage van euthanasie nader geëxploreerd. Verder worden de karakteristieken van gemelde en niet-gemelde gevallen van euthanasie vergeleken en gerelateerd aan het 'label' dat artsen aan deze gevallen toekennen. In deel 1 wordt ook gekeken naar mogelijke verklaringen voor het uitblijven van meldingen van actieve levensbeëindiging bij nuljarigen onder de huidige regeling. In deel 2 wordt onderzocht of medische besluitvorming in de laatste levensfase voor autochtone Nederlanders verschilt van die voor niet-westerse migranten in Nederland. In dit deel wordt ook de medische praktijk rond kunstmatige toediening van voeding en vocht in de laatste levensfase in zes Europese landen vergeleken en worden opinies van Nederlandse en Australische artsen over kunstmatige toediening van voeding en vocht aan patiënten met ernstige dementie in kaart gebracht.

Er zijn vier verschillende studies uitgevoerd: een grootschalig vragenlijstonderzoek onder artsen over opvattingen over en ervaringen met euthanasie en de euthanasiewet, een dossieronderzoek van gemelde euthanasiegevallen, een grootschalig vragenlijstonderzoek onder artsen naar de praktijk van medische besluitvorming in de laatste levensfase, en kwalitatieve interviews met Nederlandse en Australische artsen.
In **hoofdstuk 1** wordt gestart met een toelichting op de onderzoeksvragen en de gebruikte onderzoeksmethoden.

DEEL 1 – MAATSCHAPPELIJKE CONTROLE

In april 2002 is de Euthanasie Wet (Wet Toetsing levensbeëindiging op verzoek en hulp bij zelfdoding (Wtl)) in werking getreden. De Wet vereist dat artsen voordat zij euthanasie toepassen of hulp bij zelfdoding verlenen vaststellen of (1) het verzoek van de patiënt vrijwillig en weloverwogen is, (2) het lijden van de patiënt ondraaglijk en uitzichtloos is, (3) de patiënt is geïnformeerd over zijn/haar situatie en vooruitzichten, en (4) er geen redelijk behandelalternatief voor de patiënt voorhanden is. Daarnaast (5) dient een andere, onafhankelijke arts geconsulteerd te worden en (6) moeten euthanasie en hulp bij zelfdoding op een zorgvuldige wijze worden uitgevoerd. In **hoofdstuk 2** wordt onderzocht of artsen problemen ervaren met deze criteria. In een vragenlijstonderzoek konden artsen voor elk criterium met behulp van voorgestructureerde antwoordcategorieën aangeven welke aspecten wel eens problemen hadden veroorzaakt. Problemen betroffen voornamelijk het vaststellen van de ondraaglijkheid en uitzichtloosheid van het lijden (79%) en de vrijwilligheid en weloverwogenheid van het verzoek (58%). Dit betekent dat artsen voornamelijk problemen hebben met subjectieve, van de patiënt afhankelijke criteria.

Om na te gaan of de *problemen* van artsen zich ook weerspiegelen in het *meldingsgedrag* van artsen, wordt in **hoofdstuk 3** onderzocht hoe artsen in hun meldingsverslag beargumenteren aan de zorgvuldigheidscriteria te hebben voldaan. Dit hoofdstuk brengt ook in kaart aan welke criteria de toetsingscommissies de meeste aandacht geven. We bestudeerden 158 dossiers van gemelde gevallen van euthanasie en hulp bij zelfdoding die in 2005 waren uitgevoerd en keken naar het meldingsverslag van de arts en de oordelen van de toetsingscommissies. Artsen legden bij hun verantwoording ten aanzien van de zorgvuldigheidseisen de nadruk op fysieke aspecten. Fysieke symptomen (62%), functieverlies (33%), afhankelijkheid (28%), en aftakeling (15%) werden bijvoorbeeld vaak genoemd bij de ondraaglijkheid van het lijden. In 35% van de gevallen rapporteerden artsen dat er alternatieven waren om het lijden van de patiënt te verlichten, die door de meerderheid van de patiënten werden geweigerd. Toetsingscommissies stelden zich relatief vaak kritisch op ten aanzien van de consultatie (41% van alle gemelde gevallen waarin om extra informatie werd gevraagd) en het lijden van de patiënt (32%); ze hadden weinig vragen over mogelijke alternatieven (1%). We concluderen dat artsen vrij rechtlijnig rapporteren over de informatie die was verstrekt aan de patiënt en over de uitvoering van euthanasie. De manier waarop verantwoording wordt afgelegd over het verzoek van de patiënt, het lijden van de patiënt, de afwezigheid van redelijke behandelalternatieven, en de consultatie vertoont meer variatie. Vragen van de toetsingscommissies om extra informatie betroffen vooral het criterium dat het meest aan debat onderhevig is - de ondraaglijkheid van het lijden –, en het criterium dat dient als een garantie voor zorgvuldige besluitvorming – de onafhankelijke consultatie.

In de **hoofdstukken 4 en 5** is het doel om meer inzicht te krijgen in het meldingsgedrag van artsen. In **hoofdstuk 4** worden de trends gerapporteerd in het meldingspercentage (het aantal gemelde gevallen gedeeld door het totaal aantal gevallen van euthanasie en hulp bij zelfdoding) en worden deze gerelateerd aan het type medicatie dat door de artsen was toegediend. Deze studie toont aan dat het meldingspercentage van gevallen waarbij spierverslappers waren gebruikt (zoals aanbevolen door de Koninklijke Nederlandse Maatschappij ter bevordering der Pharmacie) sterk was toegenomen, tot bijna 100% in 2005, terwijl het meldingspercentage van gevallen waarin afwijkende medicatie werd gebruikt (zoals opioïden en sedativa) bleef steken op ongeveer 3%, in 1995, 2001 en 2005. De toename van het meldingspercentage over alle gevallen (18% in 1990, 41% in 1995, 54% in 2001 en 80% in 2005) was gerelateerd aan een toename van het gebruik van spierverslappers bij euthanasie. Euthanasiegevallen die niet waren gemeld werden door artsen vaak niet opgevat ('gelabeld') als 'euthanasie'. In **hoofdstuk 5** hebben we onderzocht *waarom* artsen levensbeëindigend handelen soms als 'euthanasie / levensbeëindiging' en soms als 'pijn- en symptoombestrijding danwel palliatieve of terminale sedatie' labelen. We legden artsen hiervoor hypothetische gevalsbeschrijvingen voor waarin een medische beslissing rond het levenseinde was genomen bij een oudere patiënt in de terminale fase van een niet meer te behandelen ziekte. Toekenning van het label 'euthanasie / levensbeëindiging' bleek sterk samen te hangen met het gebruik van een spierverslapper. De intentie van de arts en de levensverwachting van de patiënt waren andere belangrijke voorspellers. Het label dat artsen toekenden aan een handeling was daarnaast sterk geassocieerd met hun bereidheid om de betreffende handeling wel of niet te melden. Wanneer bepaalde medische handelingen die voldoen aan de definitie van euthanasie door artsen niet als zodanig gelabeld worden blijft het

meldingspercentage onder de 100% en wordt het doel van volledige maatschappelijke controle nog niet bereikt.

Actieve levensbeëindiging bij nuljarigen dient sinds 2007 te worden gemeld bij een landelijke multidisciplinaire toetsingscommissie. In september 2009 waren bij deze toetsingscommissie nog geen gevallen gemeld. In **hoofdstuk 6** wordt naar mogelijke verklaringen voor het uitblijven van meldingen gezocht middels het retrospectief analyseren van databestanden over nuljarigen uit 3 landelijke studies in 1995, 2001, en 2005. We concluderen dat het uitblijven van meldingen gerelateerd zou kunnen zijn aan verschillende veranderingen in de medische praktijk, zoals een toename van palliatieve sedatie onder nuljarigen en vroegtijdige opsporing van aangeboren afwijkingen door prenatale screening onder zwangere vrouwen. Het aantal gevallen van actieve levensbeëindiging zou hierdoor afgenomen kunnen zijn. Het is echter onaannemelijk dat er geen enkel geval meer plaats zou hebben gevonden in de afgelopen jaren. Gevallen waarin het leven werd beëindigd als een 'last resort' optie om ernstig actueel lijden te bestrijden zijn mogelijk niet gemeld omdat het handelen niet werd gelabeld als 'levensbeëindiging' maar als adequate stervensbegeleiding. Het acuut moeten handelen vanwege ernstig actueel lijden van de patiënt zou ook een rol gespeeld kunnen hebben omdat hierdoor het consultatiecriterium mogelijk moeilijk nageleefd kon worden. Een mogelijke reden waarom gevallen niet gemeld werden waarin het leven werd beëindigd omdat verwacht werd dat het kind ernstig zou gaan lijden in de toekomst, zou kunnen zijn dat de huidige regeling gericht is op het beëindigen van actueel lijden.

DEEL 2 – CULTURELE ASPECTEN

Door de praktijk van medische besluitvorming binnen en tussen landen te vergelijken, onderzochten we wat de invloed van culturele aspecten zou kunnen zijn. In **hoofdstuk 7** werd onderzocht of levenseindebeslissingen voor autochtone Nederlanders verschilden van die voor niet-westerse migranten in Nederland. Voor niet-westerse migranten werd de volgende definitie gebruikt: "in Nederland woonachtig en tenminste 1 ouder geboren in Afrika, Latijns-Amerika of Azië (uitgezonderd Indonesië en Japan)". Euthanasie werd uitgevoerd in 2.4% van alle niet-plotselinge sterfgevallen van niet-westerse migranten; onder autochtonen was dit percentage 2.7%. Het percentage waarin intensieve pijn- of symptoombestrijding met een mogelijk levensbekortend effect had plaatsgevonden was iets lager onder niet-westerse migranten (30% versus 38%). Het percentage sterfgevallen waarbij van mogelijk levensverlengende handelingen was afgezien was ongeveer gelijk in de twee groepen, maar ging gepaard met verschillende kenmerken: er werd significant minder vaak afgezien van kunstmatige voeding en vocht voor niet-westerse migranten dan voor autochtone Nederlanders (12% versus 28%) terwijl er bij autochtone Nederlanders minder vaak werd afgezien van kunstmatige beademing (38% versus 16%). Deze verschillen suggereren dat culturele aspecten een rol spelen in medische besluitvorming in de laatste levensfase.

In **hoofdstuk 8** wordt de praktijk van het afzien van kunstmatige toediening van voeding en vocht (KVV) vergeleken voor 6 Europese landen: België, Denemarken, Italië, Zweden, Zwitserland en Nederland. Beslissingen om af te zien van KVV werden het minst vaak genomen in Italië (2.6% van alle sterfgevallen) en het vaakst in Nederland (11%). In de meeste landen betroffen beslissingen om af te zien van KVV het vaakst vrouwelijke

patiënten, patiënten ouder dan 80 jaar, en patiënten die stierven als gevolg van kanker of een ziekte aan het zenuwstelsel (waaronder dementie). Patiënten bij wie was afgezien van KVV ontvingen niet méér mogelijk levensbekortende medicatie om symptomen te verlichten dan patiënten voor wie andere medische beslissingen rond het levenseinde waren genomen. Deze bevinding kan worden beschouwd als een indicatie dat het afzien van KVV geen extra lijden met zich meebracht. In **hoofdstuk 9** werd vervolgens gekeken naar KVV bij patiënten met ernstige dementie. Hiervoor werden Nederlandse en Australische artsen geïnterviewd. De onderwerpenlijst die hiervoor werd gebruikt bestond uit twee onderdelen: (1) open vragen naar algemene ervaringen met ernstig demente patiënten, en (2) open vragen over de twee meest recente gevallen van patiënten met ernstige dementie bij wie KVV was gestaakt of niet ingesteld. Nederlandse en Australische artsen hanteren vergelijkbare overwegingen wanneer zij beslissen over KVV: uitgangspunt is dat ernstig demente patiënten geen KVV ontvangen. Artsen uit beide landen blijken echter bereid te zijn KVV toe te dienen in specifieke situaties. Verschillen tussen de Nederlandse en Australische artsen werden gevonden in de manier waarop de besluitvorming tot stand kwam. De Nederlandse zorgbenadering is voornamelijk holistisch; een uitgebreide beoordeling van de actuele situatie van de patiënt en zijn/haar levensverhaal zijn bepalend in de besluitvorming. De Australische zorgbenadering daarentegen lijkt voornamelijk analytisch; objectieve maten en wetenschappelijk bewijs spelen een bepalende rol in de besluitvorming.

Discussie

In **hoofdstuk 10** worden de belangrijkste bevindingen van dit proefschrift samengevat en wordt afgesloten met een algemene discussie waarin enkele implicaties voor beleid en praktijk en verder onderzoek worden besproken.

Het Nederlandse systeem van melding en toetsing van euthanasie en hulp bij zelfdoding lijkt een zorgvuldige procedure voor maatschappelijke controle te bewerkstelligen. Er blijft echter ruimte voor verbetering op detail punten. De interpretatie van de zorgvuldigheidscriteria is bijvoorbeeld niet in alle gevallen duidelijk en dient daarom continu onder de aandacht te blijven. Hetzelfde geldt voor de huidige richtlijnen voor actieve levensbeëindiging bij nuljarigen; het kritisch onder de loep nemen van de regelgeving kan de bereidwilligheid onder artsen om gevallen te melden vergroten. Ook dienen de rol en effecten van opioïden en sedativa in verschillende klinische situaties onder de aandacht te blijven door middel van onderzoek, voorlichting en debat.

Het blijvend monitoren van de praktijk van medische besluitvorming in de laatste levensfase is gewenst, mede omdat het aantal meldingen van euthanasie is gestegen sinds 2003. Regionale verschillen dienen hierbij ook meegenomen te worden. De bevindingen in dit proefschrift zijn een indicatie dat de medische praktijk beïnvloed zou kunnen worden door de taal die artsen gebruiken. Methoden waarbij taalgebruik nader wordt bestudeerd, zoals critical discourse analysis, zou het inzicht in de werking van de huidige toetsingsprocedure kunnen vergroten. Tot slot wordt in dit hoofdstuk benadrukt dat in studies naar de invloed van cultuur, het begrip ‘cultuur’ goed gedefinieerd moet worden. Binnen dergelijk onderzoek dienen naast het artsenperspectief ook de perspectieven van verpleegkundigen, familie en patiënten meegenomen te worden.

Dankwoord

Hoe oud ben je? Ben je arts? Heb je dit persoonlijk meegemaakt? Deze vragen zijn me de afgelopen jaren vaak gesteld wanneer ik over mijn onderzoek begon te vertellen. Ik zei dan altijd dat een erg leuke vacature in de Volkskrant mij tot dit onderzoek had gebracht. Tussen het krijgen van deze baan in juni 2005 en dit moment is er veel gebeurd en heb ik veel geleerd; over euthanasie en andere medische beslissingen in de laatste levensfase, over medische ethiek, maar ook over mezelf. Net als de artsen die staan beschreven in enkele hoofdstukken van dit proefschrift 'labelde' ik. Om het niet zwaarder te maken dan nodig, was ik bijvoorbeeld geen 'promovendus' maar een 'junior' en ik sprak ook liever over mijn toekomstige 'boekje' dan over een 'proefschrift' met bijbehorende 'dissertatie'. Maar nu ik dit dankwoord aan het schrijven ben, merk ik dat die dissertatie nu wel komen mag. Het was niet altijd even makkelijk, maar terugkijkend was het wel een hele inspirerende en plezierige tijd!

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('blz 19' ☺) bezorgden mij af en toe hoofdbrekens, maar het was me een waar genoegen! Ook alle andere EEWers, leden van de promotiecommissie, co-auteurs van artikelen, en alle respondenten die tijd vrijmaakten om deel te nemen aan het onderzoek: dank jullie wel.

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About the author

Curriculum Vitae

Hilde Buiting werd geboren op 13 oktober 1980 in Zutphen. In 1999 behaalde ze haar gymnasiumdiploma aan het Staring College in Lochem en startte ze met de studie Voeding en Gezondheid aan de Wageningen Universiteit in Wageningen. Zij specialiseerde zich in Voedingsleer op een voedselconsumptieonderzoek onder schoolgaande kinderen in Benin, en in Public Health op een vragenlijstonderzoek naar het gebruik van 'Functional Foods' aan het RIVM (Rijksinstituut voor Volksgezondheid en Milieu). In 2003 kreeg zij een beurs van Wageningen Universiteit om zich 1 jaar full-time bezig te houden met de organisatie van de introductiedagen voor eerstejaars studenten. In 2004 behaalde ze haar doctoraal. Vervolgens bleef zij werken voor de afdeling Humane Voeding en Epidemiologie aan de Wageningen Universiteit. In juni 2005 werd ze aangesteld als junior onderzoeker aan de afdeling Maatschappelijke Gezondheidszorg van het Erasmus MC en voerde het onderzoek uit wat resulteerde in dit proefschrift. Tijdens dit promotieonderzoek deed zij in de periode augustus – oktober 2008 onderzoek aan de University of Sydney, Australië. Sinds januari 2009 is zij als onderzoeker werkzaam aan het EMGO$^+$ instituut (Vrije Universiteit) op de evaluatie van SCEN ('Steun en Consultatie bij Euthanasie in Nederland'). Sinds november 2009 is zij daarnaast werkzaam aan de afdeling Wijsbegeerte (Universiteit van Amsterdam) waarbij zij onderzoek doet naar indirect paternalisme.

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PhD portfolio Summary
Summary of PhD training and teaching activities

Name PhD student: Hilde Buiting
Erasmus MC Department: Public Health

PhD period: June 2005-May 2009
Promotors: Prof.dr. P.J. van der Maas
Prof.dr. J.J.M. van Delden
Supervisor: Dr. A. van der Heide

1. PhD training **General academic skills**	**Year**	**Workload** (hours / ECTS)
Academic Writing in English for PhD students, EUR, Rotterdam	2005	40 hours / 1,4 ECTS
Research skills		
Erasmus Summer programme, Erasmus MC, Rotterdam - Methods of Public Health Research - History of epidemiologic ideas	2006	40 hours / 1,4 ECTS
Radboud University Nijmegen Medical Centre, Department of ethics, philosophy and history of medicine - Advanced course suffering, death and palliative care	2007	20 hours / 0,7 ECTS
International Observatory on End of Life care, Lancaster - Research summer school	2008	40 hours / 1,4 ECTS
Presentations		
-Research Forum for the European Association for Palliative care (EAPC), Italy, Venice: *Forgoing artificial nutrition and hydration in six European countries*	2006	20 hours / 0,8 ECTS
- Research meeting, Department of Public Health, Rotterdam *End-of-life decision-making for non-western migrants and Dutch natives*	2007	10 hours / 0,4 ECTS
- Erasmus MC (LFMB), Rotterdam *Physicians' labeling of end-of-life practices*	2008	15 hours / 0,5 ECTS
- Erasmus MC, EMC onderzoeksgroep naar zorg en besluitvorming in de laatste levensfase, Rotterdam *End-of-life decision-making for non-western migrants and Dutch natives in the Netherlands*	2008	10 hours / 0,4 ECTS
- Agora, ondersteuningspunt Palliatieve Zorg, Rotterdam *Physician's labeling of end-of-life practices*	2008	10 hours / 0,4 ECTS
- Research Forum for the European Association for Palliative care (EAPC), Norway, Trondheim ▪ *Physician's labeling of end-of-life acts* ▪ *End-of-life decision-making for non-western migrants and Dutch natives in the Netherlands*	2008	20 hours / 0,4 ECTS
- Centre for Medical Psychology (University of Sydney), Sydney *Thesis presentation*	2008	15 hours / 0,5 ECTS

1. PhD Training	**Year**	**Workload** (hours / ECTS)
- Research meeting, Department of Public Health, Rotterdam *Artificial nutrition and hydration for patients with advanced dementia – Perspectives from medical practitioners in the Netherlands and Australia*	2008	10 hours / 0,4 ECTS
- Julius Centre (Utrecht) and Department of Medical Ethics (Ministry of Public Health), Utrecht *Thesis presentation*	2009	10 hours / 0,4 ECTS
- Agora, ondersteuningspunt Palliative Zorg, Rotterdam *Internationale ervaringen*	2009	5 hours / 0,2 ECTS
- International Association of Gerontology and Geriatrics (IAGG), France, Paris *Artificial nutrition or hydration for patients with advanced dementia – Perspectives from medical practitioners in the Netherlands and Australia*	2009	10 hours / 0,4 ECTS
International conferences		
- 4th Research Forum of the European Association for Palliative care (EAPC), Italy, Venice	2006	24 hours / 0,9 ECTS
- 9th Public Health Symposium, Belgium, Brussels	2007	8 hours / 0,3 ECTS
- 5th Research Forum of the European Association for Palliative care (EAPC), Norway, Trondheim	2008	24 hours / 0,9 ECTS
- 19th International Association of Gerontology and Geriatrics (IAGG) Congress, France, Paris	2009	24 hours / 0,9 ECTS
Seminars and workshops		
- Attending seminars of the Department of Public Health	2005-2009	100 hours / 3,5 ECTS
- Attending seminars of Agora	2005-2009	20 hours / 0,8 ECTS
- Journal clubs of Department of Public Health	2005-2009	40 hours / 1,6 ECTS
2. Teaching activities		
Supervising practicals and excursions		
Curriculum medical students, 4th year, Erasmus MC Rotterdam - Theme 4.2: The population as a patient	2005 2006 2007	15 hours / 0,5 ECTS 15 hours / 0,5 ECTS 15 hours / 0,5 ECTS
Supervising Masters' thesis		
	2008	60 hours / 2,4 ECTS