Medical Decision-Making at the End of Life

Experiences and attitudes of physicians and the general public

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Kvernes

Soms, onvoorzien, kom je aan
waar je wilt zijn, je ligt in het gras,
ogen dicht. Wat je zag: de weerspiegelde
blauwende bergen, van oever naar
oever een veerboot een stip in het diepe
rimpelend water, naast je de houten
stafoude kerk van Kvernes, onder
bomen bemost van zijn doden de steen –

beeld in je hoofd is het al, dat dit
deelt met je tastende hand langs de
kerkwand, de stap van je voet van
grafsteen naar grafsteen, je ligt met je
rug aan de rotsgrond, een fluister-
wind in je oorschelp, je ademt het
gras in, de geurloze warmte van
nazon, deze heldere noordse

september: hier ben ik – en even geen
denkwerk, zintuiglijker levend een
waarheid, dit alles, dat samen het
blijvende uitbeeldt (alsof niet
ergens een mens wordt vermoord op zijn
vlucht voor de honger, alsof niet), dit
heelzijn achter mijn huiddunne ooglid – toch
als gewoonlijk wint weer bewoording: zo

herbergt mijn hier nu verzadigd gestrekte
en voor mijzelf met welk geloofwaardig
innerlijk oog als vanboven daar in het
gras aan de fjordkust waarneembaar
rustende lichaam een landschap: het
werd wat het waarnam, maar weet dat, dus
blijft niet – want nergens, zelfs hier
niet, kan aankomst voorgoed zijn.

C.O. Jellema

Contents

1

Introduction

1.1 Background of end-of-life decision-making

During the past century, circumstances in which people die have substantially changed. Acute deaths due to infectious diseases have been gradually replaced by more prolonged dying trajectories.[1] Currently, one third of all deaths in the Netherlands occur suddenly and unexpectedly.[2, 3] The remaining two-third is non-sudden, and likely to involve a certain extent of end-of-life care. In these cases, patients, relatives and physicians together have to make decisions about the most appropriate medical end-of-life treatment. Developments in modern medicine have increased the possibilities to treat symptoms of terminally ill patients and to prolong their life. However, prolonging life is not always the most appropriate goal of medicine at this stage in life and preserving quality of life and alleviating suffering are increasingly recognized as important.[4] Sometimes, hastening of death can be an accepted or even appreciated result of end-of-life care.

1.2 Overview of end-of-life decisions

In this thesis, medical decisions that probably or certainly hasten death are referred to as *medical end-of-life decisions*. Such decisions can be characterized by several aspects: the acts of the physician (e.g. administering drugs or forgoing treatments); the intention of the physician (death can be explicitly intended, partly intended, or only taken into account); the involvement of the patient (actively involved in the decision-making process or not) and the life-shortening effect of the acts. Based on these characteristics, end-of-life decisions can be distinguished into five categories: euthanasia, physician-assisted suicide, ending life without an explicit patient request, alleviation of pain and symptoms with possible life-shortening effect, and non-treatment decisions (see Box 1).

Frequencies of end-of-life decisions in the Netherlands

In the Netherlands, three nationwide studies have been conducted, providing an overview of the frequencies and major characteristics of end-of-life decisions.[3, 5-7] In the most recent study it was shown that 44% of all deaths in the Netherlands in 2001 were preceded by an end-of-life decision.[3, 5] The majority of these decisions concerned non-treatment decisions (20%) and alleviation of pain and symptoms with possible life-shortening effect (20%); euthanasia was shown to precede 2.6%

of all deaths, physician-assisted suicide 0.2%, and ending life without an explicit patient request 0.7%.

Box 1 End-of-life decisions

1. Euthanasia: the administration of drugs with the explicit intention to end life at explicit request of the patient
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 at explicit request of the patient
3. Ending life without an explicit patient request: the administration of drugs with the explicit intention to end life without an explicit request of the patient
4. Alleviation of pain and symptoms, taking into account the possibility that death will be hastened or partly with the intention to hasten death
5. Non-treatment decisions: the withholding or withdrawing of treatment, taking into account the possibility that death will be hastened or with the explicit intention to hasten death

Frequencies of end-of-life decisions in other countries

The third Dutch nationwide study of frequencies and characteristics of end-of-life decision-making in 2001 was also similarly conducted in five other European countries: Belgium, Denmark, Italy, Sweden and Switzerland.[2] In all participating countries, end-of-life decisions were found to frequently precede deaths, ranging from 23% of all deaths (Italy) to 51% (Switzerland).[2] Contrary to the Dutch situation, in the five studied countries, euthanasia occurred less often than ending life without an explicit patient request. For Belgium, these percentages were 0.30% and 1.50%, respectively; for Denmark 0.06% and 0.67%; Italy 0.04% and 0.06%; Sweden 0% and 0.23% and Switzerland 0.27% and 0.42%. Alleviation of pain and symptoms and non-treatment decisions occurred more frequently than euthanasia and ending life without an explicit patient request in all countries.

Another nationwide estimate of the rate of end-of-life decisions has been made for Australia[8]. In Australia, rather high rates were found: 65% of all deaths in 1996 were preceded by an end-of-life decision.[8] Euthanasia was found to precede 1.7% of all deaths and ending life without an explicit patient request 3.5%. Other studies show that physicians in other countries are also confronted with patients who request euthanasia or assistance in suicide.[9-12] About 18% of the physicians in the United States reported to have ever received such a request, and about 6% reported to have complied with such requests at least once.[10] In England, approximately 9% of all physicians indicated to have ever complied with a

patient's request to take active steps for death to be hastened.[12] This percentage was 6% among Norwegian physicians[11] and 6-11% among German physicians.[9]

1.3 Terminal sedation

When regular treatment of severe symptoms in the last phase of life with e.g. analgesics or anxiolytics is not effective, sedatives are sometimes used as an alternative to render patients unconscious and subsequently oblivious to their symptoms.[13, 14] It is not uncommon to forgo life-sustaining treatment such as artificial nutrition or hydration in these patients, since most of them are in the dying phase. In this thesis, this practice is referred to as 'terminal sedation', defined as: "administering drugs to keep the patient continuously in deep sedation or coma until death without giving artificial nutrition or hydration". The practice of terminal sedation has been much debated in the Netherlands as well as in other countries. An important issue in such debates is whether it should be considered an end-of-life decision, that is, a decision that intentionally or unintentionally hastens death.[15-21] However, so far, little is known about the frequency and characteristics of this practice.

1.4 Legal background in the Netherlands and other European countries

The Netherlands

Euthanasia and physician-assisted suicide have been actively discussed in the medical profession, public domain, and the national parliament for several decades in the Netherlands. These practices are not considered as "normal medical practice" and therefore the Dutch parliament decided they should be reviewed. As from 1991, Dutch physicians had to report to the Public Prosecutor all cases in which they administered or supplied lethal drugs with the explicit intention to hasten the patient's death. Physicians were not prosecuted when they had met the criteria for prudent practice (see Box 2).

In 1998, the notification procedure was revised and the Public Prosecutor assessed cases only after being advised by a multidisciplinary committee of a medical, a legal and an ethical specialist. In 2002, the "Ending of Life on Request

and Assisted Suicide Review Procedures Act 2001" (Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding) came into force.[22] This Act made euthanasia and physician-assisted suicide officially no longer liable to penalty, provided that the physician had met the official criteria for prudent practice. The multidisciplinary committee informs the Public Prosecutor only about cases in which the criteria for prudent practice were not met. The Act further permits active ending of life for competent children aged 16 to 18 years provided that the parents are involved in the decision-making process and for competent children aged 12-16 years provided that the parents agree with the decision. Active ending of life for incompetent patients is only allowed for patients with an advance directive upon the active ending of life.
Non-treatment decisions, alleviation of pain and symptoms with possible life-shortening effect, and terminal sedation are considered to be part of normal medical practice and do not need to be legally assessed.

Box 2 Criteria for prudent practice

- A voluntary and well-considered request of the patient
- Unbearable and hopeless suffering
- No acceptable alternatives for treatment
- Consultation of another physician
- A medico-technical appropriate performance of euthanasia or physician-assisted suicide
- Reporting the case as an unnatural death

Other European countries

In this thesis, data from studies conducted in Belgium, Denmark, Italy, Sweden and Switzerland are used. Euthanasia and physician-assisted suicide are both prohibited in Denmark, Italy, and Sweden. In Switzerland, euthanasia is prohibited, but physician-assisted suicide is not a criminal act if it is motivated by altruistic considerations. Both physicians and citizens are allowed to perform physician-assisted suicide in Switzerland. In Belgium, euthanasia is allowed under certain conditions since 2002, while the status of physician-assisted suicide is unclear.

1.5 The perspective of the general public

During the last century, it is increasingly acknowledged that end-of-life care should be patient centered.[4] Patients and relatives have become more involved in medical decision-making and people increasingly want to experience some sense of control over their dying trajectory.[23] It is therefore important to know patients' preferences and attitudes concerning end-of-life care. However, a large study from the U.S.A. revealed that the end-of-life care provided is often not consistent with the patients' preferences, who frequently receive many medical interventions that they do not appreciate.[24] Apparently, communication between patients, physicians and relatives about such preferences is often not optimal or not timely.[25, 26] The timing of discussing end-of-life preferences is especially important since the majority of patients for whom end-of-life decisions are made are incompetent.[2] Discussion of patients' preferences at an early stage of their disease might enable patients to engage in medical decision-making concerning the end of their life. Although such advance care planning is generally assumed to be particularly relevant for older and sick people, a study of Emanuel et al. among patients and members of the general population showed that 89% of the general population desire some kind of advance care planning, such as filling out an advance directive or discussing their wishes concerning medical care at the end of life with their physician.[27] Such discussions before the patient becomes seriously ill may thus facilitate end-of-life decision-making.[28] It has been proposed that advance care planning should occur within the community and specifically within the family, and not only in hospitals when consulting a doctor.[29, 30]

Several studies have reported about the general public's acceptability of euthanasia and physician-assisted suicide. It has been shown that in the Netherlands as well as in other countries, the general public has a rather permissive attitude towards physician-assisted dying for terminally ill patients, even more permissive than attitudes of physicians.[31-34] As from 1966, the Social and Cultural Planning Office conducted surveys among the Dutch general public containing the question: "What should a doctor do when a patient asks him to put an end to his suffering by administering a lethal injection?".[35] The percentage of respondents who thought that euthanasia could be acceptable increased from nearly 50% in 1966, to about 90% in 1998. Another study, conducted in 1995 and replicated in 2001, used vignettes to elucidate attitudes of the Dutch public towards end-of-life decision-making.[36] This study showed that 83% (1995) and

88% (2001) of the respondents thought that euthanasia is acceptable for a terminally ill patient with unbearable suffering. Active ending of life in the case of a patient with dementia who asked for euthanasia in a living will and for persons without a serious illness requesting assistance in dying were only explored in the 2001 part of this study. The first was considered acceptable by about 80% of respondents, but in contrast, only about 25% accepted actively ending the life of persons without a serious illness.
Information about the public's acceptance of other end-of-life decisions such as increasing the dosage of morphine with possible life-shortening effect is scanty. Besides the study of Trappenburg et al, little is known about the public's acceptance of end-of-life decision-making in 'special' groups such as minors, patients with dementia, and patients without a serious disease, even though the acceptability of end-of-life decision making in such groups is actively discussed in the medical profession, public domain, and the national parliament.

1.6 Research questions

In this thesis, two main subjects will be addressed: medical decision-making practices at the end of life and attitudes of the Dutch general public and physicians toward such practices. The first part is focused on the practice of terminal sedation and active ending of life without an explicit patient request, in the Netherlands and in 5 other European countries. The second part explores attitudes of the Dutch public and physicians towards medical end-of-life decision-making, and includes newly discussed issues such as active ending of life in minors, patients with dementia, and patients without a serious disease. This part also addresses factors considered important for a good death. The following research questions will be addressed:

Medical end-of-life practices

1. What is the frequency and what are the characteristics of the practice of terminal sedation in the Netherlands and in other European countries? (Chapter 2 and 3)
2. What are the differences and similarities between the practice of terminal sedation and euthanasia? (Chapter 4)

3. What are the characteristics of the practice of using drugs to end life without an explicit patient request? (Chapter 5)

Attitudes towards medical decision-making at the end of life

4. What are the attitudes of the Dutch general public towards different types of end-of-life decisions in various situations, and in what aspects do they differ from attitudes of physicians? (Chapter 6)
5. What factors are important for a good death according to the Dutch general public, and how are these factors related to preferences for end-of-life decision-making? (Chapter 7)
6. What are the attitudes of the Dutch general public towards the use of life-prolonging treatments that might seriously impair their quality of life? (Chapter 8)

1.7 Methods

For this thesis, data from three different studies were used: interviews with physicians, death certificate studies among physicians, and a survey among the Dutch general public. This paragraph describes the main characteristics of these studies. The Dutch data were collected in a large-scale study that was conducted to evaluate the Dutch review procedure for physician-assisted death.

Interview study

We interviewed a stratified random sample of 410 physicians, including 125 general practitioners, 77 nursing-home physicians, and 208 clinical specialists. To be selected for the study, respondents had to be actively practicing medicine at the time of the interview and had to have done so in the previous two years in the same specialty and place. To arrive at the desired number of 410 physicians, 482 physicians were sampled (response: 85%). Physicians who were trained to administer the questionnaire conducted the face-to-face interviews. The interview period was March 2002 to October 2002. Strict rules were applied to ensure the anonymity of the physicians and patients studied. The respondents were asked to detail their most recent case of several end-of-life decisions, including euthanasia and terminal sedation. Furthermore, hypothetical case descriptions were presented and physicians were asked whether they would be willing to perform

euthanasia, to use terminal sedation, or to increase the dosage of morphine with possible life-shortening effect in these cases.

Death certificate studies

In 1995 and 2001, random samples were drawn from the central death registry of Statistics Netherlands, to which all deaths are reported. In both years, the period studied was August to December. All deaths reported during the sampling period were stratified in 5 strata for the likelihood that an end-of-life decision had preceded death. The sampling fractions were higher for strata in which the cause of death made an end-of-life decision more likely. The study design ensured anonymity for all deceased patients and precluded identification of any physician. A 4-page questionnaire was sent to the attending physician for each death included in the samples. If death was not sudden and unexpected, the physician was asked whether he or she had made any decision that might have hastened death, and details were asked about the decision-making. The response was 77% in 1995 and 74% in 2001. The final sample sizes were n=5617 in 2001 and n=4678 in 1995. As part of a larger study on end-of-life decision-making in Europe, the EURELD study, the 2001 study was simultaneously conducted in 5 other European countries: Belgium (regio of Flanders), Denmark, Italy (area of Emilia-Romagna, Trento, Tuscany, and Veneto), Sweden and Switzerland (German speaking part). The questions and study designs that were used to collect the data in these studies were identical to those in the Dutch study. The response was 59% in Belgium (n=2950), 62% in Denmark (n=2939), 44% in Italy (n=2604), 61% in Sweden (n=3248) and 67% in Switzerland (n=3355).

Survey among the general public

Written questionnaires were sent to an established sample frame of members of the Dutch general public (Panel of the "Consumentenbond"; NIVEL). The sample consisted of people aged between 20 and 93 years old, and is considered to be representative of the Dutch population older than 18 years old. Of the selected respondents, 1388 completed the questionnaire (response: 78%). Items in the questionnaire referred to attitudes and opinions about different types and situations of end-of-life decision-making.

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2

Physician Reports of Terminal Sedation without Hydration or Nutrition for Patients Nearing Death in the Netherlands

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Abstract

Background Terminal sedation in patients nearing death is an important issue related to end-of-life care.
Objective To describe the practice of terminal sedation in the Netherlands.
Design Face-to-face interviews.
Participants Nationwide stratified sample of 482 physicians; 410 responded and 211 of these reported characteristics of their most recent terminal sedation case.
Measurements Physician reports of frequency of terminal sedation (defined as the administration of drugs to keep the patient in deep sedation or coma until death, without giving artificial nutrition or hydration), characteristics of the decision-making process, drugs used, the estimated life-shortening effect, and frequency of euthanasia discussions.
Results Of respondents, 52% (95% CI, 48% to 57%) had ever used terminal sedation. Of the 211 most recent cases, physicians used terminal sedation to alleviate severe pain in 51% of patients (CI, 44% to 58%), agitation in 38% (CI, 32% to 45%), and dyspnea in 38% (CI, 32% to 45%). Physicians reported discussing with patients the decision to use deep sedation in 59% of the 211 most recent cases (CI, 52% to 66%) and the decision to forgo artificial nutrition or hydration in 34% (CI, 28% to 41%). Hastening death was partly the intention of the physician in 47% (CI, 41% to 54%) of cases and the explicit intention in 17% (CI, 13% to 22%) of cases.
Limitations The generalizability of physician reports about their most recent cases to all terminal sedation cases is uncertain. In addition, the findings are subject to recall bias and may not apply to other geographic settings.
Conclusions Terminal sedation precedes a substantial number of deaths in the Netherlands. In about two thirds of most recently reported cases, physicians indicated that in addition to alleviating symptoms, they intended to hasten death.

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2.1 Introduction

Patients nearing death frequently have symptoms such as dyspnea, agitation, pain, and anxiety.[1,2] One of the most important goals of the medical care provided to these patients is the alleviation of these symptoms.[3] If treatment with analgesic or anxiolytic agents is not effective, sedatives are sometimes used as an alternative to render patients unconscious and then oblivious to their symptoms.[4,5] Subsequently, if artificial nutrition and hydration are not given, death will follow soon.

The ethical debate about this practice focuses on the extent to which it should be considered an end-of-life decision that possibly or certainly hastens death. Previous studies have explored the differences and similarities with other end-of-life decisions, such as euthanasia and physician-assisted suicide.[6-19] However, little information exists on the medical practice of deep sedation with the forgoing of artificial nutrition or hydration in patients nearing death. Estimates about the frequency of deep sedation at the end of life vary from 15% to more than 60%, depending on the settings studied and the definitions used.[4,5,20-26]The terminology used reflects these differences in definition of the practice of deep sedation at the end of life. Although "terminal sedation" is the most commonly used term, other frequently used terms, which demonstrate the different perspectives from which this practice is viewed, are "sedation for intractable distress in the imminently dying," "palliative sedation therapy," "slow euthanasia," "opioid coma," or "anesthetic coma".[6,27-30]

The present study describes the practice of terminal sedation in the Netherlands. This study was part of the evaluation of the notification procedure for physician-assisted death in the Netherlands, which was commissioned by the ministers of Health and Justice.[31]

2.2 Methods

Respondent characteristics

We interviewed a nationwide sample of 410 physicians: 208 clinical specialists, 125 general practitioners, and 77 nursing home physicians. In the Netherlands, clinical specialists provide hospital care, general practitioners provide nonspecialized care outside the hospital, and nursing home physicians work in

long-term care institutions mainly for elderly people. The proportions of deaths in these health care settings are approximately 35%, 42%, and 23%, respectively. The specialties involved in our study covered about 95% of all deaths in the Netherlands in 2001. The respondents were selected according to the following criteria: They were required to be in active practice at the time of the interview and to have actively practiced medicine within the registered specialty for the past 2 years in the same setting. All addresses were taken from the professional registries of the relevant specialties. To arrive at the desired number of 410 physicians, we sampled 482 physicians. Seventy-two physicians (15%) declined to take part in the study: 17% of clinical specialists, 18% of general practitioners, and 3% of nursing home physicians. Nonresponders did not differ in age from responders.

Face-to-face interviews were conducted by experienced part-time working or recently retired physicians who were trained to administer the structured questionnaires. All interviews took place between March 2002 and October 2002. We applied strict rules to ensure the anonymity of all physicians and patients studied.

Interview Process

The interview schedule addressed experiences with end-of-life decision making. Terminal sedation was defined as the administration of drugs to keep the patient in deep sedation or coma until death, without giving artificial nutrition or hydration. The respondents were first asked whether they had ever used terminal sedation and, subsequently, how often they had performed this practice in 2000 and 2001. Additional questions about the practice of terminal sedation concerned the physician's most recent patient to have received terminal sedation (n=211). The physicians were asked about the patient's characteristics; whether or not sedation or the forgoing of artificial nutrition or hydration had been discussed with the patient, family, or other health care professionals; the drugs used; the intention of the physician; the estimated life-shortening effect; and whether euthanasia was discussed during the decision process.

Statistical Analysis

We calculated all estimates about the occurrence of terminal sedation in the Netherlands by weighting the estimates of individual physicians. Weighting factors were based on differences in sampling fractions and response rates for the different specialties. These sampling fractions were 125 of 7027 for general practitioners, 77 of 810 for nursing home physicians, 34 of 394 for cardiologists, 34 of 545 for neurologists, 69 of 1321 for specialists in internal medicine, 35 of 325 for pulmonologists, and 36 of 769 for surgeons. The probabilities used to determine sampling weights were 1 in 56 for general practitioners, 1 in 11 for nursing home physicians, 1 in 12 for cardiologists, 1 in 16 for neurologists, 1 in 19 for specialists in internal medicine, 1 in 9 for pulmonologists, and 1 in 21 for surgeons.

Data on the 211 most recent patients seen by physicians were not weighted. All analyses were done by using SPSS software, version 10.0 (SPSS, Inc., Chicago, Illinois).

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.

2.3 Results

Most of the 410 physicians interviewed (76%) were men; 51% were clinical specialists, 30% were general practitioners, and 19% were nursing-home physicians (tables 2.1 and 2.2).

Of all physicians, a weighted percentage of 52% (95% CI, 48% to 57%) had ever practiced terminal sedation. This percentage was 55% (CI, 49% to 62%) for clinical specialists, 48% (CI, 39% to 57%) for general practitioners, and 75% (CI, 64% to 83%) for nursing home physicians (data not shown).

Table 2.1 Characteristics of interviewed physicians

	Physicians n=410
	%
Sex	
Male	76
Female	24
Age	
30-44 year	35
45-54 year	45
≥55 year	20
Specialty	
Clinical specialist	51
General practitioner	30
Nursing-home physician	19

We asked all interviewed physicians to estimate the total number of times they performed terminal sedation in 2000 and 2001. These numbers were extrapolated to the total number of 140 377 deaths in 2001 by multiplying them with the weighting factor for each specialty and assuming that the numbers were similar for the 5% of deaths covered by hospital doctors from specialties other than the ones included in our study. This extrapolation suggests that physicians used terminal sedation in 10.0% (CI, 9.1% to 10.8%) of all deaths in that year. Of the 10.0% of deaths preceded by terminal sedation, 5.5% (CI, 5.0% to 6.1%) were attended by clinical specialists, 2.5% (CI, 1.9% to 3.2%) by general practitioners, and 2.0% (CI, 1.7% to 2.2%) by nursing home physicians.

Table 2.2 Proportion of deaths per specialty[1]

	Deaths n=140377
	%
Clinical specialist	35
General practitioner	42
Nursing-home physician	23

1. Source: Statistics Netherlands; Central Death Registry 2001[32]

Of all physicians who had ever used terminal sedation, 211 provided information about their most recent cases of terminal sedation (103 clinical specialists, 53 general practitioners, and 55 nursing home physicians). Of these most recent cases, 78% (CI, 72% to 83%) involved patients 65 years of age or older and 54% (CI, 47% to 60%) involved patients who had cancer (table 2.3). Clinical specialists and nursing home physicians also frequently reported practicing terminal sedation

in patients with cardiovascular diseases. The most frequently mentioned reasons for using terminal sedation were the alleviation of pain (51% [CI, 44% to 58%]), agitation (38% [CI, 32% to 45%]), dyspnea (38% [CI, 32% to 45%]), and anxiety (11% [CI, 8% to 16%]).

Table 2.3 Characteristics of the sample consisting of each physician's most recent case of terminal sedation[1]

	Sample consisting of physician's most recent case n=211		All deaths in the Netherlands in 2001 n=140377
	n	%	%
Sex			
Male	99	47	49
Female	112	53	51
Age[2]			
0-64 year	46	22	20
65-79 year	88	42	35
≥80 year	76	36	46
Main diagnosis			
Cancer	113	54	27
Cardiovascular diseases	51	24	25
Pulmonary diseases	14	7	10
Nervous system diseases	17	8	11
Other	16	8	27
Reason for deep sedation[3]			
Pain	108	51	NA
Agitation	80	38	NA
Dyspnea	80	38	NA
Anxiety	24	11	NA
Other	62	29	NA

1. NA = not available.
2. In 1 case, information on age was missing.
3. One or more answers possible.

In 59% (CI, 52% to 66%) of the most recent cases seen by physicians, the physician had discussed the sedation with the patient (table 2.4); in 33% (CI, 27% to 39%) of the cases, the patient had requested deep sedation. The main reasons for not discussing deep sedation with the patient were the fact that the patient was incompetent or subcomatose (25% [CI, 20% to 31%]). The decision to forgo artificial nutrition or hydration was discussed less frequently with the patient; the respondents reported discussing this topic in 34% (CI, 28% to 41%) of their most recent cases and receiving a request from the patient to forgo artificial nutrition or hydration in 9% (CI, 6% to 13%). Next to patient incompetence (37% [CI, 31% to 44%]), another frequently mentioned reason for not discussing the decision to forgo artificial nutrition or hydration was that many physicians perceived this not

as optional but rather as a given; they considered terminal sedation to preclude the concomitant use of artificial nutrition and hydration (23%; [CI, 18% to 29%]) (data not shown).

The decision to use sedation was discussed with relatives of the patient in 93% (CI, 89% to 96%) of the most recent cases seen by physicians, and the decision to forgo artificial nutrition or hydration was discussed with relatives in 73% (CI, 67% to 79%) of the most recent cases. The physicians had discussed the sedation with other caregivers in 79% (CI, 73% to 84%) of cases and had discussed forgoing artificial nutrition or hydration in 67% (CI, 60% to 73%) of cases. Clinical specialists, nursing home physicians, and general practitioners discussed the sedation with other physicians in 76% (CI, 67% to 83%), 38% (CI, 26% to 52%), and 29% (CI, 18% to 42%) of their most recent cases, respectively. Nurses were often involved in the decision making by clinical specialists and nursing home physicians. Specialists in palliative care from other institutions were rarely consulted. In 17% (CI, 12% to 22%) of the physicians' most recent cases, neither the sedation nor the forgoing of artificial nutrition or hydration was discussed with other caregivers, and in 1% (CI, 0% to 4%) of the cases, these decisions were not discussed with the patient, the relatives, or other caregivers (data not shown).

Most physicians recalled having administered benzodiazepines in their most recent cases of terminal sedation. Twenty-one percent (CI, 16% to 27%) of physicians used only these drugs; 35% (CI, 29% to 42%) combined benzodiazepines with morphine, and 4% (CI, 2% to 8%) combined benzodiazepines with another drug (table 2.5). In the remaining cases, physicians mostly used morphine. No physicians used barbiturates. General practitioners and nursing home physicians reported using benzodiazepines relatively frequently, which is in contrast to the clinical specialists, who were more likely to administer morphine only.

Of all physicians, 36% (CI, 29% to 42%) reported having made their most recent decision to perform terminal sedation without the intention of hastening death (table 2.6). The physicians had partly the intention to hasten death in 47% (CI, 41% to 54%) of cases and had the explicit intention to hasten death in 17% (CI, 13% to 22%) of cases. This explicit intention involved only the sedation in 2% (CI, 1% to 5%) of the physicians' most recent cases, only the forgoing of artificial nutrition or hydration in 14% (CI, 10% to 19%) of cases, and both sedation and the forgoing of artificial nutrition or hydration in 1% (CI, 0% to 4%) of cases.

Table 2.4 Discussion about deep sedation and forgoing artificial nutrition or hydration in each physician's most recent case of terminal sedation, by physician specialty

	Clinical specialists n=103		General practitioners n=53		Nursing-home physicians n=55		All physicians n=211	
	n	%	n	%	n	%	n	%
Deep sedation								
Discussed with patient	67	65	28	53	30	55	125	59
Requested by patient	36	35	19	36	14	25	69	33
Reason for not discussing[1]								
Patient was incompetent or sub-comatose	27	26	13	25	13	24	53	25
Deep sedation was clearly in the best interest of patient	4	4	4	8	6	11	14	7
Patient had dementia	2	2	1	2	12	22	15	7
Discussion would have done more harm than good	0	0	1	2	1	2	2	1
Other reason	5	5	5	9	3	5	13	6
Discussed with relatives[2]	94	91	48	92	53	96	195	93
Discussed with other caregivers[1, 2]	91	88	30	57	46	84	167	79
Another physician	78	76	15	29	21	38	114	54
Nurses	70	68	14	27	41	75	125	60
Specialists in palliative care from other institutions	3	3	5	10	0	0	8	4
Multidisciplinary pain management team	8	8	2	4	0	0	10	5
Other	4	4	6	12	4	7	14	7
Forgoing artificial nutrition and/or hydration								
Discussed with patient[3]	33	33	14	27	23	43	70	34
Requested by patient[3]	9	9	3	6	6	11	18	9
Discussed with relatives[3]	68	67	34	65	49	91	151	73
Discussed with other caregivers[1,4]	76	75	20	38	43	80	139	67
Another physician	58	57	10	19	14	26	82	39
Nurses	60	59	11	21	41	76	112	54
Specialists in palliative care from other institutions	3	3	1	2	0	0	4	2
Multidisciplinary pain management team	4	4	1	2	0	0	5	2
Other	1	1	4	8	4	7	9	4

1. One or more answers possible.
2. In 1 case, information was missing.
3. In 4 cases, information was missing.
4. In 3 cases, information was missing.

Table 2.5 Drugs used in each physician's most recent case of terminal sedation, by physician specialty[1]

	Clinical specialists n=103		General practitioners n=53		Nursing home physicians n=55		All physicians n=211	
	n	%	n	%	n	%	n	%
Only benzodiazepines	12	12	14	26	19	35	45	21
Benzodiazepines in combination with morphine or morphine derivatives[2]	35	34	17	32	22	40	74	35
Benzodiazepines in combination with other drugs (excl. morphine of morphine derivatives)	2	2	7	13	0	0	9	4
Only morphine or morphine derivatives	44	43	10	19	12	22	66	31
Morphine or morphine derivatives in combination with other drugs (excl. benzodiazepines)	4	4	4	8	2	4	10	5
All other drugs or combinations	5	5	1	2	0	0	6	3

1. In 1 case, information on drugs used was missing.
2. Possibly combined with other drugs.

Of the physicians reporting a recent case, 40% (CI, 34% to 45%) estimated that the patient's life had been shortened by 24 hours or less. In 27% (CI, 21% to 33%) of the cases, life was estimated to have been shortened by more than 1 week.

Thirty-seven percent (CI, 30% to 43%) of physicians discussed the option of euthanasia with the patient during the decision-making process. The main reasons for deciding against euthanasia were as follows: The patient preferred terminal sedation (9% [CI, 5% to 14%]); the patient did not explicitly request euthanasia (8% [CI, 5% to 12%]); and the patient viewed terminal sedation as less disturbing to the natural process of dying than euthanasia (4% [CI, 2% to 8%]).

2.4 Discussion

Terminal sedation is frequently used in end-of-life care in the Netherlands. Half of all physicians have practiced terminal sedation. Our study shows that terminal sedation preceded an estimated 10% (CI, 9% to 11%) of all deaths in the Netherlands. Another recent Dutch study with a different study design estimated

Table 2.6 Intention of the physician, estimated shortening of life, and discussion about euthanasia in each physician's most recent case of terminal sedation, by physician specialty

	Clinical specialists n=103		General practitioners n=53		Nursing home physicians n=55		All physicians n=211	
	n	%	n	%	n	%	n	%
Terminal sedation was used[1]								
Without the intention of hastening death[4]	35	34	17	32	23	42	75	36
Partly with the intention of hastening death[2]	51	50	25	47	24	44	100	47
With the explicit intention of hastening death[2]	17	17	11	21	8	15	36	17
Explicit intention concerned[1,2]								
Sedation	3	3	1	2	0	0	4	2
Forgoing artificial nutrition or hydration	14	14	7	13	8	15	29	14
Both sedation and forgoing artificial nutrition or hydration	0	0	3	6	0	0	3	1
Estimated shortening of life[3]								
No shortening or < 24 h	36	36	23	44	22	42	81	40
1-7 days	40	40	16	31	11	21	67	33
1-4 weeks	19	19	11	21	14	27	44	21
>1 month	6	6	2	4	5	10	13	6
Euthanasia discussed[4]	26	25	35	66	16	29	77	37
Reasons euthanasia was not performed								
Wish of the patient	4	4	11	21	4	7	19	9
No explicit patient request	5	5	8	15	3	5	16	8
Terminal sedation is palliative care, part of natural process of dying	6	6	3	6	0	0	9	4
No legal framework	3	3	3	6	0	0	6	3
Rapid dying process	1	1	3	6	2	4	6	3
Unknown / other	8	8	7	13	7	13	22	10

1. Forgoing artificial nutrition or hydration concerned the intention of "hastening death" or "not to prolong life".
2. Intention concerned either sedation or forgoing artificial nutrition or hydration.
3. In 6 cases, information on estimated shortening of life was missing.
4. In 1 case, information on whether euthanasia was discussed was missing.

the incidence of terminal sedation to be 4% of all deaths.[31] These percentages are lower than the previously reported percentages of 15% to 60% (4, 5, 20–24, 26). This difference is probably explained in part by the fact that the incidences found in most other studies do not refer to all deaths in a population but rather to deaths in a selected inpatient care setting, such as a hospital or a hospice.[4,5,20,22-25]

Another factor that may explain the higher rates of terminal sedation in other studies is our very specific definition of terminal sedation: Patients had to be deeply sedated or comatose, and patients receiving artificial nutrition and hydration were excluded. Other studies used less restrictive definitions. Some included moderately sedated patients, some included a majority of patients who were sedated intermittently, and none excluded patients receiving artificial nutrition and hydration.[4,5,20-24,26]

Clinical specialists performed half of all cases of terminal sedation, although they attended 35% of the total number of deaths in the Netherlands. Apparently, terminal sedation is more often practiced in a hospital than at home. This may be explained in part by the fact that in-hospital patients (especially those with cancer or cardiovascular disease) more often have severe symptoms or extreme exacerbations of conditions.

The sample of physicians' most recent cases of terminal sedation included about equal proportions of both sexes. Approximately one third of all deaths resulting from terminal sedation were in patients 80 years of age or older, whereas 46% of all deaths in the general population occurred in this age group.[33] The major reasons for using terminal sedation were to alleviate severe pain, agitation, dyspnea, and anxiety. In a review of 17 studies that addressed the use of sedatives in the care of patients with cancer who were in the final stages of life, a syndrome of delirium and agitation was the most frequently mentioned indication for sedative use; pain was a much less common reason for sedation.[21] However, most of these studies did not take into account the use of opioids. In addition, patients in some of these studies were only moderately sedated.

In our study, terminal sedation was performed with benzodiazepines in 60% of the most recent cases seen by physicians and with morphine or morphine derivatives in the remaining most recent cases seen. Other studies also found that benzodiazepines were most commonly used for deep sedation in patients nearing death. The use of opioids alone for deep sedation is regarded as less effective than the use of sedatives and may even be counterproductive.[8,21,22] Cherny and Portenoy have produced guidelines for the use of sedation for controlling symptoms; in their opinion, benzodiazepines are the most favored class of sedatives in palliative care worldwide.[34] Some researchers suggest that opioid use for relief of pain and other symptoms should be continued when sedation is being instituted to avoid the possibility of unobservable pain or symptoms of opioid withdrawal.[8] Opioids are frequently used in hospital settings to treat pain and

other symptoms. The relatively high proportion of morphine-induced cases of terminal sedation in our study may indicate that sedation was a consequence of pain and symptom management or of progression of the underlying disease.

In our study, terminal sedation was almost always discussed with relatives but not always with the patient, who was often no longer communicative. A remarkable finding was that general practitioners were much less likely to consult other physicians or caregivers. In addition, the physicians in our study rarely consulted specialists in palliative care from other institutions and rarely consulted pain management teams. General practitioners were less likely to involve nurses in decision making about terminal sedation than were other physicians. This may reflect the fact that nurses are less available to general practitioners than to physicians working in institutional settings.

If life-sustaining treatment, such as artificial nutrition or hydration, is forgone in patients nearing death, death will usually occur within a short time. However, in our study, 36% (CI, 29% to 42%) of the physicians made their most recent decision to perform terminal sedation without the intention of hastening death. The physicians had partly the intention to hasten death in 47% (CI, 41% to 54%) and the explicit intention to hasten death in 17% (CI, 13% to 22%) of cases. In most reported cases, this explicit intention concerned the decision not to give artificial nutrition or hydration. The estimated shortening of life was limited to less than 1 week in 73% (CI, 67% to 79%) of the most recently seen cases by physicians, indicating that the practice of terminal sedation is not restricted to patients for whom death was imminent.

When making the decision to perform terminal sedation, the physician may have considered euthanasia, that is, the administration of drugs with the explicit intention to end life at the patient's request. The Dutch euthanasia law was enacted in 2002, but from the early 1990s, physicians who met the official criteria for prudent practice were not prosecuted for performing euthanasia. Euthanasia was discussed in the course of the decision-making process in about 40% of the cases. Physicians reported that the main reasons for choosing terminal sedation rather than euthanasia were the patient's preference for terminal sedation to euthanasia and the patient's belief that terminal sedation was less intrusive than euthanasia on the natural dying process. In some cases, the physicians reported that euthanasia could not be performed because the patient did not fulfill the requirements (for example, an explicit patient request for euthanasia) of prudent

practice for euthanasia. In general, there was a lack of explicit request when the patient was incompetent or moribund.

In the Dutch context, there are some obvious ethical and practical differences between terminal sedation and euthanasia. By definition, euthanasia is the result of an explicit request of the patient. Such a request is not necessary for terminal sedation. However, the presence (33% in our study) or absence (59% in our study) of a patient's request or at least discussion with the patient can be important in the justification of terminal sedation. With euthanasia, patients die as a result of the administration of lethal drugs. By contrast, with terminal sedation, patients die naturally as a result of their disease (this is most likely when death occurs in a few days), as a result of forgoing artificial nutrition or hydration (when death occurs after more than a few days), or as a result of the administration of sedatives. In addition, physicians always use euthanasia with the explicit intention of hastening death, whereas hastening death is the primary intent in only a fraction of terminal sedation cases. Researchers have shown that approximately 2.6% of all deaths in the Netherlands are preceded by euthanasia; 20% are preceded by the alleviation of pain or symptoms; and 20% are preceded by decisions to withhold or withdraw potentially life-prolonging treatments.[33] Cases of terminal sedation in which hastening of death was not intended or taken into account cannot be considered to represent either of these end-of-life decisions. When physicians prescribe sedatives with the explicit intention of hastening death, their actions may be regarded as intentional ending of life.

Our study has several limitations. First, face-to-face interviews may be biased by interviewer interpretation. Moreover, the respondents may have felt obligated to give socially acceptable answers. We attempted to eliminate these biases by carefully selecting and training the interviewers and by ensuring strict anonymity of the respondents. Second, the respondents may have had difficulty recalling the patient's characteristics; however, recall bias was probably limited because most cases involved patients who died during the preceding 2 years. Third, the term "terminal sedation" can evoke different connotations and interpretations in respondents. We tried to avoid this problem by providing a very specific definition of the term. Last, our findings may not be generalizable to other countries because of the openness in Dutch society about end-of-life issues.

We conclude that terminal sedation precedes a substantial number of deaths in the Netherlands. Terminal sedation is an option that is used to alleviate severe symptoms in the last phase of life; in most cases, it shortens life to less than 1

week. According to our reports about physicians' most recent cases, terminal sedation is usually provided after discussion with the patient, relatives, and caregivers. In a limited number of cases, when the physician administers a sedative with the explicit intention to hasten death at the explicit request of the patient, terminal sedation seems to approximate the practice of euthanasia.

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3

Continuous Deep Sedation: Physicians' Experiences in Six European countries

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Abstract

Background Continuous deep sedation (CDS) is sometimes used to treat refractory symptoms in terminally ill patients. The aim of this paper was to estimate the frequency and characteristics of CDS in six European countries: Belgium, Denmark, Italy, the Netherlands, Sweden and Switzerland.

Methods Deaths reported to death registries were sampled and the reporting doctors received a mailed questionnaire about the medical decision-making that preceded the death of the patient.

Findings The total number of deaths studied was 20,480. The response rate ranged between 44% (Italy) and 75% (the Netherlands). Of all deaths, CDS was applied in 2.5% in Denmark and up to 8.5% in Italy. Of all patients receiving CDS, 35% (Italy) up to 64% (Denmark and the Netherlands) did not receive artificial nutrition or hydration. Patients who received CDS were more often male, younger than 80 years old, more likely to have had cancer, and died more often in a hospital compared to non-sudden deaths without CDS.

Interpretation The high variability of frequency and characteristics of continuous deep sedation in the studied European countries point out the importance of medical education and scientific debate on this issue.

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3.1 Introduction

Severe symptoms, sometimes defined as 'refractory', have high prevalence during the last days of life among terminal oncology and other diseases.[1-3] In such cases, sedation is an accepted procedure in palliative care.[4] In general, deep sedation is to be used only temporarily;[5] nonetheless, continuous deep sedation (CDS) may be the only means to control symptoms.[6]

It is already known that sedatives are rather frequently used to treat severely suffering patients nearing death. Within palliative care settings incidence estimates of the use of sedatives range from 15% to more than 60%.[7-13] Furthermore, a survey among palliative care specialists in North America and the U.K. showed that 77% of the respondents had at one time applied deep sedation in patients close to death.[14] A study from Japan showed that 64%-70% of a sample of palliative care physicians and oncologists reported having used some form of deep sedation for severe physical distress.[15] However, these estimates are difficult to compare due to differences in the settings studied and the definitions used. CDS without administering artificial nutrition and hydration is, by some authors, considered as a special kind of sedation ('terminal sedation') due to the intended or foreseen life-shortening effect.[16,17]

To gain more insight into the practice of CDS, more information on characteristics of sedated patients would be helpful. Previous studies reported that important indications for the use of sedatives in patients nearing death are intractable pain, dyspnea, delirium, agitation, and severe psychological symptoms such as anxiety and existential distress.[7,10-12,14,18,19] A nationwide Dutch study found that half of the cases of terminal sedation were performed by clinical specialists; 30% of the patients receiving terminal sedation were 80 years of age or older, and 54% were patients with cancer.[18] Further detailed and reliable information about characteristics of patients who receive CDS is needed.

In a recent death-certificate study about end-of-life decision-making in six European countries (EURELD),[20] physicians were also asked about the use of CDS. In this paper, we aim to present comparable population-based estimates for Belgium (Flanders), Denmark, Italy (four areas), the Netherlands, Sweden and Switzerland (German-speaking part) of the use of CDS with and without the use of artificial nutrition and hydration and to describe the characteristics of patients receiving CDS.

3.2 Methods

Design

In every participating country or region random samples of death certificates of people aged 1 year or older (Italy: 18 or older) were obtained from death registries. The sampling period varied from 3 to 6 months. All deaths arose between June 2001 and February 2002. In all countries (apart from Switzerland) all deaths reported during the sampling period were stratified for the likelihood that death had been preceded by an end-of-life decision. Based on the cause of death, all deaths were assigned to one of three (Belgium, Denmark, Italy and Sweden) or five (the Netherlands) strata. Sampling fractions were higher for strata in which the cause of death made an end-of-life decision more likely. Stratification was applied to enhance the efficiency and to yield smaller confidence intervals around estimates. Details have been described elsewhere.[20] In all countries the data-collection procedure precluded identification of any of the doctors or patients. A clearinghouse, usually a notary's office, was interposed in each participating country. No envelope that contained a returned questionnaire reached the researchers before all identifying information had been removed from the data set using a separate code system. An application to the Research Ethics Committee was required in all countries except in Denmark (where questionnaire research only has to be assessed by a Research Ethics Committee if it is part of a project involving biomedical research), in Switzerland (cantonal authority for data security confirmed anonymity of the data used in the study), and in the Netherlands (where the Royal Dutch Medical Association and the Health Inspectorate approved of the study).[21]

Questionnaire

For all sampled cases the attending physicians were asked if death had occurred suddenly and unexpectedly. If cases were reported to have been non-sudden, the attending doctors were asked to fill out a four-page questionnaire about the medical decision-making that had preceded the death involved. The penultimate item in the questionnaire dealt with CDS: "Did the patient receive drugs, such as barbiturates or benzodiazepines, to keep him/her continuously in deep sedation or coma until death?" Answering options were: "yes, and artificial nutrition and hydration were not given"; "yes, and artificial nutrition or hydration were given"; "no". This question was asked for all non-sudden deaths, except in the

Netherlands, where, due to a routing difference, the question was asked only if an end-of-life decision had preceded death.

Statistical analyses

If applicable, results were corrected for stratification by giving all cases a weight that is the reverse of the sampling fraction within the stratum they were assigned to. To allow the results to be representative of all deaths in the studied period an additional weight was calculated from age, sex, cause of death and place of death specific response rates. Absolute frequencies and weighted percentages on total studied deaths were reported. The prevalence of CDS was compared for different classes of sex, age, cause of death, and place of death. To calculate estimates for all countries together, an additional country-specific weighting factor (the inverse of the weighted number of deaths studied in each country) was applied. The statistical significance of differences in CDS prevalence was estimated by means of Pearson chi-squared statistic corrected for the survey design.[22] A logistic regression was fitted to the data to determine the independent association of each characteristic of deaths with CDS. The model considered non-sudden deaths without CDS as controls. Likelihood ratio tests were used to test statistical interactions. All the statistical analyses were made using the 'svy commands' of the statistical package STATA , release 8.[23]

3.3 Results

We studied 20,480 deaths. Response percentages ranged from 59% to 75%, except for Italy (44%). Table 3.1 shows that Italy and Belgium reported the highest percentages of CDS: 8.5% and 8.2% of all deaths, respectively, were preceded by the use of CDS. Denmark and Sweden reported the lowest frequencies: 2.5% and 3.2%, respectively, and Switzerland and the Netherlands were somewhat in between (4.8% and 5.7% of all deaths, respectively). The prevalence of CDS without the use of artificial nutrition and hydration varied less between countries (range 1.6% - 3.2%, Denmark and Belgium respectively). Of all sedated patients, 35%-64% did not receive artificial nutrition or hydration (Italy and Denmark/the Netherlands, respectively).

Table 3.1 Frequency of continuous deep sedation (CDS) in six European countries, by presence of artificial nutrition and hydration (ANH)

	Belgium			Denmark			Italy			The Netherlands[1]			Sweden			Switzerland		
Response percentage			59			62			44			75			61			67
Studied deaths			2,950			2,939			2,604			5,384			3,248			3,355
	n	%[2]	95% CI	n	%[2]	95% CI	n	%[2]	95% CI	n	%[2]	95% CI	n	%[2]	95% CI	n	%[2]	95% CI
CDS with ANH	120	5.0	(4.2-6.1)	24	0.9	(0.5-1.3)	191	5.5	(4.7-6.5)	89	2.0	(1.6-2.6)	52	1.4	(1.0-1.8)	64	1.9	(1.5-2.4)
CDS without ANH[3] (A)	118	3.2	(2.6-3.0)	62	1.6	(1.3-2.2)	123	3.0	(2.4-3.6)	247	3.7	(3.2-4.2)	74	1.8	(1.4-2.3)	96	2.9	(2.3-3.5)
Total CDS (B)	238	8.2	(7.1-9.4)	86	2.5	(2.0-3.2)	314	8.5	(7.5-9.6)	336	5.7	(5.0-6.4)	126	3.2	(2.6-3.9)	160	4.8	(4.1-5.5)
Ratio A/B			0.39			0.64			0.35			0.64			0.56			0.60

1. Due to a routing difference, Dutch data refer only to deep sedation until death which occurred together with another end-of-life decision.
2. Weighted percentages of CDS on total studied deaths and 95% confidence intervals.
3. CDS without ANH includes both withdrawing and withholding artificial nutrition and hydration.

Table 3.2 Characteristics of deaths in cases of continuous deep sedation (CDS) in six European countries

	Belgium		Denmark		Italy		The Netherlands[1]		Sweden		Switzerland		All countries	
	n	%[2]	n	%[2]	n	%[2]	n	%[2]	n	%[2]	n	%[2]	N	%[2]
Sex														
Male	133	9.2	48	3.1	170	9.4	159	5.8	62	3.6	80	4.8	652	6.0
Female	105	7.1	36	1.9	141	7.6	177	5.5	61	2.7	80	4.7	600	4.9
P value[3]		0.059		0.046		0.103		0.665		0.121		0.866		0.001
Age (years)														
<65	67	11.4	26	4.4	72	14.0	98	6.7	31	6.2	32	5.4	326	3.8
65-79	113	11.6	35	2.4	133	10.1	137	7.6	56	4.5	53	5.4	527	7.0
80+	58	4.7	23	1.8	107	6.3	101	3.7	36	1.7	75	4.2	400	7.7
P value[3]		<0.001		0.006		<0.001		<0.001		<0.001		0.271		<0.001
Cause of death[4]														
Cardiovascular dis.	36	7.5	12	2.2	29	4.6	28	2.9	26	2.0	30	2.5	161	3.5
Malignant dis.	127	9.9	55	4.0	260	16.3	155	6.6	79	5.0	74	9.0	750	8.7
Respiratory dis.	25	8.8	6	2.9	3	2.9	26	6.1	3	2.5	10	3.5	73	4.7
Nervous System dis.	16	7.2	6	2.6	8	14.8	25	4.4	1	2.9	23	6.4	79	5.6
Other/unknown	34	7.4	7	0.9	13	4.5	102	7.5	15	3.5	23	3.4	194	4.6
P value[3]		0.4781		0.019		<0.001		<0.001		0.002		<0.001		<0.001
Place of death														
Hospital	160	13.2	36	2.9	138	8.3	107	7.7	83	5.0	92	7.4	616	7.7
Other[5]	78	3.2	50	2.2	175	8.8	229	4.7	39	1.6	68	3.2	639	3.9
P value[3]		<0.001		0.267		0.652		<0.001		<0.001		<0.001		<0.001

1. Due to a routing difference, Dutch data refer only to deep sedation until death which occurred together with another end-of-life decision.
2. Weighted percentages of CDS on total studied deaths.
3. P value of Pearson chi-squared statistic (corrected for the survey design). Significance of difference in CDS prevalence, amongst the categories of the characteristics (sex, age, cause of death, place of death) of deaths.
4. 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.
5. 'Other' place of death includes both home and institution. 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.

Table 3.2 shows characteristics of deaths in which CDS was applied. Cancer was the cause of death with the highest prevalence of CDS in all countries. In all countries, CDS was less frequently applied in patients older than 80 years old and more frequently in hospitals.
In a multivariate analysis that considered all countries together, each characteristic of the patients was independently associated to CDS (see table 3.3). The probability of receiving CDS was increased in males by 17%, in patients dying from cancer by 15%, in patients 65-79 years old by 91%, in patients younger than 65 years old by 134%, and in patients dying in the hospital by 63%. Statistically significant (P <0.01) interactions were found between age and cause of death (effects of age and hospital were reduced in patients dying of cancer).

Table 3.3 Determinants of continuous deep sedation in six European countries. Logistic regression, non-sudden deaths only, all countries together

	RR	95% CI
Sex		
Male	1.17	1.02-1.34
Female	1	
Age (years)		
<65	2.34	1.93-2.85
65-79	1.91	1.62-2.25
80+	1	
Cause of death		
Malignant diseases	1.15	1.00-1.33
Other diseases	1	
Place of death		
Hospital	1.63	1.43-1.86
Other[1]	1	

1. Other' place of death includes both home and institution. 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.

3.4 Discussion

Our study has, for the first time, enabled an international estimation to be carried out on the incidence of the use of drugs to keep patients in continuous deep sedation (CDS) in a large sample of non-selected patients from six European countries. CDS is practiced in all countries, in hospitals as well as in other settings of care, for cancer patients as well as for other kinds of patients.

The finding that CDS is a frequently applied practice is in line with other studies conducted in palliative care settings.[1,7-13] It was expected that the estimates at a population level would have been lower than those observed in specialist palliative care settings. Another reason why our estimates are not fully comparable with other studies is that the definition of CDS we used excluded secondary and mild sedation, and intermittent deep sedation. The Dutch figures in our study are somewhat lower than those observed in another Dutch study at population level, which reported that 10% of all deaths were preceded by terminal sedation.[18] This can probably be explained by the fact that in our study the Dutch data only included cases in which an end-of-life decision was made.

Inter-country variations in total frequency were mainly due to variations in the use of CDS with continuing the use of artificial nutrition or hydration. It can be expected that in such cases the main intention is to relieve intolerable suffering and not to hasten death. Italy and Belgium have the highest estimates of CDS with artificial nutrition or hydration. It is possible that this result depends on the Catholic tradition of those countries, in which there is a widespread acceptance of the sanctity of life doctrine. Another explanation for the differences in frequency of CDS with artificial nutrition and hydration between the countries could be that there is variation in the moment when CDS is started. High frequency of CDS with artificial nutrition and hydration could be an indication that the patient is not in the dying phase yet. However, this hypothesis needs more research since we cannot conclude this from our data.

Since the first report on CDS in palliative care the appropriateness of using sedating drugs to control refractory symptoms in imminently dying patients has been brought to light.[1,4] At the same time an ethical debate emerged about the possible life-shortening effects of this medical procedure.[9,10,14,17,24-25] We found that in 35% - 64% of all CDS cases, the patient did not receive artificial nutrition and hydration. The Netherlands, where the question on CDS was asked only if an end-of-life decision preceded death, had the highest proportion of CDS without artificial nutrition and hydration, together with Denmark. We also know from a recent study that in the Netherlands 17% of CDS without artificial nutrition and hydration were performed with the explicit intention of hastening death, mainly by means of forgoing artificial nutrition and hydration.[18] In medical and ethical discussions it is debated whether forgoing artificial nutrition and hydration in deeply sedated patients shortens life, and if so, whether this should be considered as acceptable medical practice. The issue is controversial, also because forgoing

artificial nutrition and hydration can sometimes be clinically indicated in imminently dying patients,[5] and because sedation in terminally ill cancer patients has not been proved to be substantially influential on the duration of residual survival.[26] However, when the patients' estimated life expectancy is more than a week, forgoing artificial nutrition or hydration in deeply sedated patients has been indicated as a possible marker of an intention to hasten death.[16,27]

CDS is clinically indicated for imminently dying patients with severe symptoms refractory to conventional palliative treatments. It is not surprising that it was more often performed in cancer patients and in hospital settings, where there are more dying patients with the worst clinical conditions. The Italian exception (CDS more often in non-hospital settings) may be motivated by the rather high diffusion of domiciliary palliative care in the areas participating to the EURELD study. It's more difficult to find an explanation for the higher frequency of male patients among sedated patients. As far as the younger age of sedated patients is concerned this result confirms other observations reported in the literature[18] and was more prevalent in our data among non cancer patients.

Our study has some limitations. We cannot exclude the possibility that non-response has to some extent biased our result, especially for Italy. Further, our results probably cannot be extrapolated to other than the regions studied in Belgium, Switzerland and Italy. Although our definition of CDS was quite strict, excluding the secondary, intermittent and mild sedation, we did not ask for the specific intention of the reported sedation, for the specific drugs used or for the presence of refractory symptoms.

To conclude, the substantial practice of CDS in and outside hospitals and the cross-national differences point out the importance of further scientific debate and medical education on these medical procedures. Developing and implementing practice guidelines could contribute to assure high quality of this practice, and its appropriate use (i.e. after having considered all the other options and mainly the present palliative treatments available). Further studies will be necessary to describe the costs and benefits of CDS in terms of quality of dying.

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4

Terminal Sedation and Euthanasia: a Comparison of Clinical Practices

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Abstract

Background An important issue in the debate about terminal sedation is the extent to which it differs from euthanasia. We studied clinical differences and similarities between both practices in the Netherlands.

Methods Personal interviews were held with a nationwide stratified sample of 410 physicians (response: 85%) about the most recent cases in which they used terminal sedation, defined as administering drugs to keep the patient continuously in deep sedation or coma until death without giving artificial nutrition or hydration (n=211), or performed euthanasia, defined as administering a lethal drug at the request of a patient with the explicit intention to hasten death (n=123). We compared characteristics of the patients, the decision-making and medical care between both practices.

Results Terminal sedation and euthanasia both mostly concerned patients with cancer. Patients receiving terminal sedation were more often anxious (37%) and confused (24%) than patients receiving euthanasia (15% and 2%, respectively). Euthanasia requests were typically related to "loss of dignity" and "suffering without improving", whereas requesting terminal sedation was more often related to severe pain. Physicians applying terminal sedation estimated that the patient's life had been shortened by more than one week in 27%, as compared to 73% in euthanasia cases.

Conclusions Terminal sedation and euthanasia both are often applied to address severe suffering in terminally ill patients. However, terminal sedation is typically used to address severe physical and psychological suffering in dying patients, whereas perceived loss of dignity during the last phase of life is a major problem for patients requesting euthanasia.

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4.1 Introduction

One of the classical themes of medical ethics concerns the moral acceptability of interventions to modify the dying process. The discussion about euthanasia is well known but developments in the practice of palliative care give rise to new discussions about the ethical aspects of medical care at the end of life. One such issue is terminal sedation.

In the Netherlands, terminal sedation, defined as bringing the patient in deep sedation while forgoing artificial nutrition or hydration, was estimated to be applied in 4-10% of all deaths in 2001.[1, 2] In one study, 59% of all decisions to apply deep sedation were discussed with the patient.[1] There are no specific legal rules concerning terminal sedation in the Netherlands. Euthanasia is defined as the administration of drugs with the explicit intention to end life at the patient's request, and is legally accepted under certain conditions in Dutch law. In 2001, 2.6% of all deaths in the Netherlands were preceded by euthanasia. [3]

One of the characteristics of the debate about terminal sedation is that it is rather confused: people disagree about how it should be defined, about the distinction between terminal sedation and euthanasia, and about the conditions under which its use would be appropriate. Obviously, a discussion about terms often is also a discussion about norms: to call the sedation of a patient 'deep' or 'palliative' rather than 'terminal' has implications for the moral evaluation of these actions. Terminal sedation is sometimes seen as euthanasia in disguise[4, 5] or slow euthanasia[6], but according to others the two are worlds apart.[7, 8, 9] The argument of the latter authors is that in case of terminal sedation nor the physician nor the patient aims at death. They also claim that, when terminal sedation is only used in the very last phase of the illness, the cause of death of the patient is the underlying disease, not the withholding of food and fluids. Therefore, the argument goes, the death of the patient is not the result of medical interventions, which should thus not be interpreted to be euthanasia. Finally they claim that terminal sedation is used to address other clinical problems than euthanasia.

In this article we describe to what extent these claims are reflected in the empirical data that are available on medical end-of-life decisions in the Netherlands. Cases of euthanasia and terminal sedation are compared for characteristics of the physicians and patients involved, of the decision making process and of the clinical course that followed the decision. Insight into the extent to which these practices can be distinguished based on their clinical

characteristics may contribute to the debate on whether terminal sedation resembles euthanasia or not.

4.2 Methods

Population

We interviewed a nationwide stratified sample of 410 physicians: 125 general practitioners, 77 nursing home physicians, and 208 clinical specialists (cardiologists, surgeons, and specialists in internal medicine, pulmonology, and neurology). The specialties involved in our study covered about 95% of all deaths in the Netherlands in 2001. The 5 selected clinical specialties covered 86% of all in-hospital deaths. The sample size was determined by the likelihood that these specialties had covered deaths and the likelihood that they had been involved with different types of end-of-life decisions. The respondents were selected according to the following criteria: They had to be in active practice at the time of the interview and to have actively practiced medicine within the registered specialty for the past 2 years in the same setting. All addresses were taken from the professional registries of the relevant specialties. To arrive at the desired number of 410 physicians, we sampled 482 physicians. Seventy-two physicians (15%) declined to take part in the study: 17% of clinical specialists, 18% of general practitioners, and 3% of nursing home physicians. Face-to-face interviews were conducted by experienced part-time working or recently retired physicians who were trained to use the structured questionnaires. All interviews took place between March 2002 and October 2002. We applied strict rules to ensure the anonymity of all physicians and patients studied.

Measurement instruments

The interview schedule addressed experiences with end-of-life decision-making. Terminal sedation was defined as “the administration of drugs to keep the patient in deep sedation or coma until death, without giving artificial nutrition or hydration”. Questions about the practice of terminal sedation concerned the physician's most recent patient to have received terminal sedation (n=211). Euthanasia was defined as “the administration of drugs with the explicit intention of ending the patient’s life at his or her explicit request”. Questions about the practice of euthanasia concerned the physician's most recent patient to have

received euthanasia in the period 1996 - 2002 (n=123). Nursing-home physicians were not interviewed about their most recent case of euthanasia, because it is known that they perform only 2%-4% of all cases of euthanasia.[2] For both practices, we collected data on the patient's characteristics, such as age, sex, and main diagnosis. Type of physician was a proxy for place of death. Euthanasia is always provided at the request of the patient; for terminal sedation we asked the physicians whether they had discussed their decision to apply terminal sedation with the patient and relatives, and whether the patient had requested terminal sedation. Discussion about and requests for terminal sedation could concern either the deep sedation, the forgoing of artificial nutrition or hydration, or both. For both practices, the most important reasons for the request of the patient were asked. The presence of 15 symptoms -despite treatment- was evaluated on a 5-point Likert scale. Further, we asked whether other treatments aimed at curing or prolonging life were available at the time of the decision-making process, what the intention of the physician concerning the hastening of death had been, which drugs were used, what the time interval between administering the drugs and the death of the patient had been, and the estimated degree of shortening of life. The questionnaire was largely based upon questionnaires that were used in previous studies.[10, 11] Their validity was enhanced by testing them in pilot interviews.

Analyses

The 5 response categories of the questions about symptoms (1 = "symptom not present" to 5= "symptom strongly present despite treatment") were dichotomized into "symptom present despite treatment" (response category 4 and 5) and "symptom not present" (response category 1, 2 and 3). All percentages were corrected for missing values, which involved less than 5% of all cases for all variables. Student's T-tests, Chi square tests and Fisher's exact tests were used to identify differences between patients who received terminal sedation and patients who received euthanasia.

4.3 Results

Of the 410 physicians interviewed, 96 reported to have experience with both practices, 115 only with terminal sedation, 97 only with euthanasia, and the remaining 102 physicians did not have experience with either of these practices.

General practitioners reported the majority of euthanasia cases (55%) whereas most cases of terminal sedation were reported by clinical specialists (49%). This means that 55% of the euthanasia cases were performed at home, whereas 49% of the terminal sedation cases occurred in a hospital.
Of the physicians' most recent cases, patients who received terminal sedation were on average older (mean age 72 years) than patients who received euthanasia (mean age 63 years) (table 4.1).

Table 4.1 Characteristics of patients who received euthanasia or terminal sedation

	Terminal sedation n=211		Euthanasia n=123		
	Mean	SD	Mean	SD	p-value[1]
Age (years)	72.0	14.0	62.5	14.2	<0.001
	n	%	n	%	p-value[1]
Sex					
Male	99	47	69	56	0.106
Female	112	53	54	44	
Main diagnosis					
Cancer	113	54	108	88	<0.001
Cardiovascular diseases	51	24	5	4	
Other	47	23	10	8	
Specialty					
General practitioner	53	25	68	55	<0.001
Nursing-home physician	55	26	[2]	[2]	
Clinical specialist	103	49	55	45	
Decision[3,4]					
Discussed with patient	128	61	123	100	<0.001
Requested by patient	72	34	123	100	<0.001
Discussed with relatives	196	93	[5]	[5]	

1. Age: t-test; sex: Chi square test; diagnosis: Fisher's exact test; specialty: Chi square test; decision discussed with patient: Chi square test.
2. Nursing-home physicians were not interviewed about their most recent case of euthanasia.
3. The decision to apply deep sedation or to perform euthanasia.
4. Discussion about and requests for terminal sedation could concern either the deep sedation, the forgoing of artificial nutrition or hydration, or both.
5. Not asked.

Of all patients receiving euthanasia, 88% had cancer; this percentage was 54% for patients receiving terminal sedation. In the latter group, cardiovascular diseases were also rather common (24%). In 61% of the cases, the physician had discussed the application of terminal sedation with the patient; in 34% of the cases, the patient had requested the terminal sedation and in 27% the physician had discussed the possibility of terminal sedation with the patient and the patient

agreed. Relatives were involved in the decision-making in 93% of the cases. In 4% of all terminal sedation cases, there was no patient or family consent for applying deep sedation (not in table). Euthanasia was by definition requested by the patient.

Table 4.2 Symptoms[1] and availability of other treatments options at the time of the decision-making process

	Terminal sedation n=211		Euthanasia n=123		
	n	%	n	%	p-value[2]
Symptoms[1]					
Pain	120	57	63	51	0.294
Dyspnea	90	43	40	33	0.062
Coughing	53	25	29	24	0.815
Nausea	49	23	46	38	0.005
Vomiting	22	10	27	22	0.004
Constipation	37	18	22	18	0.904
Bedsores	29	14	4	3	0.002
Not active	185	88	91	74	0.001
Felt very ill	181	88	107	87	0.817
No appetite	176	85	88	72	0.003
Fatigue	150	71	99	80	0.066
Unclear consciousness	59	28	0	0	<0.001
Anxiety	78	37	20	16	<0.001
Confusion	51	24	2	2	<0.001
Depression	36	17	12	10	0.055
Absence of other treatment options[3]	182	86	95	77	0.036

1. Symptom was present despite potential treatment possibilities.
2. Symptoms: P-values calculated by Chi Square tests or Fisher's exact tests (2-sided); other treatment options: Chi square.
3. Potentially curing or life prolonging treatments.

Patients receiving terminal sedation were more often than patients receiving euthanasia reported to suffer from anxiety (37% vs. 15%; p<0.000), confusion (24% vs. 2%; p<0.000), depression (17% vs. 10%; p=0.055), bedsores (14% vs. 3%; p=0.002), to have a loss of appetite (85% vs. 72%; p=0.003), unclear consciousness (28% vs. 0%; p<0.000), and to be inactive (88% vs. 74%; p=0.001) (table 4.2). In contrast, patients who received euthanasia suffered more often from nausea (38% vs. 23%; p=0.005) and vomiting (22% vs. 10%; p=0.004). If only symptoms that were strongly present are considered, patients receiving terminal sedation were -in addition to the previously mentioned symptoms- significantly more often reported to have pain and dyspnea, and they more often felt very ill than patients receiving euthanasia (not in table). Physicians reported in

86% of the cases of terminal sedation that no other potentially curing or life-prolonging treatments were available, whereas this percentage was lower for cases of euthanasia (77%, p=0.036).

Table 4.3 Most important reasons for patients' requests for euthanasia or terminal sedation, according to physicians

	Terminal sedation Patients involved in decision making process n=72		Euthanasia n=123		
	n	%	n	%	p-value[1]
Most important reasons for patients' request[2]					
Suffering without improving	41	60	101	82	0.001
Loss of dignity	12	18	77	63	<0.001
Weakness/fatigue	26	38	53	43	0.760
Meaningless suffering	21	31	46	37	0.270
Pain	39	57	44	36	0.005
Dependency	4	6	41	33	<0.001
Fear of suffocating	17	25	30	24	0.881
Did not want to bother relatives	6	9	19	15	0.161
Invalidity	5	7	22	18	0.036
Vomiting	10	15	13	11	0.446
Being "tired of living"	8	12	7	6	0.161
Depression	1	1	1	1	1.000
Dyspnea	34	50	[3]	[3]	
Other reasons	10	14	20	16	0.658

1. P-values calculated by Chi square tests and Fisher's exact tests (1-sided).
2. One or more answers possible.
3. Not asked.

Table 4.3 shows the most important reasons for patients to request either terminal sedation (n=72) or euthanasia (all, n=123), as reported by the physicians. Euthanasia requests were mostly related to patients' sense of suffering without improving (82%) and loss of dignity (63%); these percentages were lower for patients who requested terminal sedation (60% and 18%, respectively). In addition, physicians more often reported loss of independency (33%) and a feeling of invalidity (18%) as reasons for patients to request euthanasia compared to patients requesting terminal sedation (6% and 7%, respectively). Requesting terminal sedation was more often than euthanasia related to suffering from severe pain (57% versus 36%).

Table 4.4 Drugs used, intention of the physician, estimated shortening of life, and time between administering drugs and death

	Terminal sedation n=211		Euthanasia n=123		
	n	%	n	%	p-value[1]
The decision was made with the explicit intention of hastening death[2]	36	17	123	100	<0.001
Drugs administered:					
Neuromuscular relaxants or barbiturates	0	0	108	94	<0.001
Benzodiazepines (potentially combined with morphine but not with muscle relaxants or barbiturates)	128	60	3	3	
Morphine (not combined with benzodiazepines, muscle relaxants or barbiturates)	76	36	3	3	
Other drugs	6	3	1	1	
Time between administering drugs and death					
< 1 h	2	1	115	94	<0.001
1-24 h	77	37	7	6	
1-2 days	58	28	0	0	
3-7 days	60	29	0	0	
> 1 week	9	4	0	0	
Estimated shortening of life					
No shortening or < 24 h	81	40	1	1	<0.001
1-7 days	67	33	31	26	
1-4 weeks	44	21	60	51	
>1 month	13	6	26	22	

1. P-values calculated by Mann Whitney U tests.
2. Explicit intention of terminal sedation concerned: forgoing artificial nutrition or hydration (n=29); applying deep sedation (n=4); or both (n=3).

Of all cases where physicians had applied terminal sedation, 17% involved an explicit intention of hastening death (table 4.4). This explicit intention was related to the use of sedatives in 2% of the cases, to the forgoing of artificial nutrition or hydration in 14%, and to both in 1%. Euthanasia is by definition applied with the explicit intention to hasten death. Terminal sedation was for 60% of the patients performed by administering benzodiazepines (sometimes combined with morphine) and in most remaining patients by administering morphine only, whereas euthanasia was for 94% of the patients performed by administering neuromuscular relaxants or barbiturates. Of all patients who received terminal sedation, 38% died within 24 hours and 94% within 1 week after the administration of the medication, whereas most patients receiving euthanasia died within 1 hour (94%) (p=<0.001). Physicians applying terminal sedation estimated that the patient's life had been shortened with 24 hours or less in 40% of the cases, and with more than one week in 27%. For euthanasia, these estimates were 1% and 73%, respectively (p=<0.001).

We performed all analyses for the subgroup of respondents who had experience with both practices to determine whether differences between both practices were associated with differences in physicians' preferences for these practices. Similarly, we performed all analyses only for cancer patients to determine whether differences between both practices are mainly attributable to differences in diagnosis. These analyses resulted in similar distributions of the data.

4.4 Discussion

The bottom line of both practices, terminal sedation and euthanasia, obviously is a patient who suffers severely from a fatal disease. However, there are marked differences. By definition, patients receiving euthanasia were actively involved in the decision-making process. This applies to only slightly more than half of the patients receiving terminal sedation, although relatives were almost always involved. Compared to the patients receiving euthanasia, patients who were terminally sedated were on average older, less often suffered from cancer and more often from cardiovascular disease, and less often died at home. Terminal sedation was more often used in patients with unclear consciousness, anxiety and confusion, in the absence of other treatment options. Further, patient requests for terminal sedation were more often based on pain than requests for euthanasia, which were more often based on a sense of suffering without chance of improving and on a perceived loss of dignity and independency. The intent of the physician in case of terminal sedation less often was to shorten life, and the shortening of life due to terminal sedation was limited. Thus, patients who are terminally sedated are generally sicker and closer to death than patients receiving euthanasia. Two findings may seem to contradict this conclusion: patients receiving euthanasia more often suffered from nausea and vomiting. However, terminal sedation is not obviously a medically appropriate answer to these symptoms. Furthermore, these symptoms may be closely connected to a sense of loss of dignity, which was a common reason for requesting euthanasia and not for terminal sedation.

The finding that requests for euthanasia are often inspired by a sense of loss of dignity is described by others as well. Haverkate et al found that 'avoiding loss of dignity' is one of the most important reasons to request for euthanasia.[12] In a trend analysis of requests for euthanasia and physician-assisted suicide it was

found that the importance of pain in such requests decreased significantly over a period of 20 years, whereas there was an increase of the importance of "deteriorating health".[13] In addition, during the first year of legalized physician-assisted suicide in Oregon, the decision to request and use a prescription for lethal medication was associated with concern about loss of autonomy or control of bodily functions, not with fear of intractable pain.[14] Qualitative research into the origins of the desire for euthanasia in people with HIV-1 or AIDS showed that requests were the result of a feeling of disintegration (which resulted from symptoms and loss of function) and loss of community. These factors result in a 'perceived loss of self'.[15] Whereas euthanasia appears to be used as a response to a crucial loss of dignity, terminal sedation is not. In a study within the Japanese population it was shown that respondents who reject continuous deep sedation at the end of life were significantly more likely to regard dignity and preparation for death as important as compared to respondents who would appreciate continuous deep sedation at the end of life.[16]

It was found that general practitioners more often than clinical specialists performed euthanasia, whereas clinical specialists more often performed terminal sedation than euthanasia. In the Netherlands, euthanasia is most often performed by general practitioners who typically attend patients who die at home and have cancer.[2] General practitioners are generally involved in long term care for patients, with patients registered to their practice for several years or more. Most euthanasia requests and practices are performed in this context. On the contrary, terminal sedation is more often practiced in a hospital for patients with cancer or cardiovascular diseases. In-hospital patients may more often have severe symptoms or extreme exacerbations of conditions that require the use of terminal sedation.

Pain was an important reason for patients to request terminal sedation and, to a somewhat lesser degree, euthanasia. Although previous reports have mentioned that state-of-the-art palliative care should substantially control pain in 90% of cases[17] it is also known that many terminal patients report pain at their end-of-life.[18]

It is sometimes suggested that terminal sedation may take away the need for euthanasia. Our findings indicate that terminal sedation and euthanasia often address quite different clinical problems. In case of terminal sedation, severe physical and psychological suffering prompt the physician to sedate the patient, whereas for patients requesting euthanasia perceived loss of dignity during the

last phase of life is often a major problem. However, this distinction does not apply to all cases of terminal sedation and euthanasia. Thus it is likely that for some patients, terminal sedation for refractory symptoms in the dying phase may serve as a relevant alternative for euthanasia.

Our study has several limitations. First, face-to-face interviews have the disadvantages of interviewer interpretations and socially acceptable answers. We attempted to eliminate these biases by carefully selecting and training the interviewers and by ensuring strict anonymity of the respondents. Second, the respondents may have had difficulties recalling the patient's characteristics; however, recall bias was probably limited because most cases involved patients who died during the preceding 2 years. Third, the terms "terminal sedation" and "euthanasia" can evoke different connotations and interpretations in respondents. We tried to avoid this problem by providing very specific definitions of the terms. In addition, not including euthanasia cases of nursing-home physicians may have led to some bias. However, this effect may be limited because it is known that in the Netherlands only 2%-4% of all cases of euthanasia are performed by nursing-home physicians.[2]

We conclude that terminal sedation and euthanasia are both applied to address severe suffering in terminally ill patients. However, terminal sedation is typically used to address severe physical and psychological symptoms in dying patients to avoid further suffering, while the patient or the patient's representatives may accept loss of control of the dying process. For patients requesting euthanasia, perceived loss of dignity during the last phase of life is a major problem. In these cases, patients may consider control of the dying process of utmost importance.

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5

Using Drugs to End Life without the Explicit Request of the Patient

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Abstract

Background For several countries it has been shown that a small proportion of all deaths (0.06% - 1.50%) result from the use of drugs with the intention to hasten death without an explicit request of the patient. Additional insight into the characteristics of this practice is needed for evaluating this practice.

Methods In the Netherlands in 2001, a sample was drawn from deaths reported to the central death registry. Questionnaires were mailed to reporting physicians that addressed the decision-making that preceded the patient's death. Cases of life ending without an explicit request of the patient were compared with similar cases in a study in 1995, and with such cases from Belgium, Denmark, and Switzerland. We also compared this practice with cases of euthanasia and with cases in which symptoms had been alleviated with life-shortening as a potential result.

Results In the Netherlands in 2001, patients receiving life-ending drugs without their explicit request were in 54% older than 80 years, 44% had cancer, and 47% died in a hospital. Opioids were mostly used to hasten death. The estimated life-shortening effect was less than one week in 80% of cases. Characteristics of this practice in 1995 were comparable, except for the use of neuromuscular relaxants in 1995 (19% vs. 1%). In Belgium, Denmark and Switzerland, characteristics of the practice of life ending without an explicit request of the patient were also rather comparable to the Netherlands. Physicians were in about half of the cases informed that the patient (implicitly) wished for death to be hastened. In most remaining cases, discussion was not possible because the patient was incompetent.

Conclusions In the Netherlands, the practice of life ending without an explicit request of the patient appears to be rather stable over time and concerns in a large majority incompetent patients nearing death. Its occurrence is not restricted to the Netherlands. Characteristics of this practice in other countries are rather comparable to the Dutch practice.

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5.1 Introduction

Medical end-of-life care rather often involves end-of-life decisions, that is, decisions that may hasten death. Decisions to forgo potentially life-prolonging treatment or to use highly dosed morphine to alleviate symptoms have been shown to precede a substantial number of deaths in several countries.[1-3] Administration of drugs with the explicit intention of ending a patient's life is more exceptional. In the Netherlands, the practice of euthanasia (defined as the administration of drugs with the explicit intention to end life at explicit request of the patient) and physician-assisted suicide (defined as the prescription or supply of drugs with the explicit intention to enable the patient to end his or her own life at explicit request of the patient) for severely suffering patients has been actively discussed in the medical profession, public domain, and the national parliament for the last three decades. Since 2002, euthanasia and physician-assisted suicide are legalized when practiced under certain conditions of careful practice.[4] Crucial conditions are that the patient suffers unbearably and hopelessly and that he or she makes an explicit request for the end of life to be hastened. Euthanasia was found to occur in 2.6% of all deaths in the Netherlands in 2001.[1-3] Intentionally ending of life by the use of drugs without an explicit request of the patient is legally prohibited, but has been found to occur in 0.8% of all deaths in 1990 and 0.7% in 1995 and 2001.[3,5-7] Dutch physicians increasingly reported to be reluctant to engage in this latter practice.[2, 3] The practice of intentionally ending the life of patients without their request was found to occur in other countries as well.[1, 8] In 1996, 3.5% of all deaths in Australia were found to result from this practice.[8] In 1998 in Belgium, it preceded 3.2% of all deaths.[9] In 2001, 1.50% of all deaths in Belgium were found to be the result of this practice; the percentage was 0.67% for Denmark, 0.42% in Switzerland, 0.23% in Sweden, and 0.06% in Italy.

It is sometimes suggested that the practice of life ending without an explicit request of the patient is a corollary of the Dutch practice of legalizing euthanasia.[10-12] However, the fact that life ending without an explicit request is also practiced in countries where euthanasia is not legal suggests that this cannot be the sole explanation. This article aims at providing insight in the Dutch practice of life ending without an explicit request of the patient by answering the following questions: (1) How is this practice characterized in terms of patient features, the decision-making process, and the life-shortening effect, and have

these characteristics changed as compared to 1995? (2) What are the differences and similarities with other end-of-life decisions that probably or certainly hasten death and involve the administration of drugs, that is, euthanasia and alleviation of symptoms with a potentially life-shortening effect? (3) What are the differences and similarities with similar cases from other countries?

5.2 Methods

In 2001, we studied practices of end-of-life decision-making in the Netherlands by drawing random samples from the central death registry. The period studied was August to December. A 4-page questionnaire was sent to the attending physician for each death included in the samples (response rate: 74%). The physician was asked whether he or she had made any decision that might have hastened death. Intentionally ending of life without an explicit request of the patient was defined as administering drugs with the explicit intention of hastening the patient's death without an explicit request of the patient (written or otherwise). Euthanasia was defined as administering drugs with the explicit intention of hastening the patient's death on the explicit request of the patient (written or otherwise). Alleviation of symptoms with a possible life shortening effect was defined as intensifying the alleviation of pain or symptoms while taking into account or appreciating (possible) hastening of death, whether or not on the patient's request. In the remaining part of the questionnaire, physicians were asked to detail the decision-making process and to estimate the life-shortening effect of the decision classified. We selected cases of life ending without an explicit request of patients 18 years of age or older, and we collected 36 cases.

In 1995, a similar study was conducted, with a response rate of 77%. In this study, 35 cases of life ending without an explicit request of the patient were collected. Furthermore, the 2001 study was simultaneously conducted in 5 other European countries: Belgium (region of Flanders), Denmark, Italy (area of Emilia-Romagna, Trento, Tuscany, and Veneto), Sweden and Switzerland (German speaking part): the EURELD study. Response rates were 59% for Belgium, 62% for Denmark, 44% for Italy, 61% for Sweden and 67% for Switzerland. In Belgium, we identified 55 cases, 24 in Denmark, 3 in Italy, 9 in Sweden and 14 in Switzerland. Due to the small number of cases, we excluded Italy (n=3) and

Sweden (n=9) from further analyses and tables. The questions and study designs that were used to collect the data in these studies were identical, and details have been described elsewhere.[1-3, 5] The study design ensured anonymity for all patients who died and precluded identification of any physician.
The results were weighted for stratification and response by sex, age, and place and cause of death to make them as representative as possible of all deaths in each country during the period studied. Weighting was not possible for place and cause of death in Switzerland nor for cause of death in Denmark. By means of multinominal logistic regression analyses, cases of life ending without explicit request of the patient identified in the Netherlands in 2001 were compared with such cases found in 1995, with cases of euthanasia and cases of alleviation of symptoms with a possible life-shortening effect, and with cases of life ending without an explicit request of the patient in Belgium, Denmark, Sweden and Switzerland. We used SPSS statistical software, version 11.0 (SPSS Inc, Chicago, Ill).

5.3 Results

In the Netherlands in 2001, life ending without the explicit request of the patient concerned in 54% patients who were older than 80 years, in 44% patients who had cancer, and in 47% patients who died in a hospital (table 5.1). Of all patients, 18% was considered to have been competent during the decision-making process, that is, capable to assess the situation and to make a decision about it adequately. Physicians indicated that they had discussed the hastening of death with all competent patients, short of an explicit request. The hastening of death involved the administration of opioids in 84% of all cases; in 31% of all cases, opioids were combined with sedatives. Neuromuscular relaxants were used in 1% of cases. Physicians estimated that the patient's life had been shortened with less than one day in 44% of the cases, and with less than one week in 80%.

Table 5.1 Characteristics of cases of life ending without an explicit request of the patient in 2001, compared with such cases identified in 1995 and with other medical end-of-life decisions involving the use of drugs in the Netherlands in 2001

	LWEPR 2001 n=35	LWEPR 1995 n=36	APS[1] 2001 n=1272	EUTH 2001 n=309	LWEPR 2001 vs 1995	LWEPR vs APS	LWEPR vs EUTH
	%[3]	%[3]	%[3]	%[3]	p-value[2]	p-value[2]	p-value[2]
Sex					0.958	0.864	0.342
Male	47	48	46	54			
Female	53	52	54	46			
Age					0.502	0.391	<0.001
18-64[4]	21	25	18	38			
65-79	25	35	36	41			
>80	54	40	46	21			
Cause of death					0.192	0.704	<0.001
Cancer	44	45	47	77			
Cardiovascular diseases	19	6	14	4			
Other / unknown	37	49	39	19			
Place of death					0.239	0.010	<0.001
Hospital	47	61	27	21			
Other	53	39	73	79			
Patient was competent	18	23	33	97	0.593	0.046	<0.001
Competent and decision discussed with patient	18	22	28	97			
Drugs used					0.002	0.006[5]	<0.001
Opioids only	48	69	60	15			
Opioids in combination with sedatives	31	7	11	4			
Opioids in combination with other drugs, excl. neuromuscular relaxants or sedatives	5	8	4	3			
Sedatives only	5	0	2	6			
Neuromuscular relaxants, potentially combined with other drugs	1	17	0	68			
Other combinations / unknown	9	0	22	4			
Estimated shortening of life					0.061	0.003	<0.001
Less than 1 day	44	33	60	10			
1 day to 1 week	36	62	16	36			
1 week or more	15	6	6	54			
Unknown	5	0	18	0			

Abbreviations: LWEPR – life ending without an explicit patient request; APS - alleviation of symptoms with a possible life-shortening effect; EUTH - Euthanasia

1. "Taking into account the hastening of death" or "partly with the intention to hasten death".
2. P-values calculated by multinomial regression analyses.
3. Data are weighted percentages (see Methods section for description of weighting procedure).
4. 1995: 20-64 years old.
5. For multinomial regression analyses, the category neuromuscular relaxants was added to "other combinations".

Characteristics of cases of life ending without the explicit request of the patient identified in 1995 were rather similar to those of the 2001 cases, except that in 1995 neuromuscular relaxants were more often used to hasten death (17% vs. 1%), and opioids were less often combined with sedatives (7% versus 31%) (table 5.1). Characteristics of cases in which death was preceded by the alleviation of symptoms with a possible life-shortening effect were not significantly different from patients in whom life was ended without an explicit request in terms of age, sex, and cause of death. Alleviation of symptoms occurred less often in hospital (27% versus 47%; p=0.010), patients were somewhat more often considered competent (33% versus 18%; p=0.046), opioids were less often used in combination with other drugs, and the estimated life-shortening effect was more limited, that is, less than one day for 60% of the patients (p=0.003). As compared to patients who died after the administration of lethal drugs without their explicit request, patients receiving euthanasia were significantly younger (21% older than 80 years old versus 54%), more often diagnosed with cancer (77% versus 44%), died less often in a hospital (21% versus 47%), and neuromuscular relaxants were in 68% used to end life, which was in more than half of the cases estimated to be shortened with more than one week (all p-values < 0.001).

Table 5.2 and 5.3 compare characteristics of patients who died as a result of life ending without their explicit request in the Netherlands with such patients in Belgium, Denmark, and Switzerland. In all countries, cancer was the most often reported diagnosis, and the prevalence of cancer was higher in this group than among all deaths in the general population (table 5.2). In Belgium and Denmark, patients were relatively young as compared to patients in the Netherlands. The proportion of older patients among patients who died as a result of life ending without an explicit request of the patient was similar to the proportion of older deaths among all deaths in the general population. Furthermore, in the Netherlands, life ending without an explicit request of the patient occurred more often in hospital as compared to all deaths in the general population (47% versus 33%), whereas it was more often performed outside the hospital in Denmark (27% versus 50% hospital deaths) and Switzerland (22% versus 37%). As in the Netherlands, the estimated life-shortening effect was in all countries less than 1 week in about 80% of the cases.

Table 5.2 Characteristics of cases of life ending by the use of drugs without an explicit request of the patient in 2001: the Netherlands compared[1] to Belgium, Denmark and Switzerland

	NL n=35		BE n=55		DK n=24		CH n=14	
	%[2]	(%)	%[2]	(%)	%[2]	(%)	%[2]	(%)
Sex								
Male	47	(49)	64	(51)	45	(49)	57	(49)
Female	53	(51)	36	(49)	55	(51)	43	(51)
Age								
18-64	21	(18)	21*	(17)	24	(19)	14	(17)
65-79	25	(35)	55*	(35)	42	(35)	29	(29)
>80	54	(46)	24*	(48)	35	(45)	57	(53)
Cause of death								
Malignant diseases	44	(27)	52	(28)	51	(27)	36	(24)
Cardiovascular diseases	19	(25)	15	(28)	20	(28)	29	(37)
Other	37	(48)	33	(44)	29	(45)	35	(39)
Place of death								
Hospital	47	(33)	51	(53)	27	(50)	22	(37)
Other	53	(67)	49	(47)	73	(50)	78	(63)
Estimated shortening of life								
Less than 1 day	44	NA	45	NA	60	NA	36	NA
1 day to 1 week	36	NA	34	NA	31	NA	50	NA
1 week or more	15	NA	20	NA	10	NA	14	NA
Unknown	5	NA	0	NA	0	NA	0	NA

Abbreviations: NL - the Netherlands; BE - Belgium; DK - Denmark; CH – Switzerland; NA: Not applicable.

1. P-values calculated by multinomial regression analyses. Calculated was whether characteristics of life ending without explicit request of the patient in the Netherlands differed from Belgium, Denmark and Switzerland. * signifies $p<0.05$

2. Data are weighted percentages. Between brackets: % of all deaths. Number of all deaths per year per country / region: NL=140377; BE=55793; DK=58722; CH=44036. (See Methods section for description of weighting procedure).

In all countries, the physician had discussed the hastening of death in about one third of all cases with the patient (table 5.3). Most of these patients were considered as being competent or partly competent, and had expressed a non-explicit wish for the hastening of death. In cases where the hastening of death was not discussed with the patient, most patients were considered to be fully incompetent. Some of them (14% of all patients in Denmark, 17% in the Netherlands and Belgium, and 42% in Switzerland) had previously in their illness trajectory expressed a wish for the hastening of death. In the Netherlands, Belgium and Denmark, physicians indicated that they had not discussed their decision to hasten the death of the patient mainly because the patient was unconscious or demented. A reason frequently mentioned in Denmark (26%) and Switzerland (36%) was that the physician felt that not discussing this was

clearly in the best interest of the patient. This reason was the only reason indicated in 29% of the Swiss cases, whereas in Denmark, this decision was always combined with the patient being unconscious (not in table). In Denmark, 23% of the physicians felt that such a discussion would do more harm than good to the patient.

In 78% (Switzerland) to 100% (the Netherlands), physicians had discussed the decision to hasten the patient's death with the patient's relatives. Cases where the patient's wish concerning the end of life was unknown and the decision was not discussed with relatives did not occur in the Netherlands and were rare in Belgium (5% of all cases), but were somewhat more often found in Denmark (17%) and Switzerland (16%) (not in table). In the Netherlands, the physician had discussed the hastening of death with other physicians in 60% and with nurses in 72%. Belgium showed rather similar percentages, whereas in Denmark and Switzerland, other physicians were less often involved. In Denmark, the physician had discussed the hastening of death in 13% of all cases with no one else.

5.4 Discussion

Life ending without the explicit request of the patient occurs in the Netherlands as well as in other European countries. In the Netherlands, the characteristics of this practice are more similar to characteristics of alleviation of symptoms with a possible life-shortening effect than to cases of euthanasia. Life ending without an explicit request of the patient concerns cancer patients as well as patients suffering from other diseases, patients in various age groups, and patients dying inside and outside the hospital. In half of the cases, the physician had some information about the patient's wish. In the remaining cases, the patient was considered to be fully incompetent of making decisions and the decision was discussed with the patient's relatives. Physicians used opioids, often in combination with benzodiazepines, and hastened death in most cases with a few hours to a few days.

Previous reports already showed that the frequency of life ending without an explicit request of the patient in the Netherlands is a rather stable practice, being performed in 0.8% of all deaths in 1990 and 0.7% in 1995 and 2001.[2, 3, 5]

Table 5.3 Decision-making characteristics in cases of life ending by the use of drugs without an explicit request of the patient in 2001: the Netherlands compared[1] to Belgium, Denmark and Switzerland

	NL n=35	BE n=55	DK n=24	CH n=14
	%[2]	%[2]	%[2]	%[2]
Patient				
Hastening of death discussed with patient	30	30	40	29
Patient had expressed a wish for death to be hastened, but no explicit request	25	21	30	29
Competence of patient				
Patient was competent	18	17	22	29
Patient was not fully competent	12	13	3	0
Patient was not competent at all	0	0	15	0
Hastening of death not discussed with patient	70	70	60	71
Patient had previously expressed a wish for death to be hastened, but no explicit request	17[3]	17	14	42
Competence of patient				
Patient was competent	0	5	3	0
Patient was not fully competent	4	5	6	36
Patient was not competent at all	60	60	45	21
Unknown whether patient was competent	6	0	6	14
Reasons for not discussing the hastening of death with the patient [4]				
Patient was unconscious	53	35	38	7
Patient had dementia	18	13	13	21
Patient was mentally retarded	6	0	10	0
Act was clearly in best interest of patient	0	10	26	36
Discussion would have done more harm than good	0	5	23	0
Other reason / unknown	2	17	6	7
Others				
Hastening of death discussed with:				
The patient's relative(s)	100	92*	81*	78*
One or more other physicians	60[4]	60	30*[5]	22*
Nursing staff	72[4]	66	63	86
No one	0	3	13*	0

Abbreviations: NL - the Netherlands; BE - Belgium; DK - Denmark; CH - Switzerland
1. P-values calculated by multinomial regression analyses. Calculated was whether characteristics of life ending without explicit request of the patient in the Netherlands differed from Belgium, Denmark and Switzerland. * signifies $p<0.05$.
2. Data are weighted percentages.
3. Information about 15 cases missing.
4. More than 1 answer possible.
5. Information about 3 cases missing.

The current study shows that characteristics of this practice in 2001 did not significantly differ from 1995, except that in 2001, neuromuscular relaxants were virtually never used to hasten death. It is sometimes argued that in the Netherlands, the legalization process of euthanasia and physician-assisted suicide

may have gradually led to acceptance of other forms of life ending, such as life ending without the patient's request.[10-12] Our findings do not support this idea.

Patient centered care is generally considered to be important, especially at the end of life. However, terminally ill patients nearing death are not always fully competent due to the exacerbation of symptoms or the progression of disease. For such patients, carefully communicating about their wishes concerning the dying process and about the provision of appropriate end-of-life care can be difficult. In our study, half of the Dutch patients in whom life was ended without their explicit request were to some extent involved in the decision-making, either because the physician had discussed the decision with the patient, or because the patient had previously expressed a wish upon the hastening of death. Although physicians did not interpret this involvement as an *explicit* request of the patient in these cases, it is likely that they acted according to the patients' wishes. In the other cases, patients were considered fully incompetent and no information about the patients' wishes was available. Physicians never made these decisions in isolation: relatives were always involved and in about two-third of cases, other physicians and nurses were involved in the decision-making.

As compared to euthanasia, our study shows that although the intention of hastening death in both practices is similar, ending life without the patient's explicit request largely involves other types of cases. Besides the absence or presence of an explicit request of the patient, the practices also differ according to patient characteristics and clinical performance. Euthanasia is more often than life ending without the patient's explicit request performed in younger patients and patients diagnosed with cancer, less often in a hospital, and in most cases neuromuscular relaxants are used to shorten life with several weeks. The clinical context of alleviation of symptoms with a possible life-shortening effect is much more similar to the practice of life ending without an explicit request of the patient: opioids are predominantly used, with in most cases an estimated life-shortening effect of a few hours to a few days, and the distribution of age and diagnosis of the patients is also rather comparable. A difference is that alleviation of symptoms with a possible life-shortening effect is less often to be performed in a hospital.

In our study, life ending without an explicit request of the patient was in somewhat more than one third of the patients performed with sedatives that were in most cases combined with opioids. This may suggest that life ending without an explicit request of the patient is sometimes practiced in the context

of terminal sedation. Terminal sedation is a practice in which sedating drugs are administered to make patients with refractory symptoms in the last phase of their life less aware of their symptoms. This practice was reported to have preceded 4-10% of all deaths in the Netherlands.[2, 13] In line with our findings, it was found that terminal sedation is sometimes practiced with the explicit intention to hasten the death of the patient.[13]

In the other countries studied, life ending without an explicit request of the patient was also found to be part of medical end-of-life decision-making and most characteristics of the patients did not differ substantially from the Netherlands. However, some inter-country differences in the decision-making process are conspicuous. Firstly, in Switzerland and Denmark, physicians more often indicated that they had not discussed their decision to hasten death with the patient because they felt that not discussing this was in the best interest of the patient. In Denmark, physicians also rather often felt that such a discussion would do more harm than good to the patient. Both reasons were not mentioned by Dutch physicians and seldom by Belgian physicians, which probably reflects a different attitude towards involving patients in or burdening them with such decision-making. Secondly, our results show that Dutch and Belgian physicians always discussed their decision with relatives, and in most cases with other physicians and nurses. These percentages were lower for Denmark and Switzerland, especially for discussion with other physicians. This can partly be explained by the place of death: in Belgium and the Netherlands, life ending without an explicit request of the patient was often performed in a hospital, where probably more decision-making partners are available than in a home care situation or in a nursing home.

Our study has some limitations that should be taken into account. First, since this practice does not occur often, we could select only a small sample of cases, and therefore, results have to be interpreted cautiously. Secondly, our study design did not allow us to obtain more detailed information about the patients' diagnoses and symptoms and about the course of the decision-making. Lastly, our findings are limited to the experiences of physicians. Views of patients, their family, and other caregivers were not studied.

Despite improvements in medical care for the dying and an increasing awareness that careful patient-physician communication is an important aspect of end-of-life care, life ending without an explicit request of the patient seems to be a part of medical end-of-life practices in the Netherlands as well as other

countries. Its existence might on the one hand be a reflection of sometimes ineffective and tardily communication between patients and physicians about the dying process, a topic that remains uneasy to be acknowledged and discussed. On the other hand, it demonstrates that suffering at the end of life apparently sometimes leads to far-reaching interventions that cannot always be discussed with the patient involved.

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6

A Comparison of Attitudes towards End-of-Life Decisions: Survey among the Dutch General Public and Physicians

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Abstract

Background In the Netherlands, there has been a continuing public debate about the acceptability and regulatory system for medical decision-making concerning the end of life. We studied attitudes of the Dutch general public towards different types of end-of-life decisions in various situations and compared them to attitudes of physicians.

Methods Questionnaires were mailed to 1777 members of the Dutch general public (response: 78%). A total of 391 Dutch physicians, including general practitioners, nursing home physicians and clinical specialists, were interviewed in person (response: 81%). In both the survey and the physician interviews, questions were asked about attitudes towards active ending of life, terminal sedation, and increasing morphine with premature death as a likely consequence, using hypothetical cases of different patients. By logistic regression analysis, the differences between public and physicians' attitudes were assessed, as well as the associations between attitudes of the general public and their personal characteristics.

Results Acceptance of active ending of life at request of a terminally ill cancer patient was higher among the general public (85%) than among physicians (64%). For physicians, acceptance decreased to 36% for an incompetent adult, 11% for a patient without a serious disease, and 6% for a patient with dementia. For the general public, these percentages were 63%, 37%, and 62%, respectively. Between both groups, no differences were found in acceptance of terminal sedation and increasing morphine. For the general public, determinants of support for active ending of life were: being non-religious, having a lower educational degree, and having a single household.

Conclusion Acknowledging the observed differences in appreciation of end-of-life decision-making between the general public and physicians is important in doctor-patient communication and in public debate and policymaking. Continued monitoring of practices and informing the general public and policymakers about the clinical and ethical consequences of different types of end-of-life decisions is important.

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6.1 Introduction

End-of-life decision-making in the Netherlands

Euthanasia and physician-assisted suicide have been actively discussed in the medical profession, public domain, and the national parliament for several decades in the Netherlands. Euthanasia is defined as the administration of drugs with the explicit intention to end life at the patient's request and physician-assisted suicide as the prescription or supply of drugs with the explicit intention to enable the patient to end his or her own life. While these practices do exist, they are not considered as normal and therefore, the Dutch parliament decided they should be reviewed. As from 1991, Dutch physicians had to report to the Public Prosecutor all cases in which they administered or supplied lethal drugs with the explicit intention to hasten the patient's death. Physicians were not prosecuted when they had met the official criteria for prudent practice. Since 1998, the notification procedure was revised and the Public Prosecutor assessed cases only after being advised by a multidisciplinary committee of a medical, a legal and an ethical specialist. In 2002, the Dutch euthanasia law came into force: the "Ending of Life on Request and Assisted Suicide Review Procedures Act 2001" (Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding). This Act made euthanasia and physician assisted suicide officially no longer liable to penalty, provided that the physician had met the official criteria for prudent practice. The multidisciplinary committee must inform the Public Prosecutor only about cases in which the criteria for prudent practice are not met. The Act further permits active ending of life for competent patients aged 16 to 18 years provided that the parents are involved in the decision-making process; for competent patients aged 12-16 years provided that the parents agree; and for incompetent patients with an advance directive upon the active ending of life.

Other end-of-life decisions that possibly or certainly hasten death, such as administering high dosages of opioids or benzodiazepines to alleviate suffering at the end of life, do not need to be legally assessed. Because the Netherlands has this rather tolerant policy for end-of-life decision-making, it is possible to openly investigate physicians' practices in this area. Insight in the attitudes of physicians and other participants in the Dutch end-of-life debate is important for further understanding of end-of-life practices.[1] This article focuses on the attitudes of the Dutch public and physicians towards end-of-life decisions.

The practice of end-of-life decision-making in the Netherlands has been studied extensively in 1990, 1995 and 2001.[2-4] In the most recent study, it was estimated that 3% of all deaths in the Netherlands in 2001 were preceded by euthanasia.[2] Alleviation of pain or symptoms with premature death as a likely consequence was a more common practice and preceded 20% of all deaths.[2] The rates for both practices seemed to have stabilized since 1990. Terminal sedation, defined as bringing the patient in deep sedation while forgoing artificial nutrition or hydration, was estimated to occur in 4-10% of all deaths in 2001.[5,6]

Attitudes of the Dutch general public

In the Netherlands, both physicians and the general public have been shown to have a rather permissive attitude towards physician-assisted death for terminally ill, competent patients.[2,7-10] The general public, however, tends to be even more permissive than physicians, in the Netherlands as well as in other countries.[11-14] As from 1966, the Social and Cultural Planning Office conducted surveys among the Dutch general public containing the question: "What should a doctor do when a patient asks him to put an end to his suffering by administering a lethal injection?".[7] The percentage of respondents that thought that euthanasia could be acceptable increased from nearly 50% in 1966, to about 90% in 1998. Another study, conducted in 1995 and replicated in 2001, used vignettes to elucidate attitudes of the Dutch public towards end-of-life decision-making.[8] It was shown that euthanasia is generally accepted in the Netherlands: 83% (1995) and 88% (2001) of the respondents thought that euthanasia is acceptable for a terminally ill patient with unbearable suffering. Active ending of life in the case of a patient with dementia with a living will and for persons without a serious illness requesting assistance in dying were only explored in the 2001 part of this study. The first was considered acceptable by about 80% of respondents, but in contrast, only about 25% accepted actively ending the life of persons without a serious illness.

Attitudes of Dutch physicians

Before 1990, empirical information about the practice of end-of-life decision-making in the Netherlands was not available. Similarly, reliable data about physicians' attitudes towards end-of-life decisions were lacking. In 1990, 54% of a representative sample of Dutch physicians reported that they had ever performed euthanasia or assistance in suicide; 34% had never performed such practices but

considered it acceptable; and the remaining 12% of the physicians reported that they would never perform euthanasia or assistance in suicide.[6] These percentages remained virtually unchanged in 1995 and 2001.[6] Furthermore, in 2001, 20% of the physicians reported having become more restrictive about euthanasia in the last five years, which was more than in 1995 (12%) and 1990 (14%).[2]
This article compares the attitudes of the Dutch general public and physicians towards three different end-of-life decisions: active ending of life, terminal sedation, and increasing the dosage of morphine with premature death as a likely consequence. We included newly discussed issues such as active ending of life in minors, patients with dementia, and patients without a serious disease.

6.2 Methods

General public
In September 2002, written questionnaires were sent to an established sample frame consisting of 1777 members of the Dutch general public (Panel of the "Consumers' Association" Consumentenpanel Gezondheidszorg, NIVEL/Consumentenbond). Of the selected persons, 1388 returned the questionnaire (response: 78%). The sample included persons aged between 20 and 93 years. The questionnaire addressed attitudes and opinions on various end-of-life decisions. A pilot study was conducted to investigate the level of difficulty of the questions for the general public. This resulted in the reformulation of some questions.

Physicians
As part of a larger study, in which the notification procedure for physician-assisted death in the Netherlands was evaluated, physicians were interviewed about their experiences with end-of-life decision making as well as their attitudes and opinions. The nationwide sample included general practitioners, nursing-home physicians and clinical specialists. These specialties covered about 95% of all deaths in the Netherlands in 2001. The respondents had to be in active practice at the time of the interview and had to have actively practiced medicine within the registered specialty for the past two years in the same place. All addresses were taken from the professional registries of the relevant specialties. Of the 482 physicians sampled, 72 declined to take part in the study (15%). In 19 interviews,

no information about the respondents' attitudes could be collected due to time constraints. The number of physicians interviewed was thus 391: 120 general practitioners, 72 nursing-home physicians, and 199 clinical specialists (response: 81%). Face-to-face interviews were conducted by part-time or recently retired experienced physicians who were trained to administer the structured questionnaires. All interviews took place in the period between March 2002 and October 2002. Strict rules were applied to ensure the anonymity of all participating physicians.

Vignettes

In both groups, attitudes concerning end-of-life decisions were assessed using vignettes, that is, hypothetical case descriptions of different clinical situations in which an end-of-life decision could be taken. Both physicians and the general public were presented with 6 vignettes (Box 6.1 and 6.2). The physicians were asked whether they would be willing to: (1) perform active ending of life (all vignettes), (2) apply terminal sedation, that is: bring the patient in deep sedation while forgoing artificial nutrition or hydration (vignettes 1 and 2), and (3) increase the dosage of morphine with premature death as a likely consequence (vignettes 1 to 4). Respondents from the general public were asked whether they considered it acceptable that the physician would: (1) perform euthanasia, defined as ending of life at the request of the patient by administering lethal drugs (all vignettes), (2) bring the patient in a condition of unconsciousness, being unaware of pain and dying within one week (vignettes 1 and 2), and (3) increase the dosage of pain treatment with premature death as a likely consequence (vignettes 1 to 4). To make the vignettes for the general public resemble real-life situations, the patients were described by (non-existing) names and gender. The patients described in the vignettes were similar for physicians and the general public with respect to their age, competence, type of suffering and whether or not they requested assistance in dying. Some other characteristics were changed in the general public version to avoid unintentional connotations.

Box 6.1 Vignettes general public

1. Pain, adult

Mr. Van der Buis is 61 years old and has cancer with extensive metastases. His disease is incurable and he suffers from severe pain. He explicitly requests his physician for euthanasia.

2. Pain, child

Joke Jaspema is 15 years old and has cancer with extensive metastases. Her disease is incurable and she suffers from severe pain. After discussion with her parents, she explicitly requests her physician for euthanasia.

3. Not communicative, adult

Mr. Klinkenhamer is 61 years old and has cancer with extensive metastases. His disease is incurable. Since two weeks he is unconscious and no longer able to communicate. He shows clear signs of severe pain and agitation. He has no family anymore.

4. Not communicative, child

Jan Dalhaver is 15 years old and has cancer with extensive metastases. His disease is incurable. Since two weeks he is unconscious and no longer able to communicate. He shows clear signs of severe pain and agitation. His parents explicitly request his physician to end the life of their child.

5. Absence of serious disease

Mr. Lichtkamp is 92 years old and has been incontinent for the past two years. He has difficulties with walking and deteriorating eyesight, and reports increasing difficulties with reading the newspaper. He lives alone and has almost no social contacts. In the past year, he has explicitly requested his physician three times for assistance with suicide.

6. Patient with dementia

Mr. Stokland is 62 years old and suffers from dementia. He no longer recognizes his wife and children, refuses to eat and is becoming increasingly withdrawn socially. Communication about medical treatment is no longer possible. He has no physical disease. Before he became demented, he had signed a written living will, in which he stated that he wanted his life to be ended if he developed dementia.

Box 6.2 Vignettes physicians

1. Pain, adult

Patient A is 61 years old and has cancer with extensive metastases. The pain is severe and not fully controlled by morphine. The patient explicitly requests for the active ending of life.

2. Pain, child

Patient B is 15 years old and has cancer with extensive metastases. The pain is severe and not fully controlled by morphine. The patient explicitly requests for the active ending of life, after discussing it with the parents.

3. Not communicative, adult

Patient C is 62 years old and has cancer with extensive metastases. The pain is severe and not fully controlled by morphine. The patient has progressive dementia, which makes communication about medical treatment no longer possible. The patient has signed a written declaration about the active ending of life.

4. Not communicative, child

Patient D is 15 years old and has cancer with extensive metastases. In the past two weeks, the patient has a decreased consciousness and is no longer able to communicate. The patient shows clear signs of severe pain and agitation. The parents explicitly request for the active ending of life.

5. Absence of serious disease

Patient E is 92 years old and in the past two years has experienced micturation problems as a result of benign prostate hypertrophia. On top of this, he has hearing loss and deteriorating eyesight, and reports increasing difficulty with reading the newspaper. He lives alone and feels that he is suffering unbearably and hopelessly. In the past year, he has explicitly requested for assistance with suicide on three occasions.

6. Patient with dementia

Patient F is 62 years old and has progressive dementia. He no longer recognizes his wife and children, refuses to eat and is becoming increasingly withdrawn socially. Communication about medical treatment is no longer possible. He has signed a written declaration about the active ending of life.

Statistical analyses

The 5 response categories were dichotomized into yes ("yes" and "probably yes") and no ("probably yes / probably no", "probably no", and "no"). The data of the physicians were weighted for differences in the sampling fractions for the different specialties, taking the reverse of the sampling fractions for each specialty as weighting factor. All calculations were corrected for missing values, which were less than 1% for most variables and less than 5% in all cases. Logistic regression analyses were used to assess the statistical significance of the differences between both groups. For the general public, multivariate logistic regression analyses were used to calculate odds ratios with 95% confidence intervals for the relationships between the answers to the vignettes and personal characteristics of the respondents.

Table 6.1 Characteristics of the members of the general public and the physicians interviewed

	Public n=1388		Physicians n=391	
	n	%	n	%
Sex				
Male	539	39	297	76
Female	848	61	93	24
Religious beliefs				
Yes	775	56	162	43
No	600	44	214	57
Age				
<40 year	732	41	52	13
40-55 year	485	27	248	63
>55 year	556	33	91	23
Education[1]				
Low	687	50	NA	NA
High	693	50	391	100
Health respondent				
Good	1089	79	NM	NM
Fair / bad	287	21	NM	NM
Composition household				
Living with partner	1039	77	NM	NM
Living without partner	317	23	NM	NM
Specialty				
General practitioner	NA	NA	120	31
Nursing home physician	NA	NA	72	18
Specialist	NA	NA	199	51

Abbreviations: NA=not applicable; NM=not measured.
1. Low=lower vocational education; lower secondary general education; primary school. High=intermediate vocational or higher secondary general education; higher vocational education; university.

6.3 Results

Of all responding members of the general public, 39% were men, compared to 76% of the responding physicians (table 6.1).
A lower percentage of the physicians reported having religious beliefs and they were more often than the general public aged between 40 and 55 years. The distribution of age within the sample of the general public was representative for the whole population, but women were somewhat overrepresented.

Table 6.2 Public and physician's attitudes concerning active ending of life, terminal sedation and increasing morphine with premature death as a likely consequence[1]

	Public n=1388		Physicians n=391		
Is the following treatment option acceptable for you?	n[2]	%[2]	n[2]	%[2]	p-values[3]
Pain, adult					
Active ending of life	1173	85	243	64	<0.001
Terminal sedation	809	58	226	56	0.49
Increasing morphine	1129	82	330	84	0.38
Pain, child					
Active ending of life	1122	81	220	57	<0.001
Terminal sedation	835	60	224	58	0.10
Increasing morphine	1095	79	324	83	0.10
Not communicative, adult					
Active ending of life	870	63	130	36	<0.001
Increasing morphine	1109	80	355	90	<0.001
Not communicative, child					
Active ending of life	1132	82	81	23	<0.001
Increasing morphine	1129	82	295	87	0.032
Absence of serious disease					
Active ending of life	515	37	39	11	<0.001
Patient with dementia					
Active ending of life	862	62	21	6	<0.001

1. Number, %, of respondents who answered either "yes" or "probably yes".
2. Absolute, unweighted numbers; weighted percentages.
3. P-values calculated by univariate logistics regression analyses.

For all vignettes, the acceptance of active ending of life was larger among the general public than among physicians (table 6.2). Among the general public, 85% (95% confidence interval 83% to 86%) would accept active ending of life in an incurable cancer patient with severe pain who explicitly asks for it. For the other vignettes, these percentages were between 62% (60- 65%) and 82% (80-85%), except for active ending of life in the absence of a serious disease, which was acceptable to 37% (35-40%) of the participants. Of all physicians, 64% (59-69%)

would be willing to perform active ending of life in the case of an incurable cancer patient with severe pain who explicitly requests it. This percentage was 57% (52-62%) in case the patient was a child and further decreased in case the patient was an incompetent adult (36%; 32-41%), an incompetent child (23%; 19-27%), a patient without a serious disease (11%; 8-14%), or a patient with dementia (6%; 4-8%).

The degree to which terminal sedation and increasing morphine were acceptable was rather similar among both groups and for the different vignettes. Approximately 60% of all respondents considered terminal sedation as acceptable for a competent patient with incurable cancer. Between 79% (77-81%) and 82% (80-84%) of the general public considered increasing morphine acceptable, for both competent and incompetent patients with incurable cancer. These percentages were somewhat higher, between 83% (79-87%) and 90% (86-92%), for the physicians.

For the general public, factors that were positively associated with accepting active ending of life in all or most situations were: being non-religious, having a lower educational degree, and having a single household (table 6.3). There were no associations found for sex or perceived personal health. For the vignettes about a non-communicative adult and a patient with no serious disease, increased age of the respondents was related to a higher likelihood of accepting active ending of life. The acceptance of terminal sedation and increasing morphine also increased with the age of the respondents. Religious respondents tended to be restrictive towards increasing morphine, and, in a larger proportion, towards terminal sedation, although this relation did not reach statistical significance for all vignettes. Among highly educated respondents, the acceptance of terminal sedation was less, whereas this group tended to be more permissive towards the option of increasing morphine. Women were significantly more likely to find increasing morphine acceptable as compared to men.

Table 6.3 Determinants of public attitudes concerning active ending of life, terminal sedation and increasing morphine with premature death as a likely consequence

	Age age-increase 10y		Sex female/male		Religion religious/non-religious		Education high/low		Health of respondent fair or bad/good		Composition household partner/no partner	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Pain, adult												
Active ending of life	0.95	0.85-1.06	0.97	0.70-1.35	0.28	0.19-0.41	0.82	0.59-1.12	1.01	0.68-1.50	0.72	0.48-1.08
Terminal sedation	1.13	1.04-1.22	0.86	0.68-1.09	0.81	0.64-1.01	0.87	0.70-1.10	0.77	0.58-1.03	0.93	0.71-1.22
Increasing morphine	1.14	1.03-1.26	1.48	1.10-1.99	0.91	0.68-1.22	1.11	0.83-1.48	0.87	0.61-1.24	1.09	0.77-1.52
Pain, child												
Active ending of life	0.92	0.84-1.02	0.84	0.62-1.15	0.33	0.24-0.46	0.90	0.67-1.20	1.01	0.70-1.44	0.74	0.51-1.06
Terminal sedation	1.11	1.02-1.20	0.84	0.66-1.07	0.78	0.62-0.98	0.81	0.64-1.02	0.87	0.65-1.16	0.92	0.70-1.21
Increasing morphine	1.15	1.04-1.27	1.36	1.02-1.80	0.80	0.60-1.06	1.18	0.89-1.56	0.94	0.67-1.33	1.11	0.80-1.54
Not communicative, adult												
Active ending of life	1.28	1.18-1.40	1.01	0.79-1.29	0.56	0.44-0.72	0.78	0.61-0.99	1.20	0.88-1.63	0.87	0.66-1.17
Increasing morphine	1.15	1.04-1.26	1.18	0.88-1.58	0.94	0.70-1.25	1.18	0.88-1.57	0.91	0.64-1.29	1.83	0.78-1.54
Not communicative, child												
Active ending of life	0.99	0.89-1.09	0.79	0.58-1.08	0.41	0.29-0.56	0.73	0.54-0.98	0.97	0.67-1.41	0.63	0.43-0.92
Terminal sedation	1.09	1.00-1.19	0.93	0.72-1.19	0.69	0.54-0.88	0.92	0.73-1.18	0.87	0.64-1.17	0.99	0.74-1.32
Increasing morphine	1.06	0.96-1.17	1.55	1.15-2.09	0.99	0.74-1.32	1.13	0.84-1.51	0.85	0.60-1.22	1.00	0.71-1.42
Absence of serious disease												
Active ending of life	1.23	1.14-1.34	0.94	0.74-1.21	0.50	0.39-0.64	0.73	0.57-0.92	1.11	0.83-1.50	0.65	0.50-0.86
Patient with dementia												
Active ending of life	0.97	0.90-1.05	1.02	0.80-1.30	0.56	0.44-0.71	0.70	0.56-0.89	1.12	0.93-1.68	0.63	0.47-0.84

6.4 Discussion

Insight in the differences in attitudes towards end-of-life decision-making between physicians and the general public may contribute to the public debate and policy making in this field. In this section, we will firstly discuss these differences and suggest explanations for the attitudes in both groups. Secondly, we will discuss the limitations of our study and end with general conclusions and what our findings imply for policymaking.

Differences in attitudes between the general public and physicians

Members of the general public had a more permissive attitude towards active ending of life than physicians. This is in agreement with studies from other countries that compared the attitudes of the general public with physicians using vignettes or statements.[11-13] Although the degree of acceptance seems to be relatively high in both groups in the Netherlands. No differences were found in the acceptance of terminal sedation and increasing morphine between both groups. The latter is in accordance with findings from the USA of Emanuel, who found that, in a vignette about a patient with unremitting pain, 97% of oncologists and 92% of the general public thought it would be acceptable for the physician to increase morphine even if premature death was a likely.[12]

Attitudes of the general public

In our study, members of the general public did not seem to differentiate between active ending of life and increasing morphine. The goal of achieving a good death by alleviating suffering may be considered to be more important than how that goal is achieved. This might also account for the fact that the general public, as compared to physicians, discriminate to a lesser extent between competent and incompetent patients who are terminally ill, as was also found elsewhere.[15] Accordingly, the majority of the general public did not accept active ending of life in the case of a patient without a serious illness who requested assistance in dying, probably because the respondents were not convinced that the ending of life was an appropriate response to the suffering of this patient.[16] Terminal sedation was less often considered to be acceptable than active ending of life and increasing morphine. Therefore, dying without being able to communicate may be considered as representing a less good death by the general public. This is consistent with a study of Steinhauser et al. who found that patients, in contrast

with physicians, strongly endorsed the importance of being mentally aware at the end of life.[17]

Determinants of attitudes of the general public

Apart from the restrictive influence of religious beliefs on public attitudes towards most end-of-life practices as found by others,[11,13,18,19] this study shows that a low education and having a single household were related to a higher acceptance of active ending of life in most situations. The latter might suggest that persons with a partner tend to attach more value to length of life. We also found that acceptance of terminal sedation and increasing morphine is related to increased age. This could probably be explained by the fact that elderly people value quality of life more than prolonged survival, and therefore increasingly accept practices that might ease their last phase of life. Health and composition of household were not measured for the physicians; therefore we cannot claim that these characteristics are of particular relevance to the general public.

Attitudes of physicians

Contrary to the general public, physicians were more willing to increase morphine than to perform active ending of life or terminal sedation. Giving high dosages of morphine may be considered as being part of common medical practice, whereas active ending of life and terminal sedation are exceptional and more emotionally disturbing for physicians, probably because these practices go against the physicians' inherent goals of alleviating their symptoms, and enhancing their quality of life. Furthermore, physicians discriminated more than the general public between competent and incompetent patients, and most of them regarded active ending of life in the case of a patient with dementia or a patient without a serious illness as unacceptable, even though these patients had signed a written declaration about the active ending of life. Thus, having formulated such a written declaration does generally not result in physicians performing active ending of life, which was also found in another Dutch study.[6] However, the physicians did not seem to make a clear distinction between adults and children who have cancer with unremitting pain. This may be due to the fact that they regard a child requesting for active ending of life as equally competent as an adult. However, we cannot conclude this with certainty because competence is not only determined by age, but also by the child's capacity and we did not give any indication of the level of understanding possessed by the child in this vignette.

Limitations of the study

Our study has several limitations. Firstly, short case descriptions with a limited number of possible answers do not fully take into account the complexity of end-of-life decision-making. However, the vignettes described the situations in an as concrete and recognizable manner as possible. Secondly, the methodological differences in data collection (written questionnaires versus face-to-face interviews) and the adjustment of the formulation of the vignettes for the general public might have affected the comparability, although the tenor of the question remained largely the same. In the vignette about the non-communicative adult, several characteristics were changed that might have threatened the comparability somewhat more: in the physicians' version, the patient had dementia and had a living will, whilst this was not the case in the general public's version.

Implications for policymaking

The differences in the appreciation of end-of-life decision-making between the Dutch general public and physicians can be related to other differences between both groups. First, both groups have different roles in the decision-making process. Physicians are responsible for taking and carrying out end-of-life decisions, and have to inform patients and get their consent. Patients can express preferences, whether or not after having been asked by their physician. In the Netherlands, it has been discussed that the increase in public acceptance of physician-assisted death may lead to greater opposition among physicians who feel pressured to perform euthanasia against their will.[20] Secondly, there is also a difference in knowledge between both groups. The number of options to alleviate suffering of terminally ill patients and to improve the quality of the last phase of life has increased. Members of the general public are probably less well informed about the different characteristics and consequences of all options available. This points out the importance of informing the general public about the characteristics and consequences of these options. Although these differences in the appreciation of end-of-life decisions may threaten communication between both groups, physicians' reluctance to hasten death can also be viewed as a good starting point for discussing such crucial and far-reaching decisions.

Conclusions

We conclude that physicians and the general public differ in the appreciation of end-of-life decision-making. Acceptance of active ending of life was larger among the general public than among physicians. Members of the general public did not or only slightly seem to differentiate between the active ending of life and increasing morphine with premature death as a likely consequence, but were less willing to accept terminal sedation. Physicians were most willing to increase morphine with premature death as a likely consequence, whereas active ending of life and terminal sedation were to a lesser degree, equally, acceptable. Acknowledging these differences is important in doctor-patient communication and in public debate and policymaking. Continuing monitoring of practices and informing the general public and policymakers about the clinical and ethical consequences of different types of end-of-life decisions is important.

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7

Preferences of the Dutch General Public for a Good Death and Associations with Attitudes towards End-of-Life Decision-Making

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Submitted

Abstract

Background Euthanasia and other end-of-life decisions have been shown to be acceptable to the large majority of the Dutch public. Insight in the relationships of such acceptance with the characteristics considered important for a 'good death' can contribute to the understanding of this liberal attitude.

Methods Questionnaires were mailed to 1777 members of the Dutch public (response: 78%), measuring whether 11 predetermined items were considered important characteristics of a good death. Further, personal characteristics and attitudes towards euthanasia, terminal sedation and the use of high dosages of morphine were assessed. Associations between characteristics of a good death and attitudes towards euthanasia, terminal sedation, and the use of high dosages of morphine were analyzed.

Results Characteristics that were considered important for a good death by many respondents were the possibility to say goodbye to loved ones (94%), dying with dignity (92%), being able to decide about end-of-life care (88%), and dying free of pain (87%). Items that were less often considered important were: having solved existential problems (47%) and determining the moment of death (38%). Acceptance of euthanasia, terminal sedation and the use of high dosages of morphine was related to the wish to have a dignified death and with being concerned about burdening relatives with terminal care. Acceptance of euthanasia was also associated with the wish to be able to decide about medical end-of-life treatments and about the moment of death.

Conclusion Besides saying farewell and dying pain free and with dignity, many members of the Dutch public consider values of control and maintenance of independency as important for a good death, especially people who consider euthanasia as acceptable.

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7.1 Introduction

Developments in modern medicine have increased the possibilities of prolonging life and treating symptoms of incurably ill patients. However, prolonging life is not always considered as the most appropriate goal of medicine for terminally ill patients, and preserving quality of life or alleviation of suffering are increasingly recognized as important care goals at this stage.[1] Sometimes, end-of-life care includes interventions that may involve the hastening of death, such as stopping life-sustaining treatment or using high dosages of morphine or sedatives. Hastening of death may even be the explicit goal of care, as is for example the case in euthanasia.[2-7]

In the Netherlands, a long history of extensive debate about the acceptability of euthanasia has led to acceptance of the Dutch Euthanasia Act in 2002 (Termination of Life on Request and Assisted Suicide Review Procedures Act). This Act is supported by the large majority of the Dutch public.[8-11] In other countries, the general public has been reported to accept euthanasia as well, although to a somewhat lesser extent than in the Netherlands.[12-19]

Sedation of terminal patients to make them unaware of refractory symptoms and using high dosages of morphine while taking into account a possible life-shortening effect have been found to be acceptable to about 60% and 80% of the Dutch public, respectively.[9] The question arises whether the acceptance of these practices is associated with specific ideas of what constitutes a good death. Acceptance of euthanasia is e.g. sometimes explained as a wish to die a pain free and dignified death while others explicate it as reflecting a strong wish to control the dying process.[20-23]

Empirical research of what are considered to be the characteristics of a good death has included perspectives of patients,[24-27] family members,[28] care providers,[29] or a combination of these.[30-33] Experts have also contributed to the debate.[34-36] The perspective of the general public is relatively underexposed.[37] Studies of the characteristics of a good death have been either qualitative and open, or quantitative and prestructured. In general, research has yielded three types of characteristics. Firstly, pain and symptoms need to be adequately addressed in order to have a peaceful and dignified death.[24-28, 31-39] Secondly, psychosocial aspects are important, such as being able to prepare for death, to say goodbye to loved ones and to gain a sense of completion.[24-28, 31-39] And thirdly, many people indicate to appreciate some sense of control over their illness and

dying process, including determining the place and moment of dying.[24, 25, 28, 31-38] This sense of control also refers to the wish to avoid becoming dependent of loved ones in the last phase of life,[25, 28, 37] and to having a say over who is present while dying.[24, 37] Further, having a voice in the decision-making process and in the choice of medical treatments is also frequently recognized as important.[24, 25, 28, 35, 36]

The aim of our study was to gain insight in the characteristics of a good death for the Dutch general population and to identify whether attitudes towards euthanasia, terminal sedation and using high dosages of morphine are associated with attitudes towards a good death.

7.2 Methods

Study design and population

In September 2002, written questionnaires were sent to an established sample frame consisting of 1777 members of the Dutch general public (panel of the "Consumers' Association" Consumentenpanel Gezondheidszorg, NIVEL/Consumentenbond). Of the selected persons, 1388 returned the questionnaire (response: 78%). The sample included persons aged between 20-93 years. The distribution of age within the sample was representative for the whole population, but women were somewhat overrepresented.

Questionnaire

The questionnaire addressed preferences and attitudes concerning end-of-life decision-making. Respondents were asked to indicate how important they considered 11 attributes of the dying process, e.g. "When I die, I hope that I will die at home". Respondents rated the importance of each item as "important", "not important" and "don't know". The selection of attributes was based upon the literature.[24-28, 31-39] Further, attitudes concerning the acceptability of end-of-life decisions were assessed using a vignette, that is, a hypothetical case description of an incurable cancer patient with severe suffering who explicitly asks for euthanasia (see Box 1).

Box 7.1 Vignette

Mr. Van der Buis is 61 years old and has cancer with extensive metastases. His disease is incurable and he suffers from severe pain. He explicitly requests his physician for euthanasia.
Would you consider it acceptable that the physician would:
(1) perform euthanasia, defined as ending of life at the request of the patient by administering lethal drugs.
(2) bring the patient in a condition of unconsciousness, being unaware of pain and dying within one week.
(3) increase the dosage of pain treatment with premature death as a likely consequence.

Respondents were asked whether they considered it acceptable in this situation that the physician would (1) perform euthanasia, (2) bring the patient in a condition of unconsciousness, and (3) increase the dosage of pain treatment (see Box). Answering categories were: "yes", "probably yes", "probably yes / probably no", "probably no", and "no".
Further, respondents were asked to rate their own general health status, whether they had a history of serious illness, whether they had ever experienced the death of a first-degree family member, and whether they could think of a situation in which they would consider the option of euthanasia for themselves. Lastly, sociodemographic characteristics were obtained (age, sex, educational level, religious beliefs, and composition of household). A pilot study was conducted to investigate the level of difficulty of the questions for the general public. This resulted in the reformulation of some questions.

Statistical analyses

For all items, independent relationships between preferences concerning a good death and personal characteristics of the respondents were assessed using multivariate logistic regression analyses. The 5 response categories of the vignette were dichotomized into yes ("yes" and "probably yes") and no ("probably yes / probably no", "probably no", and "no"). We used Chi-square tests to assess relationships of preferences concerning a good death with attitudes towards euthanasia, terminal sedation, and the use of high dosages of morphine. Chi-square tests were also used to assess the relationships of preferences concerning a good death with the answers to the question whether respondents could think of a situation in which they would consider the option of euthanasia for themselves. All calculations were corrected for missing values, which were less

than 1% for most variables and less than 5% in all cases. All analyses were done by using SPSS for Windows software, version 11.0.

7.3 Results

Items that were considered important for a good death by the large majority of respondents included the possibility to say goodbye to loved ones (94%), dying with dignity (92%), being able to decide about treatments at the end of life (88%), and dying free of pain (87%) (table 7.1).

Table 7.1 Opinions of the Dutch general public towards a good death

	General public n=1388		
I hope that, when I die, I:	Important %	Not important %	Don't know %
Have said goodbye to loved ones	94	2	5
Will die with dignity	92	4	4
Will be able to decide myself about treatments I do or do not want to receive	88	4	8
Will be free of pain	87	5	8
Will die at home	65	17	17
Won't be a burden on relatives	65	19	16
Will feel prepared for death	63	16	22
Will be conscious until death	61	17	22
Won't be dependent on others	60	20	20
Have solved existential issues	47	29	14
Will be able to decide myself about the moment of death	38	25	37

Items that were less often considered important were dying at home (65%), not being a burden on relatives (65%), being prepared for death (63%), being conscious until death (61%), and not depending on others (60%). Items that were considered important by less than half of the respondents were being able to decide about the time of death (38%) and having solved existential problems (47%). Items about which a substantial number of the respondents were indecisive were being able to decide about time of death (37% indecisive), and to a lesser extent being conscious until death, having the possibility to prepare for death, and not being dependent on others (20%-22% indecisive).

Table 7.2 Determinants of preferences concerning a good death

	All respondents		Die at home important		Solve existential issues important		Prepare for death important		Not dependent on others important		Not a burden on relatives important		Conscious until death important		Able to decide about moment death important	
	n=1388		n=897		n=642		n=858		n=817		n=891		n=838		n=523	
	M	M	p-value[1]	M	p-value[1]	M	p-value[1]	M	p-value[1]	M	p-value[1]	M	p-value[1]	M	p-value[1]
Age (years)	47	46	0.580	48	0.449	46	0.056	49	<0.001	49	<0.001	46	0.011	47	0.970
	%	%	p-value[1]	%	p-value[1]	%	p-value[1]	%	p-value[1]	%	p-value[1]	%	p-value[1]	%	p-value[1]
Sex															
Female	61	70	<0.001	50	0.006	64	0.059	58	0.766	63	0.849	62	0.844	41	0.084
Male	39	58		42		60		62		67		59		34	
Having religious beliefs															
Yes	56	70	<0.001	53	<0.001	69	<0.001	58	0.007	65	0.106	61	0.720	33	<0.001
No	44	60		40		55		62		65		61		45	
Education[2]															
High	50	65	0.763	46	0.841	62	0.788	57	0.520	61	0.052	58	<0.001	32	<0.001
Low	50	65		48		64		62		69		65		44	
Living with partner															
Yes	77	69	<0.001	47	0.886	63	0.450	57	0.111	64	0.778	61	0.710	37	0.039
No	23	55		49		63		66		68		60		44	

Abbreviations: M=Mean

1. Multivariate logistic regression analyses were used to test whether differences between respondents who considered the items important and respondents who did not reached statistical significance.

2. High education was defined as intermediate vocational or higher secondary general education; higher vocational education; university. Low education was defined as lower vocational education; lower secondary general education; primary school.

Table 7.2 shows the relationships between respondents' preferences for a good death and their personal characteristics. Items that were considered important by the large majority of the respondents ("dying free of pain", "dying with dignity", "saying goodbye to loved ones", and "being able to decide about treatments") are not included. Females, respondents with religious beliefs and those living with a partner more often considered dying at home important than males, respondents without religious beliefs, and those living without a partner, respectively (all $p<0.001$). Being able to decide about the moment of death was more often considered to be important among respondents without religious beliefs ($p<0.001$), lower educated respondents ($p<0.001$), and those living without a partner ($p<0.039$). Older respondents had significantly more often than younger respondents concerns about becoming dependent on others and about becoming a burden on relatives ($p<0.001$). Younger and lower educated respondents more often wished to be conscious until death than older and highly educated respondents. In addition, as compared to non-religious respondents, respondents with religious beliefs more often hoped to have solved existential issues when they would die ($p<0.001$) and to have the possibility to prepare for their death ($p<0.001$). Preferences concerning a good death were not associated with illness related characteristics of the respondents (not in table).

Acceptance of euthanasia in the vignette was significantly related to considering it important to be able to decide oneself about medical treatments in the last phase of life and about the moment of the death, the wish to die pain free and dignified, and to having concerns about becoming dependent on others and becoming a burden on relatives ($p<0.001$) (table 7.3). Being able to think of a situation in which euthanasia would be an option for themselves (mentioned by 74% of the respondents) was related to the same preferences concerning a good death (not in table). Attitudes towards terminal sedation and the use of high dosages of morphine were less strongly associated with preferences for a good death than attitudes towards euthanasia. Acceptance of terminal sedation and the use of high dosages of morphine were negatively associated with the wish to be conscious until death and positively with the wish to die with dignity and worrying about becoming a burden on relatives. Worrying about becoming dependent on others was related to acceptance of terminal sedation and the wish to die at home with acceptance of the use of high dosages of morphine.

Table 7.3 Associations between items related to a good death with acceptance of euthanasia, terminal sedation, and the use of high dosages of morphine[1]

	Acceptance of euthanasia			Acceptance of terminal sedation			Acceptance of the use of high dosages of morphine		
	Yes n=1141	No n=200		Yes n=786	No n=554		Yes n=1097	No n=239	
	%	%	p-value[2]	%	%	p-value[2]	%	%	p-value[2]
Saying goodbye to loved ones	94	91	0.128	94	94	0.876	94	93	0.670
Dying with dignity	93	85	<0.001	93	90	0.027	93	88	0.008
Deciding oneself about treatments	91	75	<0.001	89	88	0.666	89	86	0.110
Dying free of pain	89	77	<0.001	86	86	0.118	88	85	0.144
Dying at home	65	65	0.926	65	66	0.602	67	60	0.035
Not being a burden on relatives	67	50	<0.001	68	60	0.004	66	59	0.019
Feeling prepared for death	63	63	0.848	61	65	0.140	63	62	0.676
Being conscious until death	61	61	0.972	57	67	<0.001	60	67	0.037
Not being dependent on others	62	45	<0.001	63	55	0.003	61	56	0.137
Having solved existential issues	50	47	0.444	47	47	0.999	47	47	0.853
Deciding oneself about the moment of death	43	12	<0.001	38	38	0.954	38	38	0.887

1. Single items are presented by percentage of respondents who accepted euthanasia, terminal sedation, or the use of high dosages of morphine.
2. Chi-square tests were used to test whether differences in single items reached statistical significance.

We selected a subgroup of respondents who either accepted euthanasia and rejected terminal sedation (n=429) or rejected euthanasia and accepted terminal sedation (n=68) to investigate the contrasts in acceptance of both practices (table 7.4). This analyses showed that respondents who accepted euthanasia but rejected terminal sedation more often wished to decide themselves about the treatments they want to receive at the end of life and about their moment of death (both p<0.001), and more often worried about becoming a burden on relatives (p=0.014) as compared to respondents who accepted terminal sedation and rejected euthanasia.

Table 7.4 Associations between items related to a good death with accepting either euthanasia or terminal sedation[1]

	Accepting euthanasia, rejecting terminal sedation n=429	Accepting terminal sedation, rejecting euthanasia n=68	
	%	%	p-value[2]
Saying goodbye to loved ones	95	94	0.700
Dying with dignity	92	89	0.432
Deciding oneself about treatments	93	76	<0.001
Dying free of pain	90	83	0.117
Dying at home	67	68	0.847
Not being a burden on relatives	64	48	0.014
Being conscious until death	69	58	0.094
Being prepared for death	60	65	0.841
Not being dependent on others	60	53	0.332
Having solved existential issues	47	54	0.257
Deciding oneself about the moment of death	47	16	<0.001

1. Single items are presented by percentage of respondents who either accepted euthanasia and rejected terminal sedation, or who rejected euthanasia and accepted terminal sedation.
2. Chi-square tests were used to test whether differences in single items reached statistical significance.

7.4 Discussion

Our study shows that most respondents of the Dutch general public consider medical as well as non-medical characteristics important for a good death: dying a pain free and dignified death, having the possibility to say goodbye to loved ones, and being able to personally decide about end-of-life treatments. The importance of dying at home, staying conscious until death, not burdening relatives with

terminal care, having the possibility to decide about the moment of death and having solved existential issues is less obvious. Furthermore, accepting euthanasia, terminal sedation and the use of high dosages of morphine is associated with the wish to have a dignified death and concerns about burdening loved ones with terminal care. Acceptance of euthanasia is also associated with the wish to achieve some sense of control of medical end-of-life treatments and of the moment of dying.

Many persons suffer from severe symptoms at the end of life.[1, 40-42] Our finding that the large majority of the Dutch general public consider dying free of pain and with dignity important for a good death is in line with previous reports that careful anticipation and alleviation of such symptoms is generally considered to be very important.[24-28, 31-34, 36-39, 43] The finding that many respondents want to decide themselves about the treatments they do or do not want to receive is in accordance with findings of studies among patients and patients' relatives.[24, 28] Apparently, many people are concerned that they might receive burdensome treatments that are not consistent with their preferences.[44] Another interpretation may be that this wish merely reflects that people want a voice in their end-of-life care rather than specific control over each treatment decision.[25]

About two-thirds of the respondents consider dying at home as important for a good death. This percentage is comparable with other studies.[45] In the Netherlands, about 40% of the general population die at home, meaning that an initial preference for dying at home is often not met. Probably, initial preferences often change when situations change: due to deteriorating health, patients may sometimes eventually prefer a more skilled environment[45-47] or patients may want to save relatives from the burden of caring at home.[48] We found that especially females, respondents with religious beliefs, and respondents with a partner prefer to die at home. The latter two findings are consistent with studies that show that religious respondents and people living with a partner indeed more often die at home.[48]

In modern Western societies, individualism and independency are highly valued, and our findings show that these values extend to the dying phase: control, maintenance of independency and self-determination are for many people important aspects of a good death. Although findings from other countries also show that these values are important characteristics,[24-28, 32-39, 49] this may be especially true for the Netherlands. It has e.g. been shown that in the Netherlands, patients are more often than in other countries involved in medical end-of-life

decision-making.[4] Nevertheless, this is probably not the sole explanation for the high level of acceptance of euthanasia in the Netherlands, which is also considered to be a reflection of other social or cultural mechanisms, such as a strong need to discuss and regulate controversial practices.[50]

Our findings may provide some insight in the underlying reasons for accepting euthanasia: a desire to influence the dying process by deciding about treatments and determining the moment of death, feeling uncomfortable about burdening relatives with terminal care, and a wish to prevent or avoid further severe suffering and loss of dignity when becoming terminally ill. Actual requests for euthanasia in the Netherlands have been found to be based upon similar reasons, except that feeling uncomfortable about burdening loved ones with terminal care was reported in a minority (17%) of the performed euthanasia cases.[7, 51]

Among respondents who accept terminal sedation and the use of high dosages of morphine with possible life-shortening effect, concerns about burdening loved ones with terminal care and maintenance of dignity are somewhat more prevalent as compared to respondents who do not consider these practices as acceptable, whereas the wish to be conscious until death is less prevalent. Interestingly, respondents who accept terminal sedation but who reject euthanasia attach less importance to control of medical decision-making at the end of life in terms of wishing to participate in decision-making or determining place of death. This is in line with a previous Dutch study that concluded that terminal sedation is typically used to address severe suffering while the patient or the patient's representatives may accept loss of control of the dying process, whereas patients requesting euthanasia consider control of the dying process of utmost importance.[51]

Our study has some limitations. Qualitative studies have shown that preferences are not always a clearly definable entity but often take the form of a stronger or weaker leaning in one direction, qualified by speculation about how things might change with events.[48] Therefore, respondents may sometimes find it difficult to answer in predetermined answer categories, which explains the fact that about half of the statements, approximately 20% of the respondents was indecisive. Furthermore, while we presented the respondents with predetermined factors, they interact in complex ways in individuals' lives. For example, the preference to die at home can be influenced by patients' symptoms at that moment and the caring capacity of loved ones. Also, the formulation of the items may have evoked different connotations in respondents. This may especially be true for

concepts as “dying with dignity”, “being a burden”, “being prepared for death”, and “solving existential issues”.

We conclude that besides being able to say farewell and dying pain free and with dignity, many members of the Dutch public consider control and maintenance of independency as important for a good death, especially people who consider euthanasia as acceptable. Carefully managing requests for euthanasia implies consideration of the possibility that such requests can be related to the wish to control the dying trajectory, to having concerns about burdening loved ones with terminal care, or to the wish to die pain free and dignified.

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8

Striving for Quality or Length at the End-of-Life: Attitudes of the Dutch General Public

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Abstract

M**ethods** Questionnaires were mailed to 1777 members of the Dutch public (response: 78%), measuring to what extent respondents appreciate life-prolonging treatment, even if it would seriously impair their quality of life. The association between these attitudes and personal characteristics and initiatives to engage in advance care planning was analyzed.

Results About one third of the respondents prefers quality of life at the expense of survival, another third prefers length of life regardless of impaired quality, whereas the remaining third did not express a clear attitude towards quality or length of life. People who were younger, male, having children, having religious beliefs, and without a history of serious illness were more likely to strive for length, whereas the reverse associations were found for striving for quality. The latter was related to undertaking initiatives to engage in advance care planning.

Conclusions Awareness of differences in attitudes towards life-prolonging treatment within the public may improve communication about appropriate end-of-life care.

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8.1 Introduction

End-of-life care is increasingly acknowledged to be patient centered, that is, the patients' preferences and wishes should play an important role in medical decision-making. Recognizing factors that determine patients' preferences and actual choices is necessary in guiding the patient through this decision-making process. Patients' actual treatment choices are found to be most strongly predicted by the treatment preferences they had before consultation with their physician, while these preferences are explained by patients' general attitudes towards treatment, such as striving for length or quality of life.[1] Therefore, being aware of the patients' attitudes and preferences is an important prerequisite for high quality end-of-life care. These preferences include wishes concerning the use of potentially life-prolonging treatments, such as anti-tumor therapy or mechanical ventilation, which may sometimes severely impair the quality of the last phase of life.

Most studies on attitudes and preferences towards medical treatments have focused on populations of patients. Preferences concerning life-prolonging treatments of patients with varying diseases in different stages have been studied extensively.[2-9] It has been shown that preferences vary according to the type of life-prolonging treatment, its expected outcome, and the probability of that outcome.[6,9] Furthermore, younger cancer patients and cancer patients with children were found to assign more importance to striving for prolonged survival, even when this would impair their quality of life.[7]

It has been suggested that discussion about attitudes concerning end-of-life care before the patient becomes seriously ill facilitates medical decision-making at the end of life, because such discussions can provide a framework for all medical decision-making.[10] Although such advance care planning is generally assumed to be particularly relevant for older and sick people, a study of Emanuel *et al.* among patients and members of the general population showed that 89% of the general population desire some kind of advance care planning, such as filling out an advance directive or discussing their wishes concerning medical care at the end of life with their physician.[11] However, the number of people in the general public who have actually undertaken such initiatives to enhance personal control over their last phase of life is very small.[11-13]

It has been proposed that advance care planning should occur within the community and specifically within the family, and not in hospitals when consulting

a doctor.[14,15] However, little is known about whether healthy persons are willing and able to express attitudes towards the use of intensive medical treatments at the end of life, and how they weigh the benefits and disadvantages of it. The aim of our study was to gain insight in such attitudes within the Dutch general population. A second aim was to identify whether these attitudes are associated with personal characteristics and with initiatives that people undertake to enhance personal control over medical interventions during their last phase of life.

8.2 Methods

Study design and population

In September 2002, written questionnaires were sent to an established sample frame consisting of 1777 members of the Dutch general public (panel of the "Consumers' Association" Consumentenpanel Gezondheidszorg, NIVEL/Consumentenbond). Of the selected persons, 1388 returned the questionnaire (response: 78%). The sample included persons aged between 20-93 years. The distribution of age within the sample was representative for the whole population, but women were somewhat overrepresented. The sponsors of the study approved the study design, but were not involved in the data collection, data analysis, or data interpretation.

Questionnaire

The questionnaire addressed attitudes concerning various end-of-life decisions. Attitudes towards life-prolonging treatment at the end of life were assessed with the Quality Quantity Questionnaire.[7] This questionnaire contains 8 statements about accepting or rejecting life-prolonging treatment at the end of life. The questionnaire was originally developed to assess attitudes towards life-prolonging treatment of patients with cancer, but by reformulating the statements, the questionnaire could be used within the general public. For example, the original statement "If a treatment could prolong my life, I would always accept it, whatever the side-effects may be" was changed into "If I would become seriously ill, I would accept every treatment that can prolong my life, whatever the side-effects may be". Respondents were asked to what extent they agreed with the statements on a five-point Likert scale (1=totally disagree; 2=more disagree than

agree; 3=neither agree, nor disagree; 4=more agree than disagree; 5=totally agree).

To identify whether attitudes towards life-prolonging treatment were associated with initiatives that persons can undertake to enhance personal control over their last phase of life, respondents were asked whether they had filled out an advance directive, whether they had designated a surrogate decision-maker, and whether they had ever discussed wishes concerning medical treatments at the end of life with a physician. Also, the respondents were asked to rate their general health status,[16] and whether they had a history of serious illness. Lastly, sociodemographic characteristics were obtained (age, sex, educational level, having children, religious beliefs).

Statistical analyses and construction of attitude profiles

We calculated the mean and the median of responses per item. A principal-component analysis with the varimax method was carried out to reconfirm the structure underlying the relationships among the 8 items of the Quality Quantity Questionnaire. The factor solution was based on the eigenvalues (>1.0). Two factors were found to underlie the questionnaire, which is consistent with the original findings within a group of patients with cancer.[7] Factor one, explaining 43% of the variance, contained items representing an inclinement to "strive for length of life regardless of impaired quality of life". Factor two explained an additional 16% of the variance and contained items representing an inclinement to "strive for quality of life at the possible expense of survival". Sum scores were calculated for the factor "striving for length of life" (L scale) and the factor "striving for quality of life" (Q scale). For both scales, internal consistency was assessed by means of Cronbach's alpha. By distinguishing high (above the median) and low (under the median) scores on each factor, we constructed three profiles of attitudes: (1) persons with a high score on the L scale and a low score on the Q scale were categorized as "striving for length"; (2) persons with a low score on the L scale and a high score on the Q scale were categorized as "striving for quality"; (3) persons with either a high score on both scales or a low score on both scales were categorized as "no clear attitude expressed".

Table 8.1 Scores of the general public on the Quality Quantity Questionnaire[1]

	Mean	± SD	Median	Loadings factor 1[2]	Loadings factor 2[3]
In order to live a bit longer, I would clutch at any straw. (L)	3.0	1.2	3	**0.814**	-0.178
If I would become seriously ill, I would accept every treatment that can prolong my life, whatever the side effects may be. (L)	3.0	1.3	3	**0.772**	-0.177
If I would become seriously ill, I would always accept a hard-to-tolerate treatment, even if the chance of its prolonging my life was as little as one percent. (L)	2.7	1.2	2	**0.755**	-0.237
If I would become seriously ill, I would probably manage to find the strength to continue. (L)	3.4	1.0	3	**0.716**	-0.084
A moment might come in which I would say: "I have done my best, this is the limit. (Q)	4.1	1.1	4	0.044	**0.758**
If a life-prolonging treatment would prevent me from leading a normal life, then I would rather not have it. (Q)	3.6	1.1	4	-0.181	**0.748**
I can imagine some side effects being so bad that I would refuse the treatment, even if that meant a shorter life (Q)	4.0	1.0	4	-0.296	**0.686**
If I had to endure six months of hard-to-tolerate treatment in order to live for an extra half year, then I would not be willing to get that treatment. (Q)	3.6	1.2	4	-0.364	**0.654**
					Cronbach's alpha
L scale	12.1	3.7	12		0.81
Q scale	15.3	3.3	15		0.73

1. Scores per item could range from 1 to 5 (1=totally disagree; 5= totally agree).
2. Factor 1: striving for length of life regardless of impaired quality of life.
3. Factor 2: striving to quality of life at the expense of survival.
4. Scores could range from 4 to 20.

For the L and the Q scale, relationships with sociodemographic characteristics and initiatives concerning end-of-life care were calculated by Student's t-tests and Pearson's correlations. Two multivariate regression analyses were performed to identify the unique contribution of the sociodemographic characteristics to the scores on the Q scale and the L scale. In addition, multivariate logistic regression analyses were done to determine whether associations between attitudes and initiatives concerning end-of-life care would hold when the analysis was corrected for sociodemographic characteristics. All analyses were done by using SPSS for Windows software, version 10.0.

8.3 Results

Of the 1388 respondents who returned the questionnaire, 1354 had filled out all of the 8 items of the Quality Quantity Questionnaire whereas 34 respondents did not answer one or more of the 8 items of the questionnaire. Attitudes towards treatment and the item loadings on the Q and L scale are given in table 8.1.
The median score of the L scale, 12, was lower than the median score of the Q scale, which was 15. Thus, respondents were more likely to agree with items that emphasized the importance of quality of life as compared to items that emphasized the importance of length of life. Both scales had a high internal consistency, Cronbach's α= 0.81 and 0.73, respectively.

Table 8.2 Profiles of attitudes towards life-prolonging treatment among the general public

	L scale[1] >12		L scale[1] ≤12		Total	
	n	%	n	%	n	%
Q scale[1] >15	199	15[2]	474	35[4]	673	50
Q scale[1] ≤15	402	30[3]	279	21[2]	681	50
Total	601	45	753	56	1354	

1. Scores could range from 4 to 20.
2. Profile: no clear attitude expressed.
3. Profile: striving for length.
4. Profile: striving for quality.

Based on a dichotomization of the Q and L scales at their median values, 30% of the respondents could be classified as striving for length, 35% as striving for quality, and 35% as no clear attitude expressed, based on the questions of this survey (table 8.2).

Table 8.3 Relations between sociodemographic characteristics of the general public and the Q and L scale of the Quality Quantity Questionnaire

	n=1354			L scale[1]			Q scale[1]
	Mean		r	p-value[3]		r	p-value[3]
Age	46.8		-0.09	0.001		0.15	<0.001
	n	Mean	SD	p-value[3]	Mean	SD	p-value[3]
Sex[4]							
Male	527	12.5	3.7	0.002	15.0	3.4	0.034
Female	826	11.9	3.6		15.4	3.2	
Having children[5]							
No	707	11.7	3.8	<0.001	15.6	3.2	<0.001
Yes	619	12.5	3.5		14.9	3.3	
Religion[6]							
No	592	11.6	3.6	<0.001	15.7	3.0	<0.001
Yes	751	12.5	3.8		14.9	3.4	
Health status[7]							
Good	1063	12.2	3.6	0.014	15.1	3.2	0.005
Fair / poor	280	11.6	3.9		15.8	3.4	
History of serious illness[8]							
No	1129	12.2	3.7	0.038	15.1	3.3	<0.001
Yes	216	11.6	3.9		16.0	3.2	
Education[9]							
Low	666	12.4	4.0	0.284	15.6	3.4	0.006
Intermediate / high	681	12.1	3.5		15.0	3.2	

1. Scores could range from 4 to 20.
2. In 3 cases, information was missing.
3. P-values calculated by Pearson's correlations (age) or Student's t-tests.
4. In 1 case, information was missing.
5. In 28 cases, information was missing.
6. In 11 cases, information was missing.
7. In 11 cases, information was missing.
8. In 9 cases, information was missing.
9. Low: Lower vocational education; lower secondary general education; primary school. High: Intermediate vocational or higher secondary general education; higher vocational education; university. In 7 cases, information on education was missing.

Table 8.3 shows that the scores on the Q and the L scale were associated with sociodemographic characteristics of the respondents. Persons who had a relatively high score on the L scale were on average younger and more often male, and had more often children, religious beliefs, no history of serious illness, and a good health status. A high score on the Q scale was related to being older and female, to not having children or religious beliefs, and to having a history of serious illness, a fair or poor health status, and a low education.

In the multivariate regression analyses, all sociodemographic characteristics were independently related to both scales, except health status which had no

statistically significant independent relationship with either of the scores, and a history of serious illness which had no independent relationship with the Q scale (data not shown).

Low scores on the L scale and high scores on the Q scale were strongly associated with having filled out an advance directive, having designated a surrogate decision-maker, or having discussed wishes concerning end-of-life treatment with a physician (table 8.4). Multivariate logistic regression analyses showed that this association remained stable after correcting for sociodemographic characteristics of the respondents (data not shown).

Table 8.4 Relations between the scores and the Q and the L scale of the Quality Quantity Questionnaire and initiatives of the general public concerning their end-of-life care

	Total n=1354	L scale[1]			Q scale[1]		
	n	Mean	SD	p-value[2]	Mean	SD	p-value[2]
Having an advance directive[3]							
Yes	98	10.2	3.7	<0.001	16.9	3.2	<0.001
No	1244	12.2	3.7		15.1	3.2	
Designated a surrogate decision-makers[4]							
Yes	364	11.3	3.7	<0.001	16.1	3.2	<0.001
No	978	12.4	3.7		15.0	3.2	
Wishes towards medical treatment at the end of life discussed with physicians[5]							
Yes	44	9.8	3.1	<0.001	17.0	3.3	<0.001
No	1308	12.2	3.7		15.2	3.2	

1. Scores could range from 4 to 20.
2. P-values calculated by Student's t-tests.
3. In 12 cases, information was missing.
4. In 12 cases, information was missing.
5. In 2 cases, information was missing.

8.4 Discussion

Attitudes towards life-prolonging treatments at the end of life are measurable within the general public. We found that a short questionnaire can elicit attitudes of respondents with respect to their willingness to strive for prolonged survival at the expense of an impaired quality of life and their willingness to trade off survival in favor of quality of life. It was found that such attitudes vary: about one third of our sample frame can be described as predominantly striving for prolonged

survival regardless of impaired quality of life and another third as striving for quality of life at the expense of survival. Based on this questionnaire, the remaining third of the respondents did not express a clear attitude for either quality of life or length of life: they either strived for both options or for none of the two options. Advance care planning prior to becoming seriously ill might not be feasible or appreciated within this group. It also implies that quality of life and prolonged survival are not the ends of one single, continuous scale. This idea is supported by the two factors that were found to underlie the questionnaire by means of the principal-component analysis. As compared with other studies that used the Quality Quantity Questionnaire in populations of cancer patients in various stages of disease,[1,7,8] respondents of the general public scored rather similar on the quality scale but somewhat lower on the length scale. Another study also showed that seriously ill patients assign higher priority to length of life as compared to healthy subjects.[2] People may attach more importance to prolonged survival when their own death is potentially nearing due to a serious disease. Furthermore, terminally ill patients may be somewhat more used to an impaired quality of life, and thus will be more willing to bear side effects of a potentially life-prolonging treatment as compared to subjects with less limitations for whom quality-of-life reductions are rather hypothetical.[2] However, respondents of the general public with an impaired health status did not score higher on items of the L scale as compared to healthy subjects. This could be explained by the fact that health status as measured in our study has previously been found to be a multi-dimensional concept: besides physical aspects it also refers to other health dimensions such as coping, the extent to which people are able to perform, and general well being,[16] which may not directly be associated with attitudes towards life-prolonging treatment at the end of life. Respondents with a history of serious illness turned out to be significantly less striving for length of life than respondents who had no such history. Most of the illnesses mentioned by the respondents were rather serious but curable, or were conditions that allowed them to adjust to. Apparently, having faced such health-threatening illnesses and probably intensive treatments can result in appreciating limits to the application of life-prolonging treatments.

Older respondents and people without children were more inclined to strive for quality of life and assigning less importance to prolonged survival, as was also found by others.[7,17-19] Understandably, persons with children are more willing to trade off quality of life in favor of prolonged survival, whereas older persons may

increasingly consider quality of life as a priority. Having religious beliefs was positively associated with striving for length of life regardless of impaired quality, indicating that members of the general public with religious beliefs probably feel that it may be wrongful not to prolong life. This is consistent with studies that reported Catholic and Jewish physicians to be less willing to forgo life-prolonging therapies.[20,21]

Persons who undertake initiatives to enhance personal control over the last phase of life were more likely to strive for quality of life at the expense of survival as compared to persons who did not undertake such initiatives. Such persons more often had filled out an advance directive, more often had designated a surrogate decision-maker, and more often had discussed their wishes concerning end-of-life treatment with a physician. It has been reported that about one third of the patients receive more aggressive treatment than they would like.[22] People who are inclined to strive for quality of life at the possible expense of length are probably concerned that medical practice may be mainly focused at prolonging life, and therefore feel not sure that physicians will act according to their wishes at the end of life.

Conclusions

We conclude that, based on this survey, attitudes towards the use of life-prolonging treatments at the end of life vary among respondents of the Dutch general public: about one third is inclined to prefer quality of life at the expense of survival, and another third has an inclination to strive for length of life regardless of impaired quality of life. Striving for quality of life is typically related to undertaking initiatives to enhance personal control over the last phase of life. The remaining third of the respondents did not express a clear attitude towards the use of life-prolonging treatments at the end of life.

Implications for practice

The fact that attitudes are related to sociodemographic characteristics suggests that attitudes may change when personal circumstances change, although we need longitudinal data to further explore this. This can e.g. have implications for the use of advance directives: they may loose validity when filled out under different circumstances than the situation defined and when not discussed occasionally throughout the years. Therefore, in order to make end-of-life care truly patient-centered, it is not only important that caregivers are aware of the

patients' attitudes towards end-of-life care, but also that these attitudes are regularly discussed during life course. Such discussions can provide valuable information for end-of-life decision-making, in particular when people become unexpectedly incompetent e.g. due to a rapidly progressing illness or an accident.

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9

General Discussion

9.1 Introduction

The two aims of this thesis were to study several aspects of the practice of medical decision-making at the end of life and to investigate attitudes of the Dutch public and physicians towards end-of-life decision-making. In this chapter, the findings of the studies will be discussed. First, some methodological considerations will be addressed. Paragraph 9.3 discusses the findings related to the first aim. The frequency and characteristics of the practice of terminal sedation in the Netherlands and in other European countries will be discussed. Further, this paragraph discusses characteristics of the practice of using drugs to end life without an explicit patient request. In paragraph 9.4, findings related to the second aim will be addressed. Attitudes of the Dutch public towards different types of end-of-life decisions in various situations are compared with attitudes of physicians. Also, attitudes of the Dutch public towards factors that are considered important for a good death and attitudes towards the use of life-prolonging treatments are discussed. In the last paragraph, 9.5, possible implications for policy, practice and further research are considered.

9.2 Limitations of the studies

In this thesis, three different types of studies were used: interviews with physicians, death certificate studies among physicians, and a survey among the Dutch general public. These studies were conducted nationwide and include data that are considered to be representative for all Dutch physicians and the Dutch population. The guaranteed anonymity for physicians in the interview study and the death certificate study and the high response rates in all studies contribute highly to the credibility and validity of the data used in this thesis. Nevertheless, some limitations of the studies should be taken into consideration.

Physician interviews and death certificate studies

Face-to-face interviews have the possible disadvantage of a biased interpretation of the interviewers of the contents of the interview. Moreover, the respondents may feel pressed to give socially acceptable answers. We have attempted to eliminate this risk as far as possible through a careful selection and training of the interviewers (physicians) and by assuring strict anonymity of the respondents.

Another potential source of bias could have been that recalling patients' characteristics can be difficult for the respondents. However, recall bias was probably limited as most terminal sedation cases in the interview study concerned patients who died during the preceding two years and physicians in the death certificate study received the questionnaire at most 6 months after the death of the patient. Further, a limitation of focusing on physicians is that perspectives of other participants in the process of end-of-life decision-making, such as patients, relatives and nurses, are underexposed.

Survey among the general public

Studies on attitudes have some limitations. Firstly, attitudes are generally considered to be a predictor of actual behavior.[1, 2] However, other factors -such as environmental and social factors- may also influence how people eventually act.[1] Thus, attitudes may only partly explain actual behavior. Secondly, it has been shown that attitudes do not always remain stable when people become seriously ill.[3] These limitations make it rather difficult to use public opinion alone as a rational basis for regulating and organizing end-of-life decision-making. Nevertheless, information about attitudes is important because it gives insight in the arguments that people use in debates about end-of-life decision-making. It also helps to understand whether current legislation and organization of care are concordant with preferences of the public.

A last limitation derives from the fact that data on physicians' attitudes from the face-to-face interviews are compared with data from the public survey (Chapter 6). Before undertaking this study, a pilot study was conducted which resulted in reformulation of some of the survey questions. The resulting methodological differences might have affected the comparability of both studies, although the quintessence of each question remained largely the same.

9.3 Physicians' end-of-life practices

9.3.1 Terminal sedation

Defining terminal sedation

The first part of this thesis focuses mainly on describing the characteristics of the Dutch practice of terminal sedation. National and international discussions about terminal sedation are often complicated by the fact that many people use

different descriptions and definitions for this practice. Whereas we used the term 'terminal sedation', other terms that are frequently used for this practice are palliative sedation, sedation for intractable distress in the imminently dying, or slow-euthanasia.[4-8] Because discussions about terms are also implicit discussions about norms, these terms often reflect different opinions about what would constitute acceptable practice and what not.

The practice of sedation in the last phase of life can be described by several aspects: the manner of administration of sedating drugs (intermittent or continuous until death), the intensity of the sedation (mild or deep), the life-shortening effect, whether the patient requested it, and whether life-sustaining treatments -such as artificial nutrition or hydration- are forgone. In our studies, we only considered continuous deep sedation until death, and we included the forgoing of artificial nutrition and hydration in the definition. In the interview study, we defined terminal sedation as a combination of two acts: bringing the patient in deep sedation or coma until death while forgoing artificial nutrition or hydration. In the death certificate study, we avoided the term 'terminal sedation' and asked physicians whether they had administered drugs to keep the patient continuously in deep sedation or coma until death and if so, whether artificial nutrition and hydration were given or not. It is not uncommon to define terminal sedation as a combination of sedating until death and forgoing life-sustaining treatments. Quill et al. defined terminal sedation as "sedation until unconsciousness, while all life-sustaining treatments are withheld".[9] Tannsjo, in his book about terminal sedation, defined this practice as "putting the patient definitely into a state of unconsciousness (supposed to go on until the patient is death) while, at the same time, artificial nutrition and hydration of the patient are withheld".[10] We applied a comparable definition because we wanted to distinguish deep sedation in the last phase of life from other forms of sedative use, such as in surgery and intensive care or as medication for sleeping disorders. Furthermore, in the context of our study, we were particularly interested in the extent to which terminal sedation may be seen as an end-of-life decision, that is, a decision that may (intentionally or unintentionally) shorten life. This is especially relevant when life-sustaining treatments are forgone.

Frequency of terminal sedation

Terminal sedation was found to be a rather substantial practice in the Netherlands. It appears to be used for cancer patients as well as other patients, in

hospitals, nursing homes and at home. The interview study showed that 10.0% of all deaths in the Netherlands in 2001 were preceded by terminal sedation (see Chapter 2). The death certificate study showed that deep sedation until death without artificial nutrition and hydration occurred in 3.7% of all deaths (Chapter 3). This difference is partly explained by the fact that the death certificate study prevalence only refers to deaths that were preceded by an end-of-life decision that possibly or certainly hastened death. The interview study also included cases in which death was not hastened.

Deep sedation until death was found to be also frequently practiced in other European countries (see Chapter 3). It was shown that deep sedation until death without administration of artificial nutrition or hydration was practiced in 3.0% of all deaths in Italy, 3.2% in Belgium, 2.9% in Switzerland, 1.8% in Sweden and 1.6% in Denmark. The numbers are, however, not fully comparable, because outside the Netherlands the question on deep sedation until death was asked for all non-sudden deaths and not only for deaths in which an end-of-life decision was made. Corrected for this, the Dutch figure of 3.7% would be somewhat higher. Nevertheless, these findings demonstrate that deep sedation until death is frequently practiced in all studied countries. The cross-national differences suggest differences in clinical practices. The reasons for these differences are unclear and deserve further research.

The European study also showed that deep sedation until death in combination with the administration of artificial nutrition and hydration was practiced in an additional 1%-2% of all deaths in the Netherlands, Denmark, Sweden and Switzerland. In Italy and Belgium, higher percentages were reported for this practice (5%-6% of all deaths). In these countries, sedation might be used earlier in the patient's course of disease, when artificial nutrition and hydration are considered necessary to keep the patient alive. Further, these countries have a strong Roman Catholic tradition in which the 'sanctity of life' doctrine[11] may be more prevalent in physicians' practices than in countries with a less predominant Catholic tradition. Forgoing artificial nutrition and hydration while sedating a patient may be in conflict with such a doctrine because it may have the connotation that death was intended.

Other studies on the practice of sedation in the last phase of life do not report nationwide frequencies of the use of sedation prior to death but give frequencies for specific settings. A wide range of frequencies is reported (1%-88%), depending on the definition used, the setting studied, and the study methods.[12-18]

In palliative care units, generally the highest frequencies are found, which may be due to the fact that for many patients in these units the dying phase is accompanied by complex problems.
Trends in the use of sedatives have also been reported. A German trend study situated in a palliative care unit showed a considerable increase in the use of sedatives in the period 1995-2002.[17] This increase was associated with an increased use of terminal sedation for psychological symptoms, such as severe anxiety. In the Netherlands, there are also indications for an increase in prevalence of the practice of terminal sedation. Pharmacological registrations showed that in the period 1997 – 2002 the acquirement of midazolam had increased by a factor 10.[19] The reasons for this increase are unclear. Possibly, growing attention for the practice of terminal sedation from palliative care, research, and the media has contributed to this increase.

Aspects of clinical practice
In the Netherlands as well as in other countries, guidelines for the use of terminal sedation are being developed and adopted.[20-24] In the Netherlands, local guidelines are in use[20, 22] and the Royal Dutch Medical Association is currently developing a guideline. Nearly all guidelines have in common that benzodiazepines are considered as the drug of the first choice. Another aspect of many guidelines is that in difficult clinical cases, physicians should discuss the indications for and performance of terminal sedation with experts. Guidelines often include different requirements for a medico-technical appropriate performance of terminal sedation. They differ e.g. with respect to the involvement of the patient, the moment of starting the sedation, and whether physical as well as psychological suffering could be valid indications for sedation.
Our findings show that besides benzodiazepines, opioids alone are in about one-third of the patients used to induce unconsciousness (see Chapter 2). Our findings do not give insight in the reasons why physicians decided to sedate with opioids. Probably, in some patients, unconsciousness was an accepted side effect of the opioid use. Furthermore, in some patients unconsciousness may have been a result of the progression of the underlying disease instead of a result of the opioid use. Finally, in some cases, the choice to sedate with opioids may not have been based on a well-considered and well-informed choice of drugs.
Physicians had seldom consulted specialists in palliative care or pain management teams (see Chapter 2). In addition, more than half of the general

practitioners and nursing-home physicians had not consulted any other physician about their decision to perform terminal sedation. In contrast, relatives were frequently involved in the decision-making process, and nursing-home physicians and clinical specialists also rather frequently involved nurses. Apparently, some physicians consider carrying out this practice to be part of their own medical competence. In some cases, a rapid dying process of some patients may make consultation impossible. However, it is also possible that in some cases, consultation was difficult because access to experts in palliative care was not always available. Current developments in establishing palliative consultation teams may enhance such access.[25]

Terminal sedation: a form of ending life?

Terminal sedation is considered a last resort to relieve refractory, distressful symptoms in terminally ill patients. The patient's death is almost always foreseen in case of terminal sedation, and, as a result, patients are actually 'socially dead' prior to their actual passing away. Because terminal sedation is often such a weighty decision, it may sometimes evoke concerns and strong emotional reactions from caregivers as well as relatives.[26, 27] Those concerns include whether or not terminal sedation is a form of intentionally ending of life, such as is the case in euthanasia.

In the Dutch parliament, it has been discussed whether terminal sedation resembles the practice of euthanasia and whether physicians applying terminal sedation should also be externally reviewed.[28] Chapter 4 demonstrates that in the majority of cases, terminal sedation and euthanasia are fundamentally different. Terminal sedation is typically aimed at addressing severe symptoms in dying patients. It has no or a rather limited life-shortening effect in most cases. Euthanasia is always aimed at hastening death, is often used to address patients' feelings of loss of dignity and control, and often has a more substantial life-shortening effect. However, there is also a small overlap between both practices. This overlap can be described from a legal as well as a moral point of view.

From a legal point of view, intentionally ending of life is defined by three aspects: administering drugs with the intention to hasten death and a life-shortening effect of this act.[29] Cases in which life-sustaining treatments are forgone with the explicit intention to hasten death are not judged as intentionally ending of life. Nevertheless, when the decisions to sedate the patient and to forgo artificial nutrition and hydration are made simultaneously, which is true for nearly all

patients, it can be argued that the intentions of the two acts are difficult to distinguish*.[30] In our study, in 3% of the cases of terminal sedation, physicians indicated that they had administered the sedating drugs with the explicit intention to hasten the patient's end of life. In an additional 14% of the cases, artificial nutrition and hydration were forgone with the explicit intention to hasten death. Thus, 17% of the terminal sedation cases were found to be performed with the explicit intention to hasten death.

Terminal sedation is generally not considered to have a life-shortening effect when it is practiced with accurately dosed sedating medications in patients with a limited life expectancy. In those cases, patients die as a result of their underlying disease while being unaware of their symptoms. However, terminal sedation is sometimes used for patients with a life expectancy of more than one or two weeks. In those cases, terminal sedation can have a life-shortening effect because forgoing artificial hydration may cause the patient's death. In our study, physicians estimated that in most cases of terminal sedation, the patient's life had been shortened by 24 hours or less. In 27% of the cases, life was estimated to have been shortened by more than 1 week.

Thus, from a legal point of view, cases in which physicians have the explicit intention to hasten death and in which the act of terminal sedation has a life-shortening effect should be viewed as intentionally ending of life. In our study, it can be calculated that this was true for approximately 10% of all cases of terminal sedation.

To evaluate the practice of terminal sedation morally, we need to know more than the physician's intentions and the effects of terminal sedation. From a moral point of view, terminal sedation is acceptable when it can be considered to reflect proportional medical care.[30, 31] This includes that the patient suffers from severe symptoms that are refractory to other treatment and that no other reasonable treatment options are be available. This holds especially when the life-shortening effect is limited, which was found to be true in most of the cases. In such cases, applying terminal sedation fulfills the criteria of proportionality: the 'bad' consequence of the act (that is, rendering the patient unconscious or a possible

* In those cases, the decision to administer sedating drugs cannot be seen independently from the decision to forgo artificial nutrition or hydration. In those cases, the administration of the sedating drugs is the most relevant decision, because the sedation makes the patient dependent on artificial nutrition and hydration. However, this is only true for patients who were not yet dependent on artificial nutrition or hydration prior to the sedation.

hastening of death) is the lesser evil, which is compensated by the 'good' consequence, that is, the relief of pointless suffering. In those cases, terminal sedation may be considered as acceptable medical practice, without intentions having to bear the full weight of the moral evaluation. In our study, it is difficult to evaluate which cases of terminal sedation fulfill the criteria of proportionality, because we do not have detailed information about whether the patients' symptoms were refractory or whether other reasonable treatment options were available.

There are also cases in which terminal sedation seems no appropriate proportional response to the medical situation.[31] Terminal sedation sometimes seems to be used as an alternative manner to perform euthanasia, for patients with an explicit death wish. In those cases, terminal sedation can only be explained as a technique that is used to intentionally end life. However, physicians may have well considered reasons for doing so, e.g. because the patient prefers dying in sleep to a death through muscular relaxants. In our study, there are also some indications that terminal sedation was sometimes practiced as an alternative for euthanasia. This could e.g. be true for some of the cases in which physicians indicated that the option of euthanasia was discussed with the patient, but the patient preferred terminal sedation (9% of the patients who received terminal sedation).

Concluding remarks

The practice of terminal sedation is substantial, in the Netherlands as well as in other countries. Our findings show that terminal sedation is in the majority of cases practiced in severely suffering patients nearing death. Furthermore, it was shown that terminal sedation embraces a large variation in clinical practices. This variety may be an indication that terminal sedation is sometimes practiced sub-optimally. Yet, when undertaking efforts to optimize this practice, some findings deserve further attention: the fact that opioids are rather often used for sedation in stead of benzodiazepines, the fact that the application of terminal sedation is not always discussed with experts or other physicians, and the fact that terminal sedation in a limited number of cases appears to approximate the practice of intentionally ending of life.

9.3.2 End-of-life decision-making without patient involvement

End-of-life care should be patient centered, that is, the presumed wishes of the patient should play an important role in the decision-making.[32] In practice, this is sometimes difficult. Intentionally ending of life by the use of drugs appeared to be not always performed at the explicit request of the patient (see Chapter 5). In the Netherlands, this practice preceded 0.7% of all deaths in 2001 and 1995, and 0.8% of all deaths in 1990.[33-36] In the Netherlands in 2001, patients receiving life-ending drugs without their explicit request were in 54% older than 80 years, 44% had cancer, and 47% died in a hospital. Opioids were mostly used to hasten death, with an estimated life-shortening effect of less than one week in 80%. Characteristics of this practice in 1995 were comparable, except for use of neuromuscular relaxants in 1995 (19% vs. 1%). Cases of life ending without an explicit request of the patient corresponded more closely with cases of alleviation of symptoms with possible life-shortening effect than with euthanasia. Physicians indicated that half of the patients were to some extent involved in the decision-making, either through an implicit request, or because the patient had expressed a wish upon the hastening of death earlier in the course of the disease. In Belgium, Denmark and Switzerland, characteristics of the practice of life ending without an explicit request of the patient were also rather comparable to the Netherlands.

Chapter 2 shows that in two-third of the terminal sedation cases, there was no request of the patient for deep sedation. In about 40% of all cases, the physician had not discussed the sedation with the patient.

For terminal sedation as well as for life ending without an explicit request of the patient, physicians said that patients were not involved in the decision-making predominantly because they were considered to be incompetent. When patients were not able to participate in the decision-making, physicians almost always involved the patient's family.

Apparently, the necessity to alleviate symptoms of severely suffering patients sometimes leads to far-reaching interventions that cannot always be discussed with the patient involved. These findings may also suggest that anticipation of the dying phase is sometimes difficult. This can on the one hand be a reflection of difficulties with acknowledging and accepting that a patient is dying. These are feelings that have been reported by physicians as well as by patients.[37, 38] On the other hand, it is sometimes difficult to predict when a patient is actually going to die.[39] It has been suggested that promoting the use of advance directives can

prevent situations in which physicians are unaware of the patients' wishes.[40] However, it can be questioned whether this is true. Several studies have shown that advance care planning is mostly ineffective since advance directives are often vague and the factual situations are often different from the hypothetical situations described.[41-43] In addition to this, most advance directives do not specifically address terminal sedation.

In conclusion, incorporating patients' wishes into end-of-life decision-making is not always possible because many patients in the dying phase are incompetent of decision-making.[44, 45] Probably, this can sometimes be prevented through discussions with the patient earlier in the course of the disease. When this is not possible, physician and the patients' representatives have the responsibility to decide about the most appropriate end-of-life care in accordance with the patients' wishes.

9.4 Attitudes towards end-of-life decision-making

In the past decade, several developments may have shaped peoples' attitudes towards end-of-life decision-making: the debate on and the actual enactment of the Dutch Euthanasia Law, an increase in research and media attention for end-of-life decision-making, and increasing possibilities to alleviate suffering and prolong the life of the terminally ill. This thesis addresses the viewpoints towards end-of-life decision-making of two important groups involved in this debate: the general public and physicians.

Public and professionals: different perspectives

In Chapter 6, it was shown that physicians and the public differ in their appreciation of end-of-life decisions. Acceptance of active ending of life was considerably higher among the general public than among physicians for different types of patients: adults, children, incompetent patients, patients with dementia, and patients without a serious disease. The public and physicians did not differ in their appreciation of terminal sedation or the use of high dosages of morphine with possible life-shortening effect. These differences in attitudes clearly point out the liberal stance of the Dutch public, which can be interpreted in different ways.

Firstly, it can be questioned whether the public has sufficient knowledge about medical end-of-life practices to express well-informed and well-considered

attitudes.[46] Limited knowledge about the effectiveness of end-of-life care in alleviating suffering may result in acceptance of practices that address suffering rather rigorously, such as euthanasia. In addition to this, for healthy subjects who have often little experience with serious illness, it is difficult to imagine how they would feel when they would become terminally ill. People probably expect a worse quality of life than they would actually experience when they would become seriously ill.[47] Secondly, these differences may partly be explained by a difference in responsibility between both groups. It is important to realize that physicians and the public have different roles and responsibilities in end-of-life decision-making. Physicians' willingness to perform active ending of life will be mostly inspired by a conviction that the patient suffers unbearably and hopelessly or by the belief that the patient's autonomous decision should be followed. Other aspects may also play a crucial role in their decision-making process, such as complying with legal rules.[48] The latter may be less important to the general public.

The fact that physicians and the general public have different attitudes towards active ending of life may have some complications for clinical practice. Situations may arise in which physicians are reluctant to grant requests of patients or their representatives for the end of life to be hastened.[49] This is especially true when requests for euthanasia originate from reasons that physicians do not consider to be within their medical domain, such as mental suffering due to depression or being tired of life at high age. This makes careful communication between physicians and patients about patients' reasons to ask for active ending of life and the possibilities of end-of-life care of utmost importance.

Perspectives of the public on a good death

In addition to attitudes towards specific medical end-of-life decisions, we also studied the public's perspectives on medical end-of-life care and on what constitutes a good death. Chapter 7 describes the aspects that the general public considers important for a good death. Although biomedical aspects of end-of-life care are crucial, psychosocial factors are considered to be important as well, which was also found in other studies.[50-57] Dying a pain free and dignified death, having the possibility to say goodbye to loved ones, and being able to decide about end-of-life treatments were almost unanimously considered to be important. The latter is further investigated in Chapter 8. The wish to be able to decide about end-of-life treatments includes for about one third of the public

preferring life-prolonging treatments at the expense of quality of life; another third was inclined to refrain from life-prolonging interventions because quality of life is considered most important. The remaining third did not express a clear attitude towards quality or length of life. Respondents had more disparate opinions about other characteristics important for a good death. Approximately two of every three respondents considered dying at home, staying mentally alert until death, and not burdening loved ones with terminal care important. Deciding about the moment of death and being able to have solved existential issues were considered important by less than half of the respondents.

Apparently, there is no such thing as a 'single formula for a good death", and it may be true that "people die in character".[58] Nevertheless, several preferences were found to be more prevalent among certain groups of respondents. Two findings were striking: age and religious beliefs rather substantially influenced respondents' perspectives on a good death. Older age was found to be related to an inclination to strive for quality of life instead of length of life (Chapter 8). The finding that older age was also related to acceptance of terminal sedation and using high dosages of morphine with possible life-shortening effect is in line with this: elderly people value quality of life more than prolonged survival, and therefore accept practices that might ease their last phase of life (Chapter 6). Older age was also related to having concerns about becoming dependent on others and being a burden to others (Chapter 7). These findings suggest that with increasing age, people attach different meanings to illness and death. According to Callahan, the natural life span of the elderly logically implies a focus on quality of life rather than life-prolongation because the end of life is something 'natural' rather than a failure of medicine.[59]

Religious respondents less often than respondents without religious beliefs accepted practices that might hasten death (such as euthanasia, using high dosages of morphine with possible life-shortening effect and forgoing life-prolonging treatments) and less often supported the idea that being able to decide about the moment of death is important for a good death. Such a stance has in other studies sometimes been explained as adhering to the 'sanctity of life'.[11] Religious respondents also often consider it important to have solved existential issues before they die, and to be prepared for their death.

9.5 Implications for policy and practice and suggestions for further research

Policy and practice implications

A requisite for careful discussions about end-of-life decision-making is that people agree about the definitions that are used. This is especially relevant for terminal sedation, for which there is no common definition yet. Preferably, definitions should be clear and simple. They should enable a description of actual practices on the one hand and identification of the characteristics of prudent practices on the other hand. Chabot et al argue that the best definition of terminal sedation is a rather simple description of the act: bringing a patient continuously in deep sedation until death.[60] They suggest that inclusion of quality aspects of terminal sedation, such as the type of drugs used, the possible life-shortening effect, physicians' intentions, whether the patients' symptoms were refractory, and whether the patients were involved in the decision-making, precludes evaluation of the full range of the practice of terminal sedation. In our interview study, we included the forgoing of artificial nutrition or hydration in our definition of terminal sedation. We did so because we particularly aimed at studying cases of terminal sedation in which it was possible that life had been shortened. However, when discussing terminal sedation in a broader context, it is not necessary to include forgoing of artificial nutrition or hydration in the definition.

It has been suggested that the practice of terminal sedation should be legally reviewed, similar to the practice of euthanasia.[28] Our data suggest that the large majority of cases of terminal sedation could be considered as accepted medical practice. Reviewing these cases would not only be unfeasible due to the large scale at which terminal sedation is practiced, it would also signify interference with physicians' responsibilities and competency. Nevertheless, our findings also indicate that there is a small overlap between terminal sedation and intentionally ending of life. It is important that medical professionals together with legal and moral experts discuss which of these cases should be legally evaluated. In our opinion, when terminal sedation is used at the request of the patient with the explicit intention to shorten life and when it has a life-shortening effect, its legal status is similar to euthanasia, and such cases should be reviewed. It is possible that physicians are not always aware of this overlap between terminal sedation and intentionally ending of life. Therefore, efforts should be undertaken to increase physicians' knowledge about the definitions of terminal sedation,

euthanasia and the overlap between both practices. Further development of guidelines for the use of terminal sedation to optimize the quality of end-of-life care and ensure uniformity of practice seems useful too.
Medical end-of-life decision-making is complicated and often involves complex situations with many different nuances. Medical, legal, ethical, policy and personal perspectives often emphasize different elements, and those perspectives will never be perfectly integrated. Further debate on the role of physicians in achieving the aim of providing patients with a good quality of dying is needed. Policymakers and legal regulations should allow physicians sufficient freedom of movement to make their own medical-professional decisions. On the other hand, physicians should realize that they sometimes intervene at the border of their professional domain, which necessitates transparency to maintain confidence of policymakers, other caregivers, patients and their relatives, and the general public.

Suggestions for further research

The findings reported in this thesis have evoked several new research questions. First of all, the continuing debate about the acceptability and borders of end-of-life decision-making necessitates careful monitoring of end-of-life decision-making practices over time. This is also relevant for the practice of terminal sedation, especially because there are indications that its frequency is increasing rapidly.[17, 19] Furthermore, although the studies described in this thesis provide a global overview of end-of-life practices, more detailed insight is needed in patients' symptoms, level of suffering, and treatment possibilities for terminally ill patients. Thirdly, different professions have been shown to use different concepts and definitions when discussing end-of-life decision-making. Future research should therefore also investigate how physicians, nurses, lawyers, ethicists, policy makers, lay persons and members of the notification committees interpret and deal with the different concepts of end-of-life decisions. Lastly, to get a complete picture of the characteristics of and motivations for end-of-life decision-making, it is important to study the perspectives of patients, relatives, and nurses in further research. More insight is e.g. needed in costs and benefits of terminal sedation for patients and relatives in terms of quality of the dying process.

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Summary

In this thesis, two main subjects are addressed: physicians' practices concerning medical decision-making at the end of life (part 1 of the thesis) and attitudes of the Dutch general public and physicians toward such practices (part 2 of the thesis). The first part includes studies of the practice of terminal sedation as well as active ending of life without an explicit patient request, in the Netherlands and other European countries. The second part explores attitudes of the Dutch public and physicians towards medical end-of-life decision-making, and includes newly discussed issues such as active ending of life in minors, patients with dementia, and patients without a serious disease. This part also addresses opinions of the general public on what constitutes a good death. The thesis starts with a short introduction and an overview of the research questions studied and the methods used (**Chapter 1**). In total, the following research questions were investigated:

1. What is the frequency and what are the characteristics of the practice of terminal sedation in the Netherlands and in other European countries?
2. What are the differences and similarities between the practice of terminal sedation and euthanasia?
3. What are the characteristics of the practice of active ending of life without an explicit patient request?
4. What are the attitudes of the Dutch general public towards different types of end-of-life decisions in various situations, and in what aspects do they differ from attitudes of physicians?
5. What factors are important for a good death according to the Dutch general public, and how are these factors related to preferences for end-of-life decision-making?
6. What are the attitudes of the Dutch general public towards the use of life-prolonging treatments that might seriously impair their quality of life?

Three different types of studies were used to study these research questions: interviews with physicians, a death certificate study among physicians, and a survey among the Dutch general public. These studies were conducted nationwide and include data that are considered to be representative for all Dutch physicians and the Dutch population.

Physicians' end-of-life practices

Chapter 2 reports on the frequency and characteristics of the practice of terminal sedation in the Netherlands. Terminal sedation was defined as the administration of drugs to keep the patient in deep sedation or coma until death, without giving artificial nutrition or hydration. It was estimated that terminal sedation preceded 10% of all deaths in 2001, and that 52% of all Dutch physicians had ever applied terminal sedation. Terminal sedation was mostly applied to alleviate severe pain, agitation, and dyspnea. Physicians reported to have discussed the decision to apply deep sedation in about 60% of all terminal sedation cases with the patient and in more than 90% with the patients' relatives. The physicians had discussed the sedation with other caregivers in 79% of cases. Specialists in palliative care from other institutions or pain management teams were rarely consulted. It was found that terminal sedation was in about one third of the cases performed with benzodiazepines and with morphine most of the remaining cases. This chapter also describes that physicians in 17% of the terminal sedation cases had an explicit intention of hastening death whereas hastening death was partly the intention in an additional 47%. This explicit intention involved in the majority of cases the forgoing of artificial nutrition or hydration. When asked to estimate the life-shortening effect of the use of terminal sedation, physicians estimated that the patient's life had been shortened by 24 hours or less in 40% of the cases whereas in 27%, life was estimated to have been shortened by more than 1 week. Euthanasia was discussed in the course of the decision-making process regarding terminal sedation in about 40% of the cases. The main reasons for choosing terminal sedation rather than euthanasia were the patient's preference for terminal sedation to euthanasia and the patient's belief that terminal sedation was less intrusive than euthanasia on the natural dying process. In some cases, the physicians reported that euthanasia could not be performed because the patient did not fulfill the requirements of prudent practice for euthanasia.

Chapter 3 shows that deep sedation until death without the use of artificial nutrition and hydration is also used in other European countries. International death certificate studies showed that it preceded 3.2% of all deaths in Belgium, 1.6% in Denmark, 3.0% of all deaths in Italy, 3.7% in the Netherlands, 1.8% in Sweden, and 2.9% in Switzerland. Patients who received deep sedation until death were more often male, younger than 80 years old, more likely to have had cancer, and died more often in a hospital compared to non-sudden deaths

without the use of deep sedation until death. This study also showed that deep sedation until death including the administration of artificial nutrition and hydration was used in an additional 1%-2% of all deaths in the Netherlands, Denmark, Sweden and Switzerland. In Italy and Belgium, higher percentages were reported for this practice (5%-6% of all deaths).

In **Chapter 4**, the differences and similarities between the Dutch practice of terminal sedation and euthanasia are studied. Euthanasia was defined as the administration of drugs with the explicit intention of ending the patient's life at his or her explicit request. By definition, patients receiving euthanasia were actively involved in the decision-making process. This applied to only slightly more than half of the patients receiving terminal sedation, although relatives were almost always involved. Compared to the patients receiving euthanasia, patients who were terminally sedated were on average older, less often suffered from cancer and more often from cardiovascular disease, and less often died at home. Terminal sedation was more often used in patients with unclear consciousness, anxiety and confusion, in the absence of other treatment options. Further, patient requests for terminal sedation were more often based on pain than requests for euthanasia, which were more often based on a sense of suffering without chance of improving and on a perceived loss of dignity and independency. The intent of the physician in case of terminal sedation less often was to shorten life, and the shortening of life due to terminal sedation was more limited. It was concluded that terminal sedation and euthanasia are both applied to address severe suffering in terminally ill patients. However, terminal sedation is typically used to address severe physical and psychological symptoms in dying patients to avoid further suffering, while the patient or the patient's representatives may accept loss of control of the dying process. For patients requesting euthanasia, perceived loss of dignity during the last phase of life is a major problem. In these cases, patients may consider control of the dying process of utmost importance.

Chapter 5 reports that 0.7% of all deaths in the Netherlands in 2001 were found to be preceded by the use of lethal drugs without an explicit request of the patient. This practice includes cancer patients as well as patients suffering from other diseases, in various age groups, and patients dying inside and outside the hospital. In half of the cases, the physician had some information about the patient's wish. In the remaining cases, the patient was considered to be fully incompetent to make decisions and the decision was discussed with the patient's relatives. The practice of life ending without an explicit request of the

patient showed more similarities with characteristics of alleviation of symptoms with possible life-shortening effect than with characteristics of euthanasia in terms of drugs used (mostly opioids) and its estimated life-shortening effect (mostly a few hours to a few days). Characteristics of this practice in 1995 were comparable to 2001, except for a more frequent use of neuromuscular relaxants in 1995. Characteristics of this practice in Belgium, Denmark, and Switzerland were rather comparable to the Dutch practice. These findings suggest that life ending without an explicit request of the patient seems to be a part of medical end-of-life practices in the Netherlands as well as other countries. Its existence might on the one hand be a reflection of sometimes ineffective and tardily communication between patients and physicians about the dying process. On the other hand, it demonstrates that suffering at the end of life apparently sometimes leads to far-reaching interventions that cannot always be discussed with the patient involved.

Attitudes of the Dutch general public and physicians

In **Chapter 6, 7, and 8**, attitudes of the Dutch general public and physicians towards end-of-life decision-making are central.

Chapter 6 compares attitudes of the public towards several end-of-life decisions with attitudes of physicians. Acceptance of intentionally ending of life was considerably higher among the general public than among physicians for different types of patients: adults, children, incompetent patients, patients with dementia, and patients without a serious disease. The public and physicians did not differ in their appreciation of terminal sedation or the use of high dosages of morphine with possible life-shortening effect.

Chapter 7 focuses on the factors that the general public considers important for a good death. Besides saying farewell and dying pain free and with dignity, many members of the Dutch public consider values of control and maintenance of independency as important for a good death. Least important for achieving a good death were having the possibility to decide about the moment of death and solving existential issues. Acceptance of euthanasia, terminal sedation and the use of high dosages of morphine was related to the wish to have a dignified death and with being concerned about burdening relatives with terminal care.

Acceptance of euthanasia was also associated with the wish to be able to decide about medical end-of-life treatments and about the moment of death.
In **Chapter 8**, attitudes of the Dutch general public towards the use of life-prolonging treatments with possible impairments of their quality of life were examined, as well as the extent to which these attitudes associate with respondent's engagement in advance care planning. One-third of the respondents preferred quality of life at the expense of survival, another third preferred length of life regardless of impaired quality of life, and the remaining third did not express a clear attitude towards either quality or length of life. People who were younger, male, had children, had religious beliefs, and without a history of serious illness were more likely to strive for length, whereas the reverse associations were found for striving for quality. Striving for quality of life was associated with undertaking initiatives to engage in advance care planning.

Discussion

This thesis is concluded with a general discussion on the findings of the presented studies (**Chapter 9**).
The finding that terminal sedation embraces a large variation in clinical practices may be an indication that it is sometimes practiced sub-optimally. When undertaking efforts to optimize the practice of terminal sedation, two findings deserve further attention: the fact that opioids are rather often used for sedation in stead of benzodiazepines and the fact that the application of terminal sedation is not always discussed with experts or other physicians.
Further, the fact that terminal sedation sometimes approximates the practice of intentionally ending of life was discussed. From a legal point of view, cases in which physicians have the explicit intention to hasten death and in which the act of terminal sedation has a life-shortening effect should be viewed as intentionally ending of life. In our study, this is true for approximately 10% of all cases of terminal sedation. From a moral point of view, it can be argued that terminal sedation is acceptable when it can be considered to reflect proportional medical care. This includes that the patient suffers from severe symptoms that are refractory to other treatment and that no other reasonable treatment options are be available. In our study, it is difficult to evaluate which cases of terminal sedation fulfill the criteria of proportionality. Nevertheless, there are some

indications that terminal sedation is sometimes used in cases in which it seems no appropriate proportional response to the medical situation.

Chapter 9 also addresses implications for policy and practice. Firstly, it is recommended to use a common definition for terminal sedation to enhance the debate about this practice. It is argued that the best definition of terminal sedation is a rather simple description of the act: bringing a patient continuously in deep sedation until death. Exclusion of quality aspects in the definition of terminal sedation enables evaluation of the full range of the practice of terminal sedation. Secondly, our findings indicate that there is a small overlap between terminal sedation and intentionally ending of life. It is important that medical professionals together with legal and moral experts discuss which of these cases should be legally evaluated. In our opinion, when terminal sedation is used at the request of the patient with the explicit intention to shorten life and when it has a life-shortening effect, its legal status is similar to euthanasia, and such cases should be reviewed. Nevertheless, reviewing all cases of terminal sedation would be unfeasible and would also interfere with physicians' responsibilities and competency. Thirdly, further development of guidelines for the use of terminal sedation to optimize the quality of end-of-life care and ensure uniformity of practice seems useful too.

Lastly, **Chapter 9** offers suggestions for further research. It is recommended that further research should continue with carefully monitoring end-of-life decision-making practices over time. In addition to this, more detailed insight is needed in patients' symptoms, level of suffering, and treatment possibilities for terminally ill patients. Another suggestion for future research addresses the different concepts and definitions that professions use when discussing end-of-life decision-making. Future research should therefore also investigate how physicians, nurses, lawyers, ethicists, policy makers, lay persons and members of the notification committees interpret and deal with the different concepts of end-of-life decisions. Lastly, to get a complete picture of the characteristics of and motivations for end-of-life decision-making, it is stressed that further research should also address perspectives of patients, relatives, and nurses.

Samenvatting

In dit proefschrift worden twee onderwerpen behandeld: ervaringen van artsen met medische besluitvorming in de laatste levensfase (eerste gedeelte van dit proefschrift) en opvattingen van het Nederlandse publiek en artsen over medische besluitvorming in de laatste levensfase (tweede gedeelte van dit proefschrift). Het eerste gedeelte beschrijft de praktijk van terminale sedatie en levensbeëindiging zonder uitdrukkelijk verzoek van de patiënt in Nederland en in andere Europese landen. Het tweede gedeelte beschrijft de opvattingen van het Nederlandse publiek en artsen ten aanzien van medische besluitvorming in de laatste levensfase en betrekt daarbij ook nieuwe thema's zoals terminale sedatie, en actieve levensbeëindiging bij kinderen, patiënten met dementie, en patiënten zonder ernstige ziekte. Dit gedeelte beschrijft ook de opvattingen van het Nederlandse publiek over 'een goede dood'. Het proefschrift begint met een korte inleiding en een overzicht van de onderzoeksvragen en de gebruikte onderzoeksmethoden (**Hoofdstuk 1**). De volgende onderzoeksvragen werden onderzocht:

1. Wat is de omvang en wat zijn de kenmerken van de praktijk van terminale sedatie in Nederland en in andere Europese landen?
2. Wat zijn de verschillen en overeenkomsten tussen de praktijk van terminale sedatie en euthanasie?
3. Wat zijn de kenmerken van de praktijk van actieve levensbeëindiging zonder uitdrukkelijk verzoek van de patiënt?
4. Wat zijn de opvattingen van het Nederlandse publiek over medische beslissingen rond het levenseinde, en in welk opzicht verschillen deze van opvattingen van artsen?
5. Welke factoren vindt het Nederlandse publiek belangrijk voor een goede dood, en hoe zijn deze factoren gerelateerd aan opvattingen over medische beslissingen in de laatste levensfase?
6. Wat zijn de opvattingen van het Nederlandse publiek over het gebruik van levensverlengende behandelingen die de kwaliteit van leven ernstig kunnen beperken?

Drie verschillende onderzoeksmethoden werden gebruikt om deze vragen te beantwoorden: interviews met artsen, een schriftelijk onderzoek naar medische besluitvorming bij sterfgevallen, en een schriftelijke vragenlijst onder het Nederlandse publiek. Het waren allemaal landelijke studies waardoor de

gegevens representatief zijn voor alle Nederlandse artsen en de Nederlandse bevolking.

Ervaringen van artsen met medische beslissingen in de laatste levensfase

Hoofdstuk 2 beschrijft de omvang en de kenmerken van de praktijk van terminale sedatie in Nederland. Terminale sedatie wordt daarbij gedefinieerd als de toediening van middelen om een patiënt in diepe sedatie of coma te brengen, waarbij wordt afgezien van de kunstmatige toediening van voeding of vocht. Geschat wordt dat terminale sedatie werd uitgevoerd in 10% van alle sterfgevallen in Nederland in 2001, en dat 52% van alle Nederlandse artsen wel eens terminale sedatie had toegepast. De meest genoemde redenen om patiënten diep te sederen waren het verlichten van pijn, onrust, en benauwdheid. In ongeveer 60% van alle gevallen van terminale sedatie had de arts het voornemen tot diepe sedatie overlegd met de patiënt, en in meer dan 90% van de gevallen met de familie van de patiënt. De toepassing van diepe sedatie was in 79% van de gevallen met andere zorgverleners overlegd. Specialisten in palliatieve zorg of pijnbehandelteams werden zelden geconsulteerd. In ongeveer tweederde van de gevallen van terminale sedatie werden benzodiazepinen gebruikt om de patiënt te sederen. In de meeste andere gevallen werd alleen morfine gebruikt. Terminale sedatie werd in 17% van de gevallen toegepast met het uitdrukkelijke doel het levenseinde te bespoedigen en in 47% was bespoediging van het levenseinde mede een doel naast het verlichten van pijn of andere symptomen. Artsen schatten in 40% van alle gevallen dat door de toepassing van terminale sedatie het levenseinde van de patiënt met maximaal 24 uur was bekort, en in 27% van de gevallen werd de levensbekorting geschat op meer dan een week.
Tijdens de besluitvorming over terminale sedatie kwam euthanasie in 40% van de gevallen ter sprake. De meest genoemde redenen waarom uiteindelijk niet voor euthanasie werd gekozen waren dat de patiënt zelf terminale sedatie verkoos, en de opvatting dat terminale sedatie meer dan euthanasie past bij een natuurlijk stervensproces. In sommige andere gevallen gaven artsen aan dat euthanasie niet mogelijk was omdat de patiënt niet voldeed aan de zorgvuldigheidseisen die gelden voor euthanasie.

Hoofdstuk 3 laat zien dat diepe sedatie voorafgaand aan het overlijden zonder de kunstmatige toediening van voeding en vocht ook wordt toegepast in andere landen. Een internationaal vergelijkend onderzoek laat zien dat in 2001 3.2% van alle sterfgevallen in Belgie vooraf werd gegaan door diepe sedatie zonder de kunstmatige toediening van voeding en vocht; dit percentage was 1.6% in Denemarken, 3.0% in Italie, 3.7% in Nederland, 1.8% in Zweden, en 2.9% in Zwitserland. Patiënten die diep gesedeerd werden voorafgaand aan hun overlijden waren vaker man, jonger dan 80 jaar, hadden vaker kanker, en overleden vaker in het ziekenhuis dan overleden patiënten bij wie geen diepe sedatie werd toegepast. Deze studie toonde tevens aan dat diepe sedatie voorafgaand aan het overlijden werd gecombineerd met de kunstmatige toediening van voeding en vocht bij nog eens 1%-2% van alle sterfgevallen in Nederland, Denemarken, Zweden en Zwitserland. In Italie en Belgie kwam dit vaker voor (5%-6% van alle sterfgevallen).

Hoofdstuk 4 bestudeert de verschillen tussen de Nederlandse praktijk van terminale sedatie en euthanasie. Euthanasie wordt daarbij gedefinieerd als het toedienen van middelen met het uitdrukkelijke doel het levenseinde van de patiënt te bespoedigen op diens uitdrukkelijke verzoek. Patiënten bij wie euthanasie werd uitgevoerd waren per definitie altijd actief betrokken in het besluitvormingsproces. Dit was slechts voor iets minder dan de helft van de patiënten bij wie terminale sedatie werd uitgevoerd het geval. De familie van de patiënt was wel bijna altijd betrokken in het besluitvormingsproces. Patiënten bij wie terminale sedatie werd uitgevoerd waren gemiddeld ouder, hadden minder vaak kanker en vaker hart- en vaatziekten, en stierven minder vaak thuis dan patiënten bij wie euthanasie werd toegepast. Terminale sedatie werd ook vaker dan euthanasie uitgevoerd bij patiënten met een verminderd bewustzijn, bij patiënten die angstig of verward waren, en bij patiënten voor wie er geen andere behandelmogelijkheden meer waren. Verder waren verzoeken van patiënten om terminale sedatie vaker dan verzoeken om euthanasie gebaseerd op pijn, terwijl verzoeken om euthanasie vaker werden gedaan vanwege het vooruitzicht van lijden zonder uitzicht op verbetering en vanwege verlies van waardigheid en onafhankelijkheid. De intentie van de arts bij het toepassen van terminale sedatie was minder vaak om het levenseinde te bespoedigen, en de mate van levensbekorting was beperkter dan bij euthanasie. Kenmerkend voor terminale sedatie is dus dat het meestal gebruikt wordt om ernstige lichamelijke en psychische symptomen te bestrijden om verder lijden te voorkomen, terwijl de

patiënt of diens vertegenwoordigers een zeker verlies van controle van het stervensproces accepteren. Voor patiënten die een verzoek om euthanasie doen is juist verlies van waardigheid in de laatste levensfase een belangrijk probleem, en deze patiënten behouden graag de controle over hun stervensproces.

Hoofdstuk 5 rapporteert dat in 0.7% van alle sterfgevallen in Nederland in 2001 dodelijke medicatie werd toegediend zonder dat de patiënt daartoe een uitdrukkelijk verzoek had gedaan. Deze praktijk betreft zowel kankerpatiënten als patiënten met andere aandoeningen, patiënten in verschillende leeftijdsklassen, en patiënten die in of buiten het ziekenhuis overleden. In ongeveer de helft van de gevallen was de arts wel op de hoogte van de wensen van de patiënt. In de overige gevallen gaven artsen aan dat de patiënt volledig wilsonbekwaam was maar dat de beslissing wel besproken was met de familie van de patiënt. De praktijk van levensbeëindiging zonder uitdrukkelijk verzoek van de patiënt bleek sterker overeen te komen met intensivering van pijn- of symptoombestrijding met een mogelijk levensbekortend effect dan met euthanasie, wat betreft de gebruikte medicatie (meestal opioiden) en de geschatte mate van levensbekorting (meestal beperkt tot een paar uur of een paar dagen). De kenmerken van deze praktijk in 1995 waren vergelijkbaar met 2001, behalve dat in 1995 wat vaker spierverslappers werden gebruikt. Deze praktijk werd ook aangetroffen in Belgie, Denemarken en Zwitserland en was daar behoorlijk vergelijkbaar met de Nederlandse praktijk. De bevinding dat levensbeëindiging zonder uitdrukkelijk verzoek van de patiënt deel uitmaakt van de medische besluitvorming in de laatste levensfase in Nederland zowel als in andere landen zou enerzijds een reflectie kunnen zijn van het feit dat de communicatie over het stervensproces tussen artsen en patiënten soms onduidelijk is en laat in gang wordt gezet. Anderzijds kan ernstig lijden in de laatste levensfase blijkbaar soms leiden tot vergaande interventies die niet altijd meer met de patiënt overlegd kunnen worden.

Opvattingen van het Nederlandse publiek en artsen

In **Hoofdstuk 6, 7 en 8** wordt aandacht besteed aan de opvattingen van het Nederlandse publiek en artsen over medische beslissingen in de laatste levensfase.

In **Hoofdstuk 6** worden opvattingen van het Nederlandse publiek vergeleken met opvattingen van artsen. Het aantal respondenten dat actieve levensbeëindiging aanvaardbaar vond was groter onder het publiek dan onder artsen voor verschillende groepen patiënten: volwassenen, kinderen, wilsonbekwame patiënten, patiënten met dementie, en patiënten zonder een ernstige aandoening. Het percentage respondenten dat terminale sedatie en het ophogen van morfine aanvaardbaar vond was nagenoeg gelijk in beide groepen.
In **Hoofdstuk 7** is onderzocht welke factoren het Nederlandse publiek belangrijk vindt voor 'een goede dood'. Naast afscheid nemen van dierbaren, waardig sterven, en geen pijn hebben, vinden veel mensen uit het Nederlandse publiek het ook belangrijk om een gevoel van controle over het sterfproces te hebben en niet afhankelijk van anderen te zijn. De mogelijkheid om zelf het moment van overlijden te bepalen en het oplossen van levensvraagstukken werden minder belangrijk geacht. Aanvaarding van euthanasie, terminale sedatie en het ophogen van de dosering morfine met een mogelijk levensbekortend effect bleek samen te gaan met het hechten van belang aan sterven met waardigheid en met bezorgdheid om naasten niet teveel te belasten met zorg in de stervensfase. Aanvaarding van euthanasie was ook geassocieerd met de wens om zelf te kunnen beslissen over de behandelingen die men wel of niet zou willen ontvangen aan het einde van het leven en met de wens om zelf het moment van overlijden te kunnen bepalen.
In **Hoofdstuk 8** worden de opvattingen van het Nederlandse publiek onderzocht over het gebruik van levensverlengende behandelingen die de kwaliteit van leven ernstig kunnen beperken. Ook werd gekeken of deze opvattingen geassocieerd zijn met de mate waarin respondenten zich bezig houden met hun eigen levenseinde door bijvoorbeeld het opstellen van wilsverklaringen. Een derde van de respondenten had een voorkeur voor interventies die gericht zijn op kwaliteit van leven, zelfs wanneer dit ten koste zou gaan van de resterende levensduur. Daarnaast had een derde van de respondenten een voorkeur voor interventies gericht op levensverlenging, ook al zou dit de kwaliteit van leven beperken. De overige respondenten hadden geen duidelijke voorkeur voor kwaliteit van leven of levensverlenging. Jonge mensen, mannen, mensen met kinderen, religieuze opvattingen, en mensen die zelf nooit een ernstige ziekte hadden gehad hadden vaker een voorkeur voor levensverlenging, terwijl omgekeerde associaties werden gevonden voor een voorkeur voor kwaliteit van leven. Mensen met een voorkeur

voor kwaliteit van leven bleken zich vaker dan anderen bezig te houden met hun eigen levenseinde door bijvoorbeeld het opstellen van een wilsverklaring.

Discussie

Dit proefschrift wordt besloten met een algemene discussie van de belangrijkste bevindingen van dit proefschrift (**Hoofdstuk 9**).
De bevinding dat terminale sedatie een brede variatie van klinische praktijken omvat zou kunnen betekenen dat terminale sedatie soms sub-optimaal wordt uitgevoerd. Bij het bevorderen van de zorgvuldigheid van de praktijk van terminale sedatie verdienen twee bevindingen in het bijzonder de aandacht: het feit dat relatief vaak opioiden gebruikt worden voor sedatie in plaats van benzodiazepinen, en het feit dat de toepassing van terminale sedate niet altijd wordt overlegd met andere artsen of deskundigen.
Tevens wordt besproken dat de praktijk van terminale sedatie in een aantal gevallen beschouwd kan worden als actieve levensbëindiging. Juridisch gezien zouden gevallen waarin terminale sedatie wordt uitgevoerd met het uitdrukkelijke doel het levenseinde van de patiënt te bespoedigen en waarbij de toepassing van terminale sedatie tevens een levensbekortend effect heeft gehad beschouwd moeten worden als actieve levensbeëindiging. In onze studie geldt dit voor ongeveer 10% van de gevallen van terminale sedatie. Moreel gezien kan beargumenteerd worden dat terminale sedatie acceptabel is wanneer het beschouwd kan worden als proportioneel medisch handelen. Dit betekent dat de patient ernstige, refractaire, symptomen heeft waarvoor redelijkerwijs geen andere behandelmogelijkheden meer zijn. Het is moeilijk te bepalen welke gevallen van terminale sedatie in onze studie voldoen aan de criteria voor proportioneel handelen. Er zijn echter wel aanwijzingen dat in sommige gevallen terminale sedatie geen proportioneel antwoord was op de medische situatie.
Hoofdstuk 9 bespreekt ook implicaties voor beleid en praktijk. Ten eerste wordt aanbevolen om een gemeenschappelijke definitie voor terminale sedatie te gebruiken ten behoeve van de kwaliteit van het debat over deze praktijk. De voorkeur wordt gegeven aan een eenvoudige beschrijving van de handelwijze: het continu in diepe sedatie brengen van een patiënt voorafgaand aan het overlijden. Het weglaten van kwaliteitsapecten in de definitie van terminale sedatie maakt evaluatie van de brede variatie van de praktijk van terminale

sedatie mogelijk. Ten tweede laten onze bevindingen zien dat er een smalle overlap tussen terminale sedatie en actieve levensbeëindiging bestaat. Het is belangrijk dat de medische beroepsgroep samen met deskundigen op het gebied van recht en ethiek bespreekt welke van deze gevallen juridisch getoetst zouden moeten worden. Naar ons idee is de legale status van terminale sedatie gelijk aan die van euthanasie in gevallen waarin het overlijden van een patiënt het gevolg was van terminale sedatie die werd toegepast met het uitdrukkelijke doel het overlijden te bespoedigen nadat de patiënt daar uitdrukkelijk om had verzocht en waarbij de toepassing van terminale sedatie tevens een levensbekortend effect heeft gehad. Het toetsen van alle gevallen van terminale sedatie is praktisch onhaalbaar, en dit zou tevens interfereren met de verantwoordelijkheden en professionaliteitvan artsen. Ten derde lijkt het raadzaam om richtlijnen voor het toepassen van terminale sedatie verder te ontwikkelen om op die wijze de kwaliteit en de uniformiteit van medische zorg in de laatste levensfase verder te optimaliseren.

Tot slot worden in **Hoofdstuk 9** aanbevelingen voor toekomstig onderzoek gedaan. Het blijvend monitoren van medische besluitvorming in de laatste levensfase is gewenst. Tevens is er beter inzicht nodig in de symptomen, de mate van lijden, en de behandelmogelijkheden van terminaal zieke patiënten. Meer uniformiteit in de verschillende concepten en definities die gebruikt worden door de verschillende beroepsgroepen bij het discussieren over medische besluitvorming in de laatste levensfase is gewenst. Toekomstig onderzoek zou daarom ook moeten nagaan hoe artsen, verpleegkundigen, rechters, ethici, beleidsmakers, leken, en leden van de toetsingscommissies omgaan met verschillende concepten van medische besluitvorming in de laatste levensfase. Tot slot wordt in dit hoofdstuk benadrukt dat het inzicht in de kenmerken van en motivaties voor medische beslissingen in de laatste levensfase niet compleet is zonder gegevens over het perspectief van patiënten, familieleden en verpleegkundigen.

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Curriculum Vitae

Judith Rietjens werd op 21 juni 1978 geboren te Roermond. Nadat ze in 1996 haar gymnasiumdiploma behaalde aan het Bisschoppelijk College Broekhin te Roermond, startte ze haar studie Gezondheidswetenschappen in Maastricht en specialiseerde zich in Geestelijke Gezondheidkunde. In het kader van deze studie volbracht zij een praktijkstage aan de afdeling neuropsychologie van het psychomedisch streekcentrum Vijverdal te Maastricht. Tevens deed ze onderszoek naar het neuropsychologisch functioneren van volwassenen met ADHD (Attention Deficit Hyperactivity Disorder) bij GGZ Delfland in Delft. In 2001 behaalde zij haar doctoraal examen. Aansluitend bleef ze nog enkele maanden werken als onderzoeksassistent bij GGZ Delfland. In september 2001 werd ze aangesteld als junior onderzoeker bij het Instituut Maatschappelijke Gezondheid van het Erasmus Medisch Centrum Rotterdam. Hier verrichtte zij het onderzoek beschreven in dit proefschrift. In de periode augustus tot en met november 2005 was ze werkzaam aan de Northwestern University in Chicago, USA. Hier deed zij een onderzoek naar de praktijk van palliatieve sedatie. Voor dit onderzoek ontving zij een Fulbright Scholarship en subsidie van NWO. Momenteel participeert zij als postdoc onderzoeker in de de evaluatie van de Wet Toetsing Levensbeeindiging op Verzoek en Hulp bij Zelfdoding aan Instituut Maatschappelijke Gezondheidszorg.

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