Chapter 1

General introduction

Introduction

This thesis focuses on policies and guidelines for medical end-of-life decisions in health care institutions in the Netherlands. Before describing the results of the study, this chapter introduces medical end-of-life decisions and policies and guidelines in general. This is followed by a summary of the results of previous research on euthanasia and physician-assisted suicide (EAS) policy statements and practice guidelines for medical end-of-life decisions. Some developments in the field of medical end-of-life decisions in the Netherlands also will be described. Finally, the aims, objectives, and the methods of the study described in this thesis will be addressed.

Background

Medical end-of-life decisions

Medical end-of-life decisions are decisions that take into account the possibility that they might have a life-shortening effect. Although they have the potential hastening of death in common, not all medical end-of-life decisions should be grouped into one category. In general, the following end-of-life decisions are distinguished:

- withholding or withdrawing potentially life-prolonging treatment (e.g. mechanical ventilation, tube-feeding, and dialysis)
- intensified alleviation of pain or other symptoms with, for example, opioids, benzodiazepines, or barbiturates in doses large enough have the possible side effect of hastening death
- euthanasia: the administration of drugs with the explicit intention of ending the patient's life at the patient's explicit request
- physician-assisted suicide: the prescription or supply of drugs with the explicit intention of enabling a patient to end his or her life
- ending of life, by the administration of drugs- without an explicit request from the patient.[1]

In the past decade increasingly more attention has been paid to palliative sedation. Although it is primarily a last resort for the relief of refractory symptoms (by inducing deep sedation until death) that should not hasten death, it is sometimes seen as an end-of-life decision. In European countries, between 23% (Italy) and 51% (Switzerland) of all deaths are preceded by an end-of-life decision.[2] In a nationwide study in 2005, it was found that this was the case for 43% of all deaths in the Netherlands. With regard to the different end-of-life decisions, euthanasia was performed in 1.7% of all deaths and physician assisted suicide in 0.1%. The frequency of ending of life without an explicit request from the patient was 0.4%. The percentages of intensified alleviation of symptoms and withholding or withdrawing potentially life-prolonging treatment were 24.7% and 15.6% respectively in 2005.[3] These figures show that medical end-of-life decisions are frequently made in the Netherlands. However, this does not mean that individual physicians frequently make end-of-life decisions. It is known that 69% of physicians in the Netherlands care for between 1 and 10 terminal patients per year, and the number of terminal patients they care for differs between specialties. Pulmonologists for instance, were found to care for a median of 20 terminal patients per year, nursing home physicians for 15, specialist in internal medicine for 10, neurologists for 5, and gynaecologists for 1 per year.[4] Approximately 1 out of 10 deceased patients in the Netherlands had requested euthanasia prior to their death.[5] Other studies have reported that explicit and persistent requests for physician-assisted suicide are also not uncommon in Dutch psychiatric practice.[6]

As end-of-life decision-making is complex, and it is important that it is based on prudent practice, physicians need to have sufficient knowledge (e.g. about regulations, the effects of drugs, and alternative treatment options) and skills (e.g. how to discuss the issue with patient and family) in order to make appropriate decisions. Especially in view of the fact that many physicians do not have regular experience with end-of-life decision-making, both education on end-of-life care in the medical curriculum, and practice guidelines for medical end-of-life decisions could be valuable in supporting physicians in this complex decision-making process.

Guidelines

The Institute of Medicine in the United States defines practice guidelines as "systematically developed statements to assist practitioner and patients decisions about appropriate health care for specific clinical circumstances".[7] In general, the principal benefit of guidelines is to improve the quality of the care that is received by patients.[8,9] Guidelines can improve the consistency of the care, provide healthcare professionals with explicit recommendations on how to proceed, and also include authoritative recommendations that support them in the appropriateness of their treatment policies.[9] These aspects are also relevant for practice guidelines concerning medical end-of-life decisions, which are difficult decisions due to the ethical and legal aspects. Moreover, multiple health care providers (physicians, nurses) are involved in these decisions.

Shekelle et al.[10] described the following steps that are involved in developing evidence-based guidelines: identifying and refining the subject area of the guideline, running guideline development groups, identifying and assessing the evidence by systematic review, translating evidence into a clinical practice guideline, and reviewing and updating the guidelines.[10] However, practice guidelines on medical end-of-life decisions are usually not based on scientific evidence (evidence-based), but more on consensus among professionals. In the Netherlands, professional organisations such as the Royal Dutch Medical Association[11-13] and the Dutch Association of Nursing Home Physicians[14] have been active in the development of practice guidelines for medical end-of-life decisions. These guidelines can be supportive for physicians and nurses in the medical end-of-life decision-making process.

However, the actual presence of practice guidelines does not guarantee that they are applied in medical practice, or that they contribute to the quality of care that is provided for patients. Physicians must also be aware of the existence of the guidelines and actually use them. Research has demonstrated that involving physicians in the development of guidelines is important, because the best used guidelines are developed by those who are going to use them.[8] Other studies have reported that potential barriers and facilitators to integrating guidelines into practice can act at different levels: the guideline itself (e.g. feasibility), the characteristics of the professionals (e.g. knowledge, skills), and the characteristics of the patient (e.g.

knowledge, compliance) combined with the social (e.g. colleagues), organizational (e.g. available resources), economic, and political context (e.g. regulation, policies).[15,16]

Institutional policies and practice guidelines for medical end-of-life decisions

In this thesis an EAS policy statement is defined as the position taken by the management of a health care institution with regard to whether or not EAS is allowed in the institution (i.e. is it not allowed, is it allowed under certain conditions, or is it left to the judgement of the attending physician). Practice guidelines are defined as a written protocol to guide caregivers in their approach to a problem that includes a decision-making process and/or a phased care plan.

Several national practice guidelines for medical end-of-life decisions have been developed in the Netherlands, such as guidelines for palliative sedation (PS)[11,12], guidelines for do-not resuscitate (DNR) decisions[14] and euthanasia and physician assisted suicide (EAS) guidelines.[17] These are not mandatory guidelines, but they can provide a basis upon which health care institutions can formulate their own policy statements and develop practice guidelines for medical end-of-life decisions at institutional level.

Several studies have been carried out in the Netherlands and in Belgium to investigate the existence, dissemination and content of policies and practice guidelines for medical end-of-life decisions at institutional level.[18-27]

In 1994, the existence of institutional policy statements and practice guidelines was investigated in hospitals, nursing homes, psychiatric hospitals, and institutions for the mentally disabled in the Netherlands. This study showed that 69% of the hospitals, 74% of the nursing homes, 13% of the psychiatric hospitals and, 16% of the institutions for the mentally disabled had issued/formulated an EAS policy statement. In most hospitals and nursing homes where EAS was allowed to take place, there were also practice guidelines for EAS. Moreover, 60% of the hospitals, 35% of the nursing homes, and 17% of the institutions for the mentally disabled had practice guidelines for one or more other medical end-of-life decisions.[18]

Research in Belgium showed that 79% of Catholic hospitals and 30% of Catholic nursing homes had a written ethics policy statement on euthanasia in 2002.[19] In 2005 the prevalence of euthanasia policies was studied in all hospitals and nursing

homes in Flanders. Two thirds (63%) of the hospitals and 15% of the nursing homes had a written ethics policy on euthanasia.[20,21] In 2007 written policies for most types of end-of-life decisions were widespread in Flemish hospitals (euthanasia 97%, DNR decisions 98%, palliative sedation 79%).[22] It is remarkable that the existence of palliative sedation policies in Flanders increased from 27% in 2005[20] to 79% in 2007.[22]
The dissemination of written EAS policy statements was also studied at institutional level in Dutch and Flemish Catholic hospitals and nursing homes in 1994 and 2004, respectively.[18,23] The results of these studies showed that the majority (between 67% and 94%) of Dutch and Flemish Catholic hospitals and nursing homes systematically disseminated their written EAS policy statements to physicians and nurses. However, in both countries it appeared that the patients were much less frequently informed than the physicians and the nurses, especially in hospitals; only 4% of the Dutch hospitals and 3% of the Flemish Catholic hospitals systematically disseminated their written EAS policy statement to their patients. In 2007 Flemish hospitals systematically disseminated their written euthanasia policies to 76% of the physicians, 82% of the nurses, and 17% of the patients and/or family. Systematic dissemination of other medical end-of-life policies to health care providers varied between 71% and 91%, but to patients and/or their relatives this percentage was much lower (between 29% and 50%).[22]
The content of EAS and DNR practice guidelines was studied in Dutch nursing homes and Dutch hospitals, respectively in 1994.[24,25] These studies showed that only 65% of the EAS guidelines in Dutch nursing homes described all the official due care requirements. An analysis of the content of euthanasia policy documents has also been carried out in Flemish hospitals and nursing homes.[26,27] Most of the hospital policies contained procedures based on the euthanasia law and focused on the role of the physicians and nurses. However, little attention was paid to the hospital's stance in incompetent terminally ill patients, or to the role of patients and relatives and the aftercare provided for relatives and caregivers. The guidelines in both institutions also paid little attention to providing psychological and spiritual support for caregivers during the entire process. A study on the impact and meaning of euthanasia guidelines in clinical practice showed that physicians and nurses felt positively supported by the euthanasia policy in the euthanasia care process on practical and professional level.[28]

Developments in the field of medical end-of-life decisions in the Netherlands

There have been various developments in the field of medical end-of-life decisions in the Netherlands since 1994, when the first Dutch study of policy and guidelines for medical end-of-life decisions was carried out. In 1994, the first notification procedure of the practice of EAS started in the Netherlands. A change in the procedure in 1998 led to the enactment of the Dutch euthanasia law in 2002. This development was accompanied by a public and professional debate on EAS. Together with professional developments such as the SCEN-project, in which the professional consultation is provided for euthanasia requests, and other several court cases that resulted in case law, there was increasing clarity concerning what was considered to be prudent practice in EAS.[29] The enactment of the Dutch euthanasia law was followed by a modest decrease in the rates of EAS, and an increase in the rate of continuous deep sedation near the end-of-life.[3] The increase in the attention paid to continuous deep sedation in the past decade has resulted in a national guideline on palliative sedation[11,12], among others things because there were indications that physicians had misconceptions about palliative sedation and how it was related to euthanasia.[30]

Research aims

Institutional practice guidelines could be very valuable in the field of medical end-of-life decisions. In the past decade there have been several developments in this field as described above, so the major aims of this thesis were to obtain insight into the impact of these developments on:

- the existence and dissemination of institutional EAS policy statements and practice guidelines for medical end-of-life decisions
- the awareness of physicians and their use of institutional practice guidelines for medical end-of-life decisions
- the content of institutional EAS and DNR practice guidelines
- the opinions and knowledge of Dutch medical students with regard to education on end-of-life care.

Objectives

The objective of this study were subdivided over 2 levels:

I. Institutions

a) Description of the existence of EAS policy statements and practice guidelines for all medical end-of-life decisions in Dutch health care institutions.
b) Description of the development and dissemination of institutional practice guidelines for medical end-of-life decisions and EAS policy statements to relevant parties in Dutch health care institutions.
c) Description of the content of institutional EAS guidelines in hospitals and nursing homes, and description of the content of hospital guidelines for DNR decisions.
d) Comparison of the existence, development, dissemination and content of EAS policies and practice guidelines on medical end-of-life decisions in 2005 and in 1994.

II. Physicians and medical students

a) Description of the awareness and use of institutional EAS, DNR and PS practice guidelines by physicians in Dutch hospitals.
b) Description of the opinions and knowledge of medical students with regard to education on end-of-life care in the medical curriculum.

Methods

This section presents a short overview of the research methods applied in this study. These are described in more detail in the separate chapters of this thesis.

a. Questionnaire survey institutions (objective I a,b,d)

In the Dutch health care institutions study a questionnaire was sent to the management of all Dutch hospitals, nursing homes, general psychiatric hospitals, institutions for the mentally disabled, and hospices (n=306, response 68%). The questionnaire contained questions about the background characteristics of the institution (e.g. type, size, religious affiliation), the existence of a written EAS policy

statement and the content of this policy statement, and the existence of practice guidelines for all medical end-of-life decisions, including the date on which these were formulated or revised.

b. Content analysis of EAS and DNR practice guidelines (objective I c)

In the survey of the institutions, the management of Dutch hospitals and nursing homes were asked to provide a copy of their guidelines. Of the 281 nursing homes and hospitals which responded (68%), 154 institutions indicated that they had EAS guidelines, and 150 of these institutions provided a copy of the guidelines. Of the 150 guidelines, 99 were included in the analysis, because they met our definition of EAS guidelines i.e. a written protocol to guide caregivers in their approach to a problem that includes a decision-making process and/or a phased care plan, and at least a description of the due care criteria to some extent.

A total of 56 hospitals indicated that they had guidelines for DNR decisions, and provided a copy of their guidelines. In total, 41 hospital guidelines were analyzed. The other 15 guidelines were excluded because they were very brief, or provided no practical guidance for caregivers on how to react in case of a cardiac arrest, and therefore were not considered to meet the definition of guidelines in our study.

The guidelines were analyzed with a checklist. The checklist for EAS guidelines included the following main topics: a) general characteristics of the practice guidelines: format of the document, formulation, and whether the guidelines categorically ruled out the possibility of granting a request from some patients groups (dementia patients, coma patients, incompetent patients) which is categorically stricter than the law; b) request: involved parties and their roles, conscientious objections and advance euthanasia directives; c) decision-making: due care criteria, involved parties and their roles, refusal of euthanasia requests; d) performance: involved parties and their roles, reporting, and aftercare. The checklist for guidelines for the use of DNR decisions included a) general characteristics of the practice guidelines: definition of DNR and default position, b) decision-making: involved parties and their roles, and c) registration and evaluation of the decision.

c. Questionnaire survey physicians (objective II a)

All physicians in the departments of internal medicine, pulmonology, neurology, cardiology, pediatrics and anesthesiology in 12 hospitals with at least one set of guidelines for euthanasia received a written questionnaire (n=325, response 52%).

The questionnaire consisted of yes/no questions about the physicians awareness, use and perceived supportiveness of the practice guidelines for (1) EAS, (2) DNR decisions, and (3) palliative sedation. They were also asked whether they had been in a situation in which they had to make a decision about these specific end-of life decisions. If they had been in such a situation, they were asked in an open-ended question why the specific guidelines had (not) been supportive for them in daily practice. Their reasons for not reading and not using the practice guidelines were also asked in an open ended question. One part of the questionnaire consisted of general statements about practice guidelines on medical end-of-life decisions.

d.Questionnaire survey medical students (objective II b)

In the 2006/2007 academic year medical students in their final year at the VU University Medical Center in Amsterdam attending a mandatory tutorial in their public health clerkship (n=204, response 68%), received a written questionnaire. In the questionnaire they were asked about their opinion regarding the quantity and content of education on end-of-life care. They were asked to score the quantity and content on a 3-point scale (bad, moderate, good), and their opinion about attention to specific topics in the medical curriculum on a 3-point scale (sufficient, insufficient, too much). Questions concerning their knowledge about the euthanasia act and the euthanasia definition were also included in the questionnaire, together with questions on their opinions about specific statements on a 5-point scale (strongly agree to strongly disagree). Additional questions concerned demographic characteristics such as age, gender and religious affiliation were also asked.

Outline of the thesis

Chapter 2 presents the results concerning the existence of EAS policy statements and practice guidelines for all medical end-of-life decisions in Dutch health care institutions in 2005, and the existence of practice guidelines related to the characteristics of the institutions.
Chapter 3 presents the results of the development and dissemination of practice guidelines for medical end-of-life decisions in Dutch health care institutions.
Chapter 4 focuses on the content of EAS guidelines in hospitals and nursing homes, and Chapter 5 describes the content of DNR guidelines in hospitals.
Chapter 6 presents the results of the awareness and use of practice guidelines for medical end-of-life decisions among physicians in Dutch hospitals.
Chapter 7 presents the opinion and knowledge of students on education on end-of-life care in the medical curriculum.
Finally, in Chapter 8, the results of all the studies described in this thesis are discussed.

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Chapter 2

Policy statements and practice guidelines for medical end-of-life decisions in Dutch health care institutions: developments in the past decade

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Abstract

Objectives: To describe the existence of policy statements on euthanasia and physician-assisted suicide (EAS) and practice guidelines for all medical end-of-life decisions in Dutch health care institutions in 2005, whether the existence of practice guidelines is related to characteristics of institutions, and to compare the existence of policies in 2005 and 1994.

Methods: Questionnaires were sent to 566 institutions (all Dutch hospitals, nursing homes, general psychiatric hospitals, institutions for the mentally disabled, hospices) from October 2005 through March 2006.

Results: Most institutions (70%) had a written policy statement concerning EAS. EAS was usually allowed under specific conditions (75%). Institutions mainly had practice guidelines for EAS and do-not-resuscitate decisions (62% and 63%). A minority had guidelines on palliative sedation (27%), alleviation of symptoms (27%) and withdrawing or withholding treatment (33%). In general, there were more practice guidelines in 2005 than in 1994. Larger institutions and institutions with an ethics committee more often had practice guidelines. Religious affiliation of an institution did not seem to be related to the existence of guidelines.

Conclusions: Since many institutions still do not have practice guidelines for medical end-of- life decisions, they should be stimulated to introduce practice guidelines, being a first step in improving the quality of the care on institutional level.

1. Introduction

In the past decade there has been growing interest in the development of institutional policies and practice guidelines in health care institutions. The principal benefit of guidelines, in general, is to improve the quality of the care that is received by patients.[1] Guidelines can improve the consistency of care, and make it more likely that patients will be cared for in the same manner, regardless of where or by whom the care is provided. Guidelines also have potential benefits for professionals, who are involved in the practice described in the guidelines. They offer them explicit recommendations on how to proceed, and also contain authoritative recommendations that reassure practitioners about the appropriateness of their treatment policies.[2] Guidelines can also be relevant because of the ethical and legal aspects of medical decision-making, and this applies in particular to medical end-of-life decision-making. Most important professionals regarding medical end-of-life decision making in institutions are physicians and nurses[3-6] and practice guidelines therefore should be useful and available for them.

In the Netherlands, several practice guidelines for medical end-of-life decisions have been issued at national level, for instance concerning palliative sedation[7,8], do-not resuscitate orders[9] and euthanasia and physician-assisted suicide (EAS).[10] EAS-decisions differ from other medical end-of-life decisions because of their legal status. Specific requirements for EAS have been formulated on the basis of jurisprudence and debate among medical professionals. The Royal Dutch Medical Association has issued these requirements in a guideline and has renewed this guideline several times, most recently in 2003, after the Dutch Termination of Life on Request and Assisted Suicide Act (the Euthanasia Act) came into effect.[10]

The Dutch State Commission on Euthanasia suggested in 1985 that institutions such as hospitals and nursing homes should clarify their policy statement on EAS.[11] It is important that institutions formulate a written statement describing their stance with regard to EAS, making it clear to professionals and patients alike whether or not EAS is allowed in the institution.

In 1994, the existence of policy statements and practice guidelines on medical end-of-life decisions at institutional level was investigated in Dutch hospitals, nursing homes, psychiatric hospitals and institutions for the mentally disabled. In that study it was found that 69% of the hospitals, 74% of the nursing homes, 13% of the psychiatric hospitals and 16% of the institutions for the mentally disabled described their policy statement with regard to EAS. Most hospitals and nursing homes in which EAS was allowed also had practice guidelines for EAS. Furthermore, 60% of the hospitals, 35% of the nursing homes and 17% of the institutions for the mentally disabled had practice guidelines for one or more other medical end-of-life decisions.[12,13]

Since 1994, there have been several developments in the field of medical end-of-life decisions in the Netherlands, such as the Euthanasia Act which came into effect in 2002[14], and growing attention is being paid to palliative sedation, which resulted in the publication of a practice guideline at national level in 2005[7], and a revision of it in 2009.[8] These developments have probably resulted in an increase in the existence of policies on medical end-of-life decisions at institutional level.

In 2005 we replicated the 1994 study and studied, among other thing, the existence of policies and practice guidelines on medical end-of-life decisions in Dutch health care institutions. The aims of this paper were: (1) to describe the existence of policy statements with regard to EAS, (2) to describe the content of EAS statements, (3) to describe the existence of practice guidelines for EAS and other medical end-of-life decisions, (4) to determine whether the existence of practice guidelines is related to characteristics of the institutions, and (5) to compare the existence of policies and practice guidelines on medical end-of-life decisions in 2005 and in 1994.

2. Methods

2.1. Design

The data used in the present study were collected for the 'Evaluation of the Euthanasia Act'.[15] The study focused on medical practice according to the written policies in health care institutions in 2005, and is a replica of the study carried out by Haverkate and van derWal[12], extented with attention for palliative sedation as current

important medical end-of-life decision and hospices as current important institution for medical end-of-life care. Data were collected from October 2005 through March 2006 by means of a structured written questionnaire.

2.2. Study population

Questionnaires were sent to the following five types of Dutch health care institutions: hospitals, nursing homes, general psychiatric hospitals, institutions for the mentally disabled, and hospices. The study is based on the institution as the unit of measurement. The questionnaire was addressed to the management of each institution, but only those institutions that provided 24-h nursing care, treatment and assistance were included. As an additional criterion, all hospices had to have an autonomous management. Questionnaires were sent to a total of 566 health care institutions. Of these, 113 institutions had to be excluded because they had merged with other institutions in the meantime, or did not meet the criteria for inclusion, for instance only providing day-care. Of the 453 remaining institutions, 306 returned the questionnaire (68%). The response rate differed per type of institution. The highest response came from hospitals and hospices (73% and 76%), followed by nursing homes (66%), general institutions for the mentally disabled (66%) and general psychiatric hospitals (62%). The responding institutions did not differ significantly from the non-responding institutions, except for nursing homes of which the larger institutions responded more often (Table 1). There were fewer institutions in this study than in the 1994 study (480 versus 306), partly because the number of institutions has decreased in the past ten years (from 558 to 453), due to mergers. Furthermore, the response rate was higher in the first study (86%), possibly because the questionnaire was sent by the Health Inspectorate in 1994.

2.3. Definitions

Based on the Dutch Euthanasia Act[14] euthanasia is defined as death resulting from medication that is administered by a physician with the explicit intention of hastening death at the explicit request of the patient. In physician-assisted suicide, the patient self-administers medication that was prescribed by a physician. The four other medical end-of-life decisions in this study were described as: (1) palliative

sedation, (2) alleviation of symptoms with possible life-shortening effect, (3) do-not- resuscitate (DNR) decisions, and (4) withdrawing or withholding treatment on medical grounds, taking into account that this could possibly lead to hastening death. For EAS, we made a distinction between the existence of a written policy statement with regard to EAS and the existence of practice guidelines. We asked the institutions whether EAS was never allowed, allowed under specific circumstances, or the decision to grant or refuse EAS was left entirely to the physicians. Practice guidelines (existence asked for all medical end-of-life decisions) are defined as a written protocol to guide caregivers in approaching a problem that includes a decision-making process and/or a phased care plan.

2.4. Questionnaire

The questionnaire was based on the questionnaire used by Haverkate and van der Wal.[12] Its face validity was assessed by presenting the initial questionnaire to six professionals working in the field of health care (physicians, managers, a lawyer), and on the basis of their comments some changes were made in the wording of the questions.

The questionnaire contained questions about the background characteristics of the institution (e.g. type, size, religious affiliation), the existence of a written EAS policy statement and the content of this policy statement, the existence of practice guidelines for all medical end-of-life decisions, including the date it was formulated or revised.

2.5. Analysis

The data were analysed with descriptive statistics. All data are presented in percentages. Data with $n<40$ are presented in percentages with absolute numbers between brackets. We compared the data of the present study with the data of the 1994 study[12], except for the data on hospices (which were not included in the 1994 study) and palliative sedation (which was not investigated in 1994). Since all health care institutions, and not a sample of them, were approached for the study (both in 1994 and 2005), there was no necessity of testing differences in percentages between the studies and subgroups within the studies.

Table 1a: Characteristics of institutions in 2005 and 1994[a]

	Hospitals						Psychiatric hospitals					
	1994 N=117		2005 n=73		2005 (non r.) n=27		1994 n=38		2005 n=26		2005 (non r.) n=16	
	%	CI	%	CI	% (n)	CI	% (n)	CI	% (n)	CI	% (n)	CI
Size of hospitals[b]												
≤500 beds	67	(59-76)	58	(45-69)	60 (15)	(39-79)	54 (20)	(37-71)	54 (14)	(33-73)	50 (6)	(21-78)
501-750 beds	22	(15-30)	23	(14-35)	12 (3)	(3-31)	30 (11)	(16-47)	19 (5)	(7-39)	17 (2)	(2-48)
>750 beds	10	(5-16)	19	(11-30)	28 (7)	(12-49)	16 (6)	(6-32)	27 (7)	(12-48)	33 (4)	(10-65)
Region												
North-East	10	(5-16)	15	(8-25)	16 (4)	(4-35)	16 (6)	(6-32)	12 (3)	(25-30)	8 (1)	(1-36)
Middle	28	(20-36)	22	(13-33)	27 (7)	(12-48)	35 (13)	(20-53)	23 (6)	(9-44)	38 (5)	(14-68)
West	37	(29-46)	43	(31-55)	39 (10)	(20-59)	30 (11)	(16-47)	31(8)	(14-54)	38 (5)	(14-68)
South	24	(17-32)	21	(12-32)	19 (5)	(7-39)	19 (7)	(8-35)	35 (9)	(17-56)	15 (2)	(2-46)
Religious affiliation												
Yes	48		44				38 (14)		4 (1)			
Ethics committee												
Yes	[c]		89				[c]		35 (9)			

[a] Rounded percentages. For n<40 absolute numbers in parenthesis, missing observations: between 0 and 4

[b] Classification used by Haverkate and Van der Wal[12]

[c] No data available for 1994

Table 1b: Characteristics of the institutions in 2005 and 1994[a]

	Nursing homes						Institutions for the mentally disabled						Hospices[2]	
	1994 n=270		2005 n=119		2005 (non r.) n=62		1994 n=93		2005 n=72		2005 (non r.) n=37		2005 n=16	2005 (non r.) n=5
	%	CI	%	CI	%	CI	%	CI	%	CI	% (n)	CI	% (n)	
Size of institution[b]														
<100 beds	12	(8-16)	10	(5-16)	11	(4-22)	17	(10-27)	19	(10-30)	8 (2)	(1-19)	100 (16)	100 (4)
100-200 beds	56	(50-62)	26	(18-34)	68	(55-80)	24	(16-34)	14	(7-25)	12 (3)	(2-23)	0	0
>200 beds	32	(27-38)	64	(55-73)	21	(11-34)	58	(48-69)	67	(55-78)	81 (21)	(41-75)	0	0
Region														
North-East	13	(9-17)	8	(4-15)	12	(5-23)	7	(2-14)	11	(5-21)	6 (2)	(1-19)	0	0
Middle	27	(22-32)	29	(21-37)	33	(21-46)	33	(24-44)	39	(28-51)	34 (12)	(19-52)	25 (4)	60 (3)
West	39	(33-44)	36	(28-45)	28	(17-41)	27	(18-37)	28	(18-40)	17 (6)	(7-34)	50 (8)	20 (1)
South	22	(17-27)	27	(19-35)	28	(17-41)	33	(24-44)	22	(13-34)	43 (15)	(26-61)	25 (4)	20 (1)
Religious affiliation														
Yes	57		48				70		50				50 (8)	
Ethics committee														
Yes	[c]		46				[c]		40				-	

[a] Rounded percentages. For n<40 absolute numbers in parenthesis, missing observations: between 0 and 15 (for nursing homes 1994) and 16 for hospices concerning ethics committee

[b] Classification used by Haverkate and Van der Wal[12]

[c] No data available for 1994

3. Results

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3.1. Characteristics of the institutions

In general, there were fewer, but larger institutions in 2005, compared to 1994 (Table 1). This applied especially to the nursing homes: 119 versus 270 nursing homes in the present study and in 1994, respectively, and 64% versus 32% had more than 200 beds. The hospices were very small: they had 5–10 beds. Approximately half of all institutions had a religious affiliation, except for the psychiatric hospitals, almost all of which had no religious affiliation.

The majority of the hospitals had an ethics committee (89%), compared with less than half of the other types of institutions, except for hospices. None of the hospices had answered this question.

3.2. Existence and content of written EAS policy statements

Table 2 shows that most institutions (70%) had a written policy statement concerning EAS, especially hospitals (80%), nursing homes (90%) and hospices (88%). If there was no written policy statement, we asked if there were any verbal agreements about EAS. In total, 15% of the institutions only had verbal agreements. Almost a quarter of the psychiatric hospitals and 42% of the institutions for the mentally disabled had no EAS policy statement at all. Compared to 1994, the percentage of all types of institutions with written policy statements had increased.

Table 2 also shows that if an institution had a written policy statement concerning EAS, it was usually only allowed under specific conditions (75%). This applied to all types of institutions, except to hospices. In 57% of the hospices with a written EAS policy statement, it was never allowed. Most mentioned specific condition under which EAS was allowed, was that the judicial requirements for EAS had to be met, and/or that EAS was performed as described in the institutional guideline.

In half of the institutions in which EAS was 'never allowed', they reported that EAS was not in accordance with the religious affiliation, and in 30% EAS was never allowed because the patients who were treated were incompetent (psychogeriatric or mentally disabled) (not in table).

In nursing homes, psychiatric hospitals, and institutions for the mentally disabled there was a shift from 'never allowed' in 1994 to 'allowed under specific conditions' in 2005. In most hospitals, EAS was already allowed in 1994 (90% in 1994 and 2005). Of the institutions with only a verbal EAS policy statements, in 38% EAS was 'never allowed', in 29% it was 'allowed under specific conditions' and in 33% the decision concerning EAS was left entirely to the physicians (not in table).

3.3. Reasons for not having (written) EAS policy statements

If an institution only had a verbal EAS policy statement, the most frequently mentioned reasons for not having a *written* EAS policy statement were that the decision concerning EAS was left entirely to the physicians (32%), and that everybody was expected to know that EAS was never allowed in that institution (22%). If an institution had no written or verbal EAS policy statement (mainly institutions for the mentally disabled), the most frequently mentioned reasons were: requests for EAS (almost) never occurred in the institution (32%) and a written policy statement was planned for the future (30%) (not in table).

3.4. Existence of practice guidelines on EAS and other medical end-of-life decisions

Table 3 shows that the institutions mainly had practice guidelines for EAS and DNR decisions (62% and 63%),and especially hospitals (89% and 83%) and nursing homes (79% and 78%). A minority of the institutions had practice guidelines on palliative sedation (27%), alleviation of symptoms with possible life shortening effect (27%) and withdrawing or withholding treatment on medical grounds (33%). Withholding or withdrawing food and fluids was described as specific treatment decision in half of the guidelines on withdrawing or withholding treatment on medical grounds, and withholding or withdrawing antibiotics in one third of these guidelines (not in table). In general, the percentage of institutions with practice guidelines had increased in 2005 compared to 1994, especially in the institutions for the mentally disabled. Furthermore, there were relatively more institutions with practice guidelines on DNR decisions in 2005, compared to 1994.

Table 2: Existence and content of EAS policy statements in Dutch health care institutions in 2005 and 1994[a]

	Hospitals		Psychiatric hospitals		Nursing homes		Institutions for the mentally disabled		Hospices[b]	Total
	1994 n=117 %	2005 n=73 %	1994 n=38 % (n)	2005 n=26 % (n)	1994 n=270 %	2005 n=119 %	1994 n=93 %	2005 n=72 %	2005 n=16 % (n)	2005 n=306 %
Existence EAS policy										
Written policy	69	80	13 (5)	50 (13)	74	90	16	33	88 (14)	70
Verbal policy	13	12	45(17)	27 (7)	17	8	42	25	13 (2)	15
No policy	18	8	42(16)	23 (6)	9	3	41	42	0	15
Content written policy	n=81 %	n=58 %	n=5 % (n)	n=13 % (n)	n=193 %	n=107 %	n=15 % (n)	n=24 % (n)	n=14 % (n)	n=216 %
-EAS is never allowed	6	2	40 (2)	15 (2)	32	15	73 (11)	33 (8)	57 (8)	16
-EAS is allowed under specific conditions	90	90	60 (3)	85 (11)	62	75	20 (3)	58 (14)	29 (4)	75
-The EAS decision is left entirely to physicians	4	9	0	0	5	10	7 (1)	8 (2)	14 (2)	9

[a] Rounded percentages. For n<40 absolute numbers in parenthesis

[b] No data available for 1994

3.5. Revisions of practice guidelines

In total, 81% of the hospitals had revised their EAS practice guideline after the Euthanasia Act came into effect (2002). On the other hand, 40% of the nursing homes and hospices, and 50% of the psychiatric hospitals and institutions for the mentally disabled had not revised their EAS practice guideline after the Euthanasia Act. The practice guidelines on palliative sedation had been revised or formulated quite recently: 68% of all the institutions had done this since 2004. Also approximately half of all the institutions had formulated or revised their practice guidelines on the alleviation of symptoms and on DNR decisions quite recently, since 2004, and approximately one third had done so for withdrawing or withholding treatment.

Approximately one quarter of all the institutions had not formulated or revised their practice guidelines on alleviation of symptoms or on withdrawing or withholding treatment since 2000, and 15% had not done this for DNR decisions (data not shown).

3.6. Relationship between existence of practice guidelines and characteristics of the institutions

In institutions with one or two practice guidelines, most often these were practice guidelines on EAS or DNR. Table 4 shows that larger institutions (more than 200 beds) more often had practice guidelines on EAS and DNR, and that they also more often had more than two practice guidelines.

Whether or not an institution had a religious affiliation did not seem to be related to the existence of practice guidelines on EAS or DNR, or the number of practice guidelines. Approximately three quarters of the institutions with (70%) or without (78%) religious affiliation allowed EAS under specific conditions. However, 74% of the institutions in which EAS was never allowed, had a religious affiliation (not in table). Institutions with an ethics committee more often had practice guidelines than institutions with no ethics committee. Three quarters of the institutions with an ethics committee had practice guidelines on EAS and DNR, compared to half of the institutions with no ethics committee. Moreover, institutions with an ethics committee more often had more than two practice guidelines.

Table 3: Existence of practice guidelines for medical end-of-life decisions in Dutch health care institutions in 2005 and 1994[a]

	Hospitals		Psychiatric hospitals[2]	Nursing homes		Institutions for the mentally disabled		Hospices[b]	Total
	1994 n=117 %	2005 n=73 %	2005 n=26 % (n)	1994 n=270 %	2005 n=119 %	1994 n=93 %	2005 n=72 %	2005 n=16 % (n)	2005 n=306 %
EAS:									
Guidelines at management level	91	83	42 (11)	75	78	[b]	18	38 (6)	60
Guidelines at ward level	[b]	6	0	[b]	1	[b]	3	0	2
No guidelines	9	11	58 (15)	25	21	[b]	79	63 (10)	38
Palliative sedation:									
Guidelines at management level	[b]	30	8 (2)	[b]	24	[b]	13	38 (6)	22
Guidelines at ward level	[b]	11	0	[b]	5	[b]	3	0	5
No guidelines	[b]	59	92 (24)	[b]	71	[b]	85	63 (10)	73
Alleviation of symptoms:									
Guidelines at management level	16	29	8 (2)	19	29	8	17	13 (2)	23
Guidelines at ward level	8	10	0	5	3	1	4	0	4
No guidelines	76	61	92 (24)	77	69	91	79	88 (14)	73
Do-not-resuscitate decisions:									
Guidelines at management level	37	77	27 (7)	16	73	3	29	19 (3)	57
Guidelines at ward level	17	6	12 (3)	4	5	4	7	0	6
No guidelines	46	17	62 (16)	80	22	92	64	81 (13)	37
Withdrawing or withholding treatment:									
Guidelines at management level	26	39	12 (3)	16	35	7	22	13 (2)	30
Guidelines at ward level	4	7	0	5	2	2	6	0	4
No guidelines	69	54	89 (23)	79	64	90	72	88 (14)	67

[a] Rounded percentages. For n<40 absolute numbers in parenthesis, missing observations: Hospitals 3, Nursing homes 1
[b] No data available for 1994

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Table 4: Characteristics of the institutions associated with the existence of EAS guideline, DNR guideline, and number of guidelines[a]

	Number of beds		Religious affiliation		Ethics committee	
	<200 n=88	≥ 200 n=218	Yes n=134	No n=172	Yes n=158	No n=107
	%	%	%	%	%	%
EAS guideline						
Yes	48	68	61	62	73	54
No	52	32	39	38	27	46
DNR guideline						
Yes	47	69	64	61	76	51
No	53	32	36	39	24	49
Number of guidelines						
No guidelines	39	22	25	27	15	39
1-2 guidelines	32	32	28	35	34	28
> 2 guidelines	30	47	46	38	51	33

[a] Missing observations: number of beds: 2-6, religious affiliation 0-4, ethics committee 42-45

4. Discussion

Most institutions have a written policy statement concerning EAS, describing that EAS is allowed in the institutions if the judicial requirements are met. Only in more than half of the hospices and one third of the institutions for the mentally disabled, EAS is never allowed.

The existence of practice guidelines on medical end-of life decisions varies between the institutions. Hospitals and nursing homes more often have practice guidelines than psychiatric hospitals, institutions for the mentally disabled and hospices. Also the existence of the different practice guidelines varies. Practice guidelines for EAS and DNR are most often available, and practice guidelines for palliative sedation and alleviation of symptoms only exist in about one in four institutions. Larger institutions (>200 beds) and institutions with an ethics committee more often have practice guidelines on EAS and DNR, and more often have practice guidelines for more than two medical end-of-life decisions. The percentage of institutions with a written policy statement on EAS and institutions with practice guidelines on the different medical end-of-life decisions has increased between 1994 and 2005.

4.1. Methodological considerations

A strength of this study is the broad perspective of existence of EAS policy statements and practice guidelines for all medical end-of-life decisions in the Netherlands, covering all health care institutions and patient groups relevant for medical end-of-life care. Furthermore, this is the first study which shows developments in availability of policy statements and practice guidelines in the past decade. Limitations of this study are that it is based on self report of the management of institutions. Furthermore, the response rate in 2005 (68% total (range 76% and 62% per institution) was lower compared to 1994, probably because the questionnaire in 1994 was sent by the Health Inspectorate. However, we think the response rate is sufficient. Only larger institutions are somewhat underrepresented in the 2005 study, but not significantly, except for nursing homes. The differences in number of institutions between 1994 and 2005, due to mergers, makes it difficult to conclude that the *number* of institutions in which policy statements and practice guidelines are available, is increased. However, we can conclude that the percentages of institutions with policy statements and practice guidelines are increased. Since institutions are larger in 2005, due to the mergers, the number of patients that are treated in an institution with EAS policy statements and practice guidelines for all medical end-of-life decisions has increased.

4.2. Existence and content of EAS policy statements

Compared to 1994, the percentage of institutions with an EAS policy statement has increased, and the percentage of institutions in which EAS is never allowed has decreased (from 27% in 1994 to 16% in 2005). This difference might be the result of the Euthanasia Act, which came into effect in 2002, which allows EAS under specific conditions. A similar trend was found in Belgium. After the enactment of the Belgian Euthanasia Act in 2002, there was an increase in the existence of written ethics policies on euthanasia in Flemish hospitals.[16,17] Institutions seem to follow changes in the legal system, and include it in their policy statement, which is positive.

Most often specific condition that was mentioned by the institutions was that the requirements for due care described in the Act had to be met. In other words, these institutions accept performance of EAS in their institutions, when performed according to formal law. Since another often mentioned condition is that the performance of EAS should be in line with the institutional guideline, it is not clear

whether institutions have determined extra conditions for allowance of EAS in their institution, nor whether the practical procedures described in the guideline provide more detail than procedures required by law, since we have not studied the content of the institutional guidelines.

4.3. Existence of practice guidelines on EAS and other medical end-of-life decisions

Two thirds of all the institutions had practice guidelines for EAS in 2005, with an especially high percentages of hospitals (83%) and nursing homes (78%). Practice guidelines for intensified alleviation of symptoms with possible life-shortening effect and withholding or withdrawing life-prolonging treatments existed in only one quarter to one third of the institutions, although these decisions are made far more often in the Netherlands.[15] A Belgian study also showed that in catholic health care institutions there were more EAS practice guidelines than practice guidelines on other medical end-of-life decisions.[18] It might be easier to make guidelines for EAS, because the requirements for EAS are more clearly defined in the Act. However, practice guidelines for intensified alleviation of symptoms with possible life-shortening effect can be very useful in institutions, since it is a common medical end-of-life decision.[15] In this practice guideline, attention should be paid to the role of nurses, since they are often involved in this medical end-of-life decision, but their role is often unclear.[4,5] Furthermore, it should include information about the life-shortening effects of pain medication, since there is still uncertainty about this among physicians.[19]

The existence of practice guidelines for DNR has increased considerably since 1994. There has also been an increase in the number of DNR decisions and the involvement of competent patients in these decisions since 1994[20], possibly influenced by the increase in the DNR guidelines.

Practice guidelines for palliative sedation had only been formulated in a quarter of all the institutions in 2005, mostly in hospitals (41%) and hospices (38%). This was before the national guideline for palliative sedation was introduced in the Netherlands.[7] Therefore the number of institutions with practice guidelines for palliative sedation might have increased since the availability of the guideline after our research. Also the debate about the proper performance of palliative sedation in The Netherlands (and abroad) might be stimulating for institutions to adopt this

guideline.[21,22] The availability of such a practice guideline for palliative sedation in institutions is important, because a study in 2005 showed that palliative sedation occurs in about 7% of all deaths in the Netherlands[23], and also in other countries palliative sedation often occurs.[24] Above that, it can give physicians clarity about the proper way of performing palliative sedation. In 2008, an evaluation study regarding this national guideline was started and the Royal Dutch Medical Association revised the 2005 national guideline in 2009.[8]

4.4. Practice guidelines for specific patient groups

Most institutions for the mentally disabled did not have practice guidelines on medical end-of-life decisions (between 64% and 85% for the different medical end-of-life decisions). However, a Dutch study showed that medical end-of-life decisions are an important aspect of medical end-of-life care for the mentally disabled people. The proportion of medical end-of-life decisions that had been taken in the deaths of mentally disabled people is almost the same as medical end-of-life decisions overall. Medical end-of-life decision making in this group predominantly involved decisions to forgo potentially life-prolonging treatment, and EAS did not occur.[25] Therefore, the necessity of practice guidelines for EAS might not be obvious in institutions for the mentally disabled, but this does not apply to guidelines for the other end-of-life decisions.

In 2007, the NVAVG (Netherlands' Society of Physicians for People with Intellectual Disabilities) issued a general guideline on medical end-of-life decisions concerning people with mental disabilities.[26] Also national guidelines for DNR decisions concerning mentally disabled people have been published in 2007.[27] Assuming that these documents are developed following sound procedures by national organizations, it would be advisable that institutions adopt or amend these practice guidelines for their own institution. Furthermore, it is recommended that a similar research as for the practice guideline for palliative sedation will start, to see whether and how the national guideline is implemented, evaluated by the professionals and its effects on daily practice.

Despite the fact that the percentage of written policy statements on EAS has increased in psychiatric hospitals, a quarter of them still had no written or verbal

EAS policy statement in 2005. Also more than half of the psychiatric hospitals had no practice guidelines on EAS. This is remarkable, since explicit and persistent requests for physician-assisted suicide are not uncommon in Dutch psychiatric practice.[28] In 1998, practice guidelines were formulated to assist psychiatrists in handling requests for physician-assisted suicide from psychiatric patients.[29] These guidelines assume that a request for physician-assisted suicide has to be interpreted as a request for help.

4.5. Revisions of practice guidelines

There are several situations that may require practice guidelines to be updated (or withdrawn)[30-32], such as available interventions or evidence of the benefits and disadvantages of existing interventions. Shekelle et al.[31,32] used a model to assess the current validity of guidelines, and concluded that half of the guidelines were certainly outdated within 5.8 years. To keep guidelines up-to-date they recommend that as a general rule guidelines should be reviewed no later than three years after formulation. This 3-year limit should be extended or reduced if there is any evidence that focus on a specific guideline is evolving quickly or slowly. The policy at the Dutch Institute for Healthcare Improvement CBO is to reconsider a review after 5 years.[30] Many practice guidelines that were identified in our study had been formulated or revised more than 5 years ago. Although we have no information that these guidelines were indeed outdated, with regard to the study mentioned above, it seems advisable that all practice guidelines are regularly and frequently reviewed.

4.6. Relationship between existence of practice guidelines and characteristics of the institutions

Our study showed that institutions with an ethics committee more often had practice guidelines (on EAS, DNR, or more than two guidelines) than institutions with no ethics committee. This is consistent with the results of other studies in which it was found that nursing homes with an ethics committee more often had written policies on EAS than those with no ethics committee[18], and that nursing homes in which ethics committees had an important role, both in developing and approving institutional ethics policies, more often had written EAS policies.[17] Furthermore,

larger institutions more often had more than two practice guidelines. It is possible that these are merged institutions and that they adopted practice guidelines that were available in one of the institutions.

4.7. Conclusion

Despite the increase in the percentage of institutions with policy statements on EAS and practice guidelines for medical end-of-life decisions in the past decade, it still does not cover all health care institutions in the Netherlands. Winkler[33] argued that having an institutional policy is preferable to individual decision-making, because it is better suited to preserving the autonomy of the parties involved, to treating like cases alike, to allocating resources in an efficient way, and to improving the result through advanced planning and co-ordination of care, thus enabling all parties involved to rely as fully as possible on the predictability of the process and of the outcome. Therefore, institutions should be stimulated to develop or adopt existing practice guidelines in order to improve the quality of the care that is provided. However, this is just a first step in improving the quality of care on institutional level. It is also important that these practice guidelines can be, and are used in medical practice. Therefore, institutions are not only responsible for introducing practice guidelines in their institutions, but also for educating and stimulating their professionals to use these guidelines. It is important that not only physicians, but also nurses are involved in this, since they are often involved in medical end-of-life decisions.[3-6] Finally, practice guidelines are just a helpful tool for quality care. Ultimately, the professional can improve the quality of care by providing individual care based on the professional standard and the patient's needs and wishes.

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Chapter 3

Development and dissemination of institutional practice guidelines on medical end-of-life decisions in Dutch health care institutions

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Abstract

Objectives: To describe how Dutch healthcare institutions develop and disseminate institutional
practice guidelines on medical end-of-life decisions and policy statements on euthanasia and physician-assisted suicide (EAS) to relevant parties, and to describe supportiveness of EAS guidelines experienced by Dutch physicians.

Methods: Questionnaires to all Dutch health care institutions in 2005. Questionnaire to sample of Dutch clinical specialists and nursing home physicians.

Results: In most health care institutions, physicians (79%), ethics committees (79%), board of directors (64%) and nurses (61%) were involved in the development of guidelines. The Euthanasia Act and national guidelines were the most frequently reported sources for the development (73% and 71%, respectively). Not all institutions disseminated their written EAS policy statements and practice guidelines on medical end-of-life decisions to all relevant parties. Dutch physicians who reported the presence of a written guideline for EAS in their institution, felt supported by it in their decision-making after a patient's request for EAS.

Conclusions: It is recommended that more health care institutions pay attention to the dissemination of their policy statements and practice guidelines to relevant parties. This will only lead to improvement in medical practice if this is accompanied by efforts to also stimulate the use of guidelines in practice.

1. Introduction

Medical end-of-life decisions require careful decision-making and physicians do not always have very much experience in this respect. Therefore, practice guidelines on medical end-of-life decisions can help to improve the quality of care for the dying. They can improve the consistency of patient care by making recommendations for the treatment and care that is provided for patients, and can support health care professionals in the decision-making process.[1] It is also desirable that health care institutions in the countries and states in which euthanasia and assisted suicide (EAS) is allowed formulate a written statement, providing clarity to professionals and patients as to whether or not EAS is allowed in the specific institution.

In 2005, 85% of all Dutch health care institutions had a policy statement regarding EAS (of which 70% in writing and 15% verbal), and two thirds of all Dutch health care institutions had EAS practice guidelines, especially hospitals (83%) and nursing homes (78%). One quarter to one-third of the institutions had practice guidelines for intensified alleviation of symptoms and withholding/ withdrawing life-prolonging treatments. In general, the number of institutions with practice guidelines for medical end-of-life decisions had increased in 2005 compared to 1994.[2,3] Also in Belgium, in 2004, the majority of Flemish Catholic hospitals (79%) had a written ethics policy on EAS, but only 30% of the Flemish Catholic nursing homes had such a policy.[4] Taking all (Catholic and other) Flemish nursing homes into account, the percentage of nursing homes with a written ethics policy on EAS was only 15% in 2006.[5]

To encourage the use of practice guidelines, physicians and nurses must be aware of both the existence and the content of the guidelines. Research showed that the most effective guidelines are developed by those who are going to use them.[6,7] Therefore, one way to improve knowledge about and acceptance of institutional guidelines might be involving physicians and other relevant persons in the development of these guidelines. Besides that, other strategies for dissemination are important too. The dissemination of written EAS policy statements was investigated at institutional level in Dutch and Catholic Flemish hospitals and nursing homes in 1994 and 2004, respectively.[3,4] The results of these studies showed that the majority of Dutch and Catholic Flemish hospitals and nursing homes systematically disseminated their

written EAS policy statements to physicians and nurses (between 67% and 94%). These studies also looked at dissemination of EAS policies to patients, and it appeared that patients in both countries were much fewer informed than physicians and nurses, especially in hospitals; 4% of Dutch hospitals and 3% of Flemish Catholic hospitals systematically disseminated their written EAS policy statement to patients, and 31% of Dutch nursing homes and 57% of Flemish Catholic nursing homes systematically informed patients about these policies.[3,4]

No recent information is available about the development and dissemination of written EAS policy statements and institutional practice guidelines on medical end-of-life decisions in Dutch health care institutions, even though there have been many changes in the field of medical end-of- life decisions in the Netherlands. In 2002 the Euthanasia Act came into effect[8] and the increased attention being paid to palliative sedation, which resulted in a national guideline on palliative sedation.[9,10]

Therefore the major aims of this study were to describe (1) the professionals and sources involved in the development and revision of institutional guidelines on medical end-of-life decisions in Dutch health care institutions and (2) the dissemination of written EAS policy statements to all relevant parties and the dissemination of institutional practice guidelines on medical end-of-life decisions to physicians and nurses. The following institutional practice guidelines on medical end-of-life decisions were considered: euthanasia and physician-assisted suicide (EAS), palliative sedation, alleviation of symptoms with a possible life-shortening effect, do-not-resuscitate (DNR) decisions, and withdrawing or withholding treatment on medical grounds, taking into account that this could possibly lead to hastening death. Finally, the supportiveness of EAS guidelines experienced by Dutch physicians in decision-making when there is a request for EAS was investigated, to get information about the importance of developing and disseminating these guidelines to physicians.

2. Methods

2.1. Design

The data used in the present study were collected from two studies, which were both part of the Evaluation study of the Euthanasia Act.[11] The first study (study A) investigated the presence of institutional practice guidelines among Dutch health care institutions, the management of which received a written questionnaire. This study was carried out from October 2005 to March 2006. The second (study B) was a questionnaire survey concerning end-of-life care among a representative sample of Dutch physicians, in which questions were also asked about the use of institutional practice guidelines on EAS. This study was carried out from February 2006 to November 2006.

2.2. Study population

In study A, questionnaires were sent to Dutch hospitals, nursing homes, general psychiatric hospitals, institutions for the mentally disabled, and hospices. The study was based on the institution as the unit of measurement, and the questionnaire was sent to the management of each institution. The inclusion criteria were the provision of 7×24-h in-patient nursing care, treatment and assistance. As an additional criterion for hospices, all hospices had to have an autonomous management. The questionnaires were sent to a total of 566 health care institutions, of which 113 had to be excluded because they did not meet the inclusion criteria, or they had merged with another institution. Of the 453 remaining institutions, 306 returned the questionnaire (68%). The response rate differed per type of institution: the highest response came from hospitals and hospices (73% and 76%), followed by nursing homes (66%), general institutions for the mentally disabled (66%) and general psychiatric hospitals (62%).

In study B, questionnaires were sent to a total of 2100 Dutch physicians: 1300 clinical specialists, 500 general practitioners and 300 nursing home physicians. Respondents were selected according to the following criteria: (1) they were clinically active at the time they completed the questionnaire, (2) they had actively practiced medicine within the registered speciality for at least 1 year, and (3) they had to be living in

the Netherlands. For this paper we made a selection of physicians who worked in an institution, thus excluding general practitioners, since this paper describes institutional policies. A total number of 527 clinical specialists (46%) and 212 (75%) nursing home physicians responded.

2.3. Definitions

In the Dutch Euthanasia Act[8] euthanasia is defined as death resulting from medication that is administered by a physician with the explicit intention of hastening death, at the explicit request of the patient. In assisted suicide, the patient self-administers medication that was prescribed by a physician.

An EAS policy statement is defined as the position by the management of a health care institution with regard to whether or not EAS is allowed in the institution (i.e. is it not allowed, it is allowed under certain conditions, or is it left to the judgement of the attending physician). Practice guidelines are defined as a written protocol to guide caregivers in approaching a problem that includes a decision-making process and/or a phased care plan.

2.4. Questionnaires

In study A the questionnaire was based on the questionnaire used by Haverkate and van der Wal in 1994.[3] Its face validity was assessed by presenting the initial questionnaire to six professionals working in the field of health care (i.e. physician, manager, lawyer), and on the basis of their comments some changes were made in the wording of the questions.

The questionnaire contained questions about the background characteristics of the institution (i.e. type, size, religious affiliation), the dissemination of a written EAS policy statement to physicians, nurses, the patients council, patients or relatives, and general practitioners working in the community where the institution is situated (for whom it can be relevant to know the institution's EAS policy), the dissemination of practice guidelines on medical end-of-life decisions to physicians and nurses (the professionals who have to work with the guidelines), and which professionals and sources had been involved in the development and/or revision of practice guidelines on medical end-of-life decisions. With regard to the dissemination of a written

EAS policy statement and practice guidelines on EAS and other medical end-of-life decisions, we asked about the method of dissemination (systematically, on request). The questionnaire used for the national survey (study B) among Dutch physicians specifically focused on experiences with and attitudes towards the Dutch law on euthanasia. The questionnaire was pre-tested in a pilot study among 16 respondents who had little or no problems with regard to the interpretation of the questions. Physicians were asked whether they had ever performed EAS since the enforcement of the Euthanasia Act and whether they had reported these cases. The questionnaire included items related to physicians' attitudes and experiences towards EAS and end-of-life issues in general. Demographic characteristics like specialty, sex and age were also collected. The questionnaire also included a question about the presence of a practice guideline for EAS in their institution followed by a question about the supportiveness of this guideline. Physicians who filled in that guidelines for EAS present in their institutions, were asked about the supportiveness of this guideline when they receive a request for EAS. Physicians who filled in that such a guideline was not present in their institution were asked if they felt a need for such a guideline. These last questions were used for this paper.

2.5. Analysis

The data were analysed with descriptive statistics. Although data of all types of institutions are shown in Table 4, we only discussed the dissemination of practice guidelines on medical end-of-life decisions for hospitals and nursing homes. The reason for this is that only 1–10 psychiatric hospitals, institutions for the mentally disabled and hospices had such guidelines. The data of study B were weighted for different sampling fractions and response rates, in order to make the results representative for all physicians in the relevant disciplines. Logistic regression was used to determine whether religious affiliation and size of the health care institution were associated with the dissemination of institutional practice guidelines.

3. Results

3.1. Characteristics of the institutions and physicians

Approximately half of all institutions had a religious affiliation, except for the psychiatric hospitals, almost all of which had no religious affiliation. The majority of the hospitals had an ethics committee (89%), compared with less than half of the other types of institutions, except for hospices. None of the hospices had answered this question (Table 1).

Two thirds of the nursing home physicians and one in five clinical specialists were women. Most nursing home physicians (41%) were between 40 and 50 years old, and most clinical specialists (42%) were between 50 and 60 years old (not in table).

3.2. Development and revision of institutional practice guidelines on medical end-of-life decisions

Table 2 shows that in most health care institutions the physicians (79%), the ethics committee (79%) (if present), the board of directors (64%) and the nurses (61%) were involved in developing/revising the institutional practice guidelines. If selected for the presence of an ethics committee, the ethics committee was more often involved in hospitals (86%) than in institutions for the mentally disabled (79%), nursing homes (71%) and psychiatric hospitals (67%). Frequently mentioned 'others' involved in the development of institutional practice guidelines were client councils and judicial partners.

In most institutions the Euthanasia Act and the national guidelines (73% and 71%, respectively) were the most frequently reported source for the development of institutional guidelines on medical end-of-life decisions (Table 2).

Table 1: Characteristics of the institutions in 2005 [a]

	Hospitals n=73		Nursing homes n=119		Psychiatric hospitals n=26		Institutions for the mentally disabled n=72		Hospices n=16	
	n	%	n	%	n	%	n	%	n	%
Size of hospitals[b]										
≤500 beds	42	58			14	54				
501-750 beds	17	23			5	19				
>750 beds	14	19			7	27				
Size of other institutions[b]										
<100 beds			12	10			13	18	16	100
100-200 beds			31	26			10	14	0	0
>200 beds			76	64			47	65	0	0
Religious affiliation										
Yes	32	44	57	48	1	4	36	50	8	50
Ethics committee[c]										
Yes	65	89	55	46	9	35	29	40		

[a] Rounded percentages for n=40 and more, absolute numbers for n<40 (with percentages in parenthesis)
[b] Classification used by Haverkate and Van der Wal[3]
[c] Missing observations: Nursing homes 15, Psychiatric hospitals 4, Institutions for the disabled 6, Hospices 16

Table 2: Professionals and sources involved in the development and revision of institutional practice guidelines on medical end-of- life decisions[a]

	Hospitals n=63		Nursing homes n=106		Psychiatric hospitals n=14		Institutions for the mentally disabled n=23		Hospices n=10		Total n=216	
Professionals involved in developing institutional guidelines on end-of-life decisions												
	n	%	n	%	n	%	n	%	n	%	n	%
Physicians	50	79	85	80	10	71	17	74	9	90	171	79
Ethics Committee[b]	50	86	35	71	4	67	11	79	-	-	100	79
Board of directors	44	70	62	58	11	79	16	70	6	60	139	64
Nurses	41	65	61	58	7	50	13	57	9	90	131	61
Spiritual care	37	59	43	41	4	29	10	43	2	20	96	44
External experts	12	19	8	8	3	21	3	13	2	20	28	13
Others	13	21	22	21	3	21	7	30	2	20	47	22
Sources used in developing institutional guidelines on end-of-life decisions												
	n	%	n	%	n	%	n	%	n	%	n	%
Act on Euthanasia	53	84	78	74	7	50	15	65	4	40	157	73
National guidelines	50	79	70	66	14	100	13	57	7	70	154	71
Experiences of physicians	41	65	55	52	8	57	11	48	7	70	122	56
Guidelines from other institutions	42	67	47	44	3	21	11	48	5	50	108	50
Experiences of nurses	37	59	35	33	5	36	10	43	6	60	93	43
Scientific publications	27	43	45	42	8	57	7	30	4	40	91	42
Position papers	26	41	37	35	6	43	7	30	3	30	79	37
Others	3	5	15	14	0	0	3	13	2	20	23	11

[a] Total number of institutions with guidelines on medical end-of-life decisions at institutional level is 216

[b] Total number of institutions having Ethics Committees: Hospitals 58, Nursing homes 49, Psychiatric hospitals 6, Institutions for the disabled 14, Hospices 0

3.3. Dissemination of written EAS policy statement to all relevant parties

Table 3 shows that the majority of all institutions (78%) systematically disseminated their written EAS policy statements to institutional physicians. Also most institutions (73%) systematically disseminated their written EAS policy statements to institutional nurses and nursing staff. Compared to the other institutions, nursing homes least often systematically disseminated their written EAS policy to nurses (66%) but more often only disseminated them on request to them (32%).

Systematic dissemination of the EAS policy statement to patients and/or relatives was less common in institutions. Fifty-five percent of the nursing home systematically disseminated their written policy to patients and/or relatives, whereas 38% of institutions for the mentally disabled and hospices, and only 16% of the hospitals and 1 psychiatric hospital did so. Most institutions only informed patients and/or relatives about the EAS policy statement on request (Table 3).

The most mentioned methods used in institutions to inform physicians and nurses about the EAS policy of the institution were a quality-handbook (34% and 36%, respectively), the intranet-website (33%) and a conservation at the beginning of the employment (32% and 22%, respectively).

Patients/family were informed about the EAS policy of the institution by a folder/ information letter (31%) and information at admission in the institutions (30%) (not in table).

Table 3: Dissemination of written EAS policy statements to involved parties in Dutch health care institutions in 2005 [a]

	Hospitals		Nursing homes		Psychiatric hospitals		Institutions for the mentally disabled		Hospices		Total	
	n=58		n=107		n=13		n=24		n=14		n=216	
	n	%	n	%	n	%	n	%	n	%	n	%
Is policy made known to:												
Institutional physicians												
Systematically	45	80	75	82	8	73	15	71	8	62	151	78
On request	10	18	15	16	3	27	3	14	5	38	36	19
Never	1	2	2	2	0	0	3	14	0	0	6	3
Institutional nurses and nursing staff												
Systematically	45	80	61	66	8	73	17	81	10	77	141	73
On request	10	18	29	32	2	18	3	14	3	23	47	24
Never	1	2	2	2	1	9	1	5	0	0	5	3
Residents'/patients' council												
Systematically	28	50	65	71	5	45	12	57	9	69	119	62
On request	15	27	23	25	5	45	7	33	4	31	54	28
Never	13	23	4	4	1	9	2	10	0	0	20	10
Patients/relatives												
Systematically	9	16	51	55	1	9	8	38	5	38	74	38
On request	36	64	38	41	8	73	12	57	8	62	102	53
Never	11	20	3	3	2	18	1	5	0	0	17	9
General practitioners/ external sources of referral												
Systematically	12	21	20	22	1	9	1	5	3	23	37	19
On request	27	48	50	54	7	64	12	57	7	54	103	53
Never	17	30	22	24	3	27	8	38	3	23	53	28

[a] Rounded percentages/absolute numbers

3.4. Dissemination of institutional practice guidelines on medical end-of-life decisions to physicians and nurses working in hospitals and nursing homes

Table 4 shows that most hospitals and nursing homes systematically disseminated their institutional practice guideline on medical end-of-life decisions to physicians and nurses, most often the institutional practice guideline for palliative sedation (76% and 85%, respectively) and least often the institutional practice guideline for withholding or withdrawing treatment (69% and 62%, respectively). Institutional practice guidelines on medical end-of-life decisions were hardly available in psychiatric hospitals, institutions for the mentally disabled and hospices (Table 4).

Health care institutions with a religious affiliation more often systematically disseminated their institutional practice guidelines on EAS and DNR(OR 2.8 and 3.4, respectively). The size of the institution was not associated with the systematic dissemination of the institutional practice guidelines (not in table).

3.5. Supportiveness of written institutional practice guidelines on EAS by physicians

Table 5 shows that the majority of clinical specialists and nursing home physicians indicated that there was a written practice guideline on EAS in their institution (75% and 78%, respectively). The majority of clinical specialists and nursing home physicians, who indicated that there was a written practice guideline in their institution, felt supported by them in the decision-making process when considering a request for EAS from a patient (74% and 81%, respectively).

Clinical physicians and nursing home physicians who indicated that there was no written practice guideline on EAS in their institution, felt a need for such guideline (54% and 45%, respectively).

Table 4: Dissemination of institutional practice guidelines on medical end-of-life decisions to involved physicians and nurses in Dutch health care institutions in 2005[a]

	Hospitals		Nursing homes		Psychiatric hospitals		Institutions for the mentally disabled		Hospices		Total	
EAS practice guidelines:	n=57		n=77		n=9		n=10		n=5		n=158	
	n	%	n	%	n	%	n	%	n	%	n	%
Systematically	43	75	56	73	5	56	8	80	5	100	117	74
On request	9	16	16	21	4	44	2	20	0	0	31	20
Other	5	9	5	6	0	0	0	0	0	0	10	6
Palliative sedation practice guidelines:	n=21		n=26		n=1		n=8		n=3		n=59	
	n	%	n	%	n	%	n	%	n	%	n	%
Systematically	16	76	22	85	1	100	6	75	3	100	48	81
On request	4	19	3	12	0	0	2	25	0	0	9	15
Other	1	5	1	4	0	0	0	0	0	0	2	3
Alleviation of symptoms practice guidelines:	n=20		n=28		n=1		n=8		n=1		n=58	
	n	%	n	%	n	%	n	%	n	%	n	%
Systematically	13	65	22	79	1	100	6	75	1	100	43	74
On request	5	25	5	18	0	0	2	25	0	0	12	21
Other	2	10	1	4	0	0	0	0	0	0	3	5
Do-not-resuscitate decisions practice guidelines:	n=50		n=67		n=3		n=10		n=1		n=131	
	n	%	n	%	n	%	n	%	n	%	n	%
Systematically	36	72	48	72	2	67	8	80	0	0	94	72
On request	11	22	13	19	1	33	2	20	0	0	27	21
Other	3	6	5	7	0	0	0	0	1	100	9	7
Withdrawing or withholding treatment practice guidelines:	n=29		n=34		n=2		n=9		n=1		n=75	
	n	%	n	%	n	%	n	%	n	%	n	%
Systematically	20	69	21	62	1	50	7	78	1	100	50	67
On request	6	21	11	32	1	59	2	22	0	0	20	27
Other	3	10	2	6	0	0	0	0	0	0	5	7

[a] Total number of institutions with guidelines on medical end-of-life decisions at management level is 216; n per type of medical end-of-life decision is shown in the table

Table 5: Supportiveness of written institutional practice guidelines on EAS [a]

	Clinical specialists n=527		Nursing home physicians n=212	
	n	%	n	%
Guidelines for euthanasia and assisted suicide present[b]				
Yes	395	75	164	78
No	24	5	36	17
Do not know	89	17	8	4
Not applicable: physician does not work in an institution	6	1	3	1
If yes[b]: Guideline supports physician in decision-making when there is a request for euthanasia and assisted suicide from a patient	n=395		n=164	
	n	%	n	%
Yes	290	74	136	81
Sometimes	40	10	11	7
No	7	2	8	5
Not applicable: physician does not receive request for EAS	56	14	13	8
If no[b]:	n=24		n=36	
	n	%	n	%
Physician has a need for such a guideline	13	54	15	45

[a] Weighted rounded percentages
[b] Missing observations: 4-46

4. Discussion

In all health care institutions the majority of the physicians (79%), the ethics committee (79%) (if present), the board of directors (64%), and the nurses (61%) were involved in the development/revision of institutional practice guidelines on medical end-of-life decisions. In most institutions the Euthanasia Act and the national guidelines (73% and 71%, respectively) were the most frequently reported source for the development of institutional practice guidelines on medical end-of-life decisions. Not all institutions systematically disseminated their written EAS policy statements to all relevant parties, and not all hospitals and nursing homes systematically disseminated their institutional practice guidelines on medical end-of-life decisions

to physicians and nurses. Finally, the physicians who reported the presence of written institutional practice guidelines on EAS in their institution felt supported by them in the decision-making when they received a request for EAS from a patient.

4.1. Methodological considerations

This study has some limitations. The results from study A are based on management self-report about the dissemination of written EAS policy statements and the dissemination and development/revision of institutional practice guidelines on medical end-of-life decisions. From the results of study A we do not know whether the dissemination resulted in people actually being well informed about the policy statement or practice guidelines. Study B adds information in this respect, indicating how often physicians were aware of institutional EAS guidelines. However, from this study we do not know whether some physicians were perhaps sometimes unaware of the presence of guidelines. To get a clear picture of the effect of dissemination of policy statements and institutional practice guidelines for medical end-of-life decisions and the process of development, additional quantitative or qualitative research among participants (physicians, nurses, patients) is needed.

Furthermore, the response rate of clinical specialist in study B was somewhat low (46%), therefore the results may not provide a fully representative sample of clinical specialists. Lack of time was the most important factor mentioned by the clinical specialists for not completing the questionnaire.

Comparison of clinical specialists with the national data showed that the distribution of the clinical specialists' characteristics with regard to gender did not differ from the national data on gender.[12]

4.2. Development and revision of institutional practice guidelines on medical end-of-life decisions

Since it is known that guidelines are most effective when they are developed by those who are going to use them[6,7], it is important that both physicians and nurses are involved in guideline development. Compared with physicians, far fewer nurses are involved in the development and revision of the institutional practice guidelines on medical end-of-life decisions. However, it is also important that nurses are involved,

since several research projects in The Netherlands and Belgium showed that nurses have an important role in daily end-of-life care and medical end-of- life decisions.[13-16] It can be debated if it is necessary to involve (future) patients in guideline development. We have not asked explicitly if patients were involved in the development of institutional practice guidelines, but several institutions mentioned that they involved the client council in the development process. It might be suitable for guidelines on medical end-of-life decisions, which might not be purely based on biomedical evidence, but to an important part on patients' preferences.

4.3. Dissemination of written EAS policy statements to all relevant parties

Approximately a quarter of all institutions did not systematically disseminate their written EAS policy statement to their physicians and nurses. Compared to data from The Netherlands in 1994, nurses in nursing homes in 2005 are less often systematically informed about the EAS policy in their institution (90% and 66%, respectively). In 2005, one third of the nursing homes only disseminated these policy statements to nurses on request.

The systematic dissemination of the EAS policy statement to patients is much lower than to physicians and nurses, but has increased compared to 1994. In hospitals the percentage has increased from 4% to 16% and in nursing homes from 31% to 55%. This increase might be the result of a change in the question. In 1994 dissemination to patients was asked and in 2005 dissemination to patients and/or relatives. However, it might also be the result of increasing attention for patient participation in end-of-life decisions or the enactment of the Medical Treatment Act (1995) and the Participation of Clients in Care Institutions Act (1996). The purpose of both Acts is to strengthen the position of the patient.[17]

The results of a Belgian study[4] also showed that in Flemish Catholic hospitals and nursing homes physicians and nurses were more often informed about ethics policies on EAS, than the patients, although more than half of the Flemish Catholic nursing homes always informed their patients about their policy.

It is important for physicians and nurses that they are aware of the institutions' EAS policy statement, because they are both confronted with requests for EAS. For individual patients it is questionable whether an EAS policy statement should always be actively communicated.

However it is recommended that the written EAS policy statement in a hospital or nursing home should be made available for all patients who wish to know about it. For this purpose an information leaflet containing the hospital or nursing home EAS policy statement could be used.

One explanation for why nursing homes more often systematically disseminate their EAS policy statement to patients and their relatives, compared to hospitals, could be that patients normally stay much longer in nursing homes than in hospitals, and generally are admitted in the last phase of life. Moreover, the condition of many hospital patients is not life-threatening. In such cases the dissemination of an EAS policy statement would be not applicable or could even be confusing.

4.4. Dissemination of institutional practice guidelines on medical end-of-life decisions to physicians and nurses working in hospitals and nursing homes

Not all hospitals and nursing homes systematically disseminate their institutional practice guidelines on medical end-of-life decisions to physicians and nurses working in the institution.

Hospitals and nursing homes systematically disseminated institutional practice guidelines on palliative sedation (76% versus 85%) more often to physicians and nurses than the other institutional practice guidelines. A probable explanation for this could perhaps be the increased attention that is being paid to palliative sedation. However all institutional practice guidelines on medical end-of-life decisions should be systematically disseminated to professionals working in the institution, because only then can they be of any influence in the difficult practice of medical end-of-life decision-making.

4.5. Experienced supportiveness of written institutional practice guidelines on EAS by physicians

The majority of the clinical specialists and nursing home physicians who reported the presence of guidelines on EAS in their institution felt supported by them in their decision-making process when considering a request for EAS from a patient. These findings are consistent with data from another Dutch study on the availability/presence and use of guidelines on medical end-of-life decisions in institutions.[18]

More than half of the physicians who reported that there were no practice guidelines on EAS in their institutions felt a need for such guidelines. These results indicate that guidelines can be more important than just paperwork, because it is likely that if they are present, they will actually be supportive and used in practice.

4.6. Conclusions

Institutional practice guidelines can only improve quality of care if they are used in practice. A first step in achieving this is to make potential users aware of their existence. Our study shows that there is still room for improvement regarding this first step, as not all institutions disseminate their practice guidelines systematically. After that the next step for institutional practice guidelines being used in medical practice is to develop multiple strategies to implement guidelines in medical practice (i.e. educational interventions, audits).[6,7,19,20]

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