

Chapter 6

Awareness and use of practice guidelines on medical end-of-life decisions in Dutch hospitals

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Abstract

Objective: To describe awareness, use and supportiveness for physicians of three practice guidelines on medical end-of-life decisions, and to identify factors associated with increased awareness of these guidelines.

Methods: Questionnaires were sent to 793 physicians from 12 hospitals in 2005 (response 52%).

Results: Most physicians were aware of the existence of the practice guidelines for euthanasia (75%) and do-not-resuscitate decisions (63%), and 35% were aware of the existence of the guidelines for palliative sedation. Physicians who had read the guidelines and had been in a situation in which they had to consider a euthanasia request, 88% had used the guidelines for euthanasia; corresponding figures are 92% for do-not-resuscitate and 100% for palliative sedation. When used, almost all physicians felt the guideline had been supportive. More positive attitudes towards guidelines and involvement in guideline development were associated with increased awareness of the presence of guidelines.

Conclusion: It appears that practice guidelines on medical end-of-life decisions are useful for physicians: when they are aware of the presence of such guidelines in their institution, they gain support when using them.

Practice implications: Health care institutions should be encouraged to disseminate guidelines among caregivers, and also involve them in the development of the guidelines.

1. Introduction

During the past decade there has been growing interest in the development of practice guidelines on medical end-of-life decisions in health care institutions. This growing interest is reflected in the Netherlands by the development of several practice guidelines for medical end-of-life decisions at national level, such as practice guidelines on euthanasia and physician-assisted suicide (EAS)¹, palliative sedation (PS)^{2,3} and do-not-resuscitate orders (DNR).⁴

For end-of-life decisions, that must be based on careful decision-making, and with which physicians do not always have very much experience, practice guidelines can help to improve the quality of the care they provide for the dying. Practice guidelines on medical end-of-life decisions focus mainly on procedures for decision-making. The quality of care can be improved by the possible benefits of guidelines for patients, healthcare professionals and the health care system. Improvements in the consistency of the care and the possibility to make more informed healthcare choices can be seen as potential benefits for patients.

Health care professionals can benefit because guidelines on medical end-of-life decisions can help them to improve the quality of their clinical decision-making by offering authoritative recommendations that reassure them about the appropriateness of their treatment policies. Improving efficiency, by standardizing care, can be seen as a potential benefit for health care systems.⁵ However, the existence of practical guidelines alone is not enough to achieve improvements in care. Physicians must also be aware of the existence of the guidelines and use them. Research has demonstrated that involving physicians in the development of guidelines is important, because the most effective guidelines are developed by those who are going to use them.⁶ Other studies showed that potential barriers and facilitators to integrating practice guidelines into practice can act at different levels: the innovation (e.g. feasibility); characteristics of the professionals (e.g. knowledge, skills) and patient (e.g. knowledge, compliance) involved; and social (e.g. colleagues), organizational (e.g. available resources), economic and political (e.g. regulation, policies) context.^{7,8}

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R1 In 2005 Dutch health care institutions mainly had practice guidelines only for EAS
R2 and DNR decisions (respectively 62% and 63%), mostly in hospitals (89% and 83%)
R3 and nursing homes (79% and 78%). Only 41% of the hospitals had PS guidelines.⁹
R4 Nevertheless, the presence of practice guidelines in hospitals does not guarantee
R5 that they are read, or used, or are perceived as useful when used by the physicians.
R6 There is a lack of information in this respect. Are physicians aware of the existence of
R7 practice guidelines on medical end-of-life decisions? If they are aware, do they use
R8 the practice guidelines and, if they use them, do the practice guidelines support their
R9 medical end-of-life decision-making? Therefore, these are the research questions
R10 that we addressed by investigating the practice guidelines on EAS, DNR and PS in
R11 Dutch hospitals. Furthermore, opinions of physicians with regard to institutional
R12 guidelines on medical end-of-life decisions in general, and the possible association
R13 of physician characteristics with reported awareness of the presence of practice
R14 guidelines were studied.
R15 Although other professionals are also important in end-of-life decisions, we focus
R16 on physicians, since they are, together with the patient, responsible for end-of-life
R17 decisions.
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R20 **2. Methods**

R21 *2.1. Design and study sample*

R22 This survey is a sub-study for the 'Evaluation of the Euthanasia Act'.¹⁰ The survey,
R23 which was carried out from October 2005 to March 2006, focused on the awareness
R24 and use of physicians of guidelines on medical end-of-life decisions in daily practice
R25 in Dutch hospitals. Questionnaires were sent to physicians working in different
R26 hospitals.
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R28 The criterion for inclusion of hospitals was that the hospital had a practice guideline
R29 on EAS (47 hospitals in total). Additional characteristics of hospitals for selection
R30 were: the presence of practice guidelines on DNR or PS, size of the hospital, region
R31 and academic or general hospital.
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We included 10 hospitals with DNR guidelines and 7 with PS guidelines (5 hospitals with DNR guidelines, 2 hospitals with PS guidelines and 5 hospitals with both DNR and PS guidelines); 3 academic hospitals and 9 general hospitals; hospitals in all four regions of the country (2 in the North east, 3 in the Centre, 5 in the West and 2 in the South); and hospitals of different size (3 with less than 500 beds, 4 with 500–700 beds and 5 with more than 750 beds).

From the 12 selected hospitals, all physicians working in the following departments were approached: internal medicine, lung diseases, surgery, neurology, cardiology, paediatrics and intensive care units. These are departments in which end-of-life care is most frequently provided.

Postal questionnaires were sent to all 793 physicians working in the above mentioned departments. Their names and addresses were obtained from the 'Geneeskundig Adresboek 1994/1995' (a publication containing the names and work addresses of all physicians in the Netherlands). After four weeks, all non-responders were sent a reminder letter together with a new questionnaire. Another four weeks later, a reminder by e-mail was sent to the non-responding physicians. A total of 114 physicians had to be excluded because they were no longer working in the hospital or department, or they were working in outpatient care (35%). Twenty-five questionnaires were returned to us undelivered. Of the remaining 619 physicians, 325 returned the questionnaire (52%).

2.2. Definitions

In the questionnaire a practice guideline was defined as a written protocol to guide caregivers in approaching a problem that includes a decision-making process and/or a phased care plan.

2.3. Questionnaire

The questionnaire was developed and monitored within the project group, existing of physicians and researchers. The questionnaire was pre-tested by 4 physicians working in a hospital.

The questionnaire consisted of 34 questions, organized into 5 parts. The first 3 parts consisted of yes/no questions about the physicians awareness, use and supportiveness of the practice guidelines on (1) euthanasia and assisted suicide, (2)

R1 do-not-resuscitate orders, and (3) palliative sedation, and whether they had been in
R2 a situation to make a decision about the above end-of-life decisions. If they had been
R3 in such a situation, an open-ended question was asked why the specific guideline
R4 had (not) been supportive in daily practice for them. Reasons for not reading and
R5 not using the practice guidelines were also asked with an open-ended question. Part
R6 four of the questionnaire consisted of general statements about practice guidelines
R7 on medical end-of-life decisions. Physicians had to rate their attitudes on a 5-point
R8 Likert-type scale. The fifth part of the questionnaire collected information about each
R9 respondent's demographic characteristics, department type, clinical experience and
R10 involvement in the development of the three practice guidelines.
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R12 *2.4. Analysis*

R13 Descriptive statistics were used to investigate the awareness, use and supportiveness
R14 of practice guidelines on EAS, DNR and PS for physicians working in Dutch hospitals.
R15 For the open-ended question about why the practice guidelines were (not) supportive,
R16 the answers were coded and categorized. Logistic regression was used to determine
R17 whether background variables were associated with reported awareness of the
R18 practice guidelines. The following variables were considered in this analysis: gender,
R19 age, involvement in the development of the practice guidelines, work experience,
R20 type of department and (strong) (dis)agreement with statements about practice
R21 guidelines on medical end-of-life decisions in general. All variables were first analyzed
R22 by applying univariate logistic regression. Subsequently, all significant variables were
R23 included in a stepwise backward multivariate logistic regression analysis.
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R26 **3. Results**

R27 *3.1. Characteristics of physicians*

R28 Table 1 shows that 25% of the included physicians were female, and 51% of all
R29 physicians were in the 40–50 age group. The majority of the physicians were
R30 specialists and working in an internal medicine or paediatrics department. Fifteen
R31 percent of the physicians had been involved in the development of guidelines on
R32 EAS, DNR or PS. The distribution of the characteristics with regard to gender and age
R33 did not differ from national data on gender and age.¹¹
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Table 1: physician characteristics

	N=325	
	n	%
Being Female	81	25
Age		
< 40	33	10
40-50	163	51
51-60	106	33
>60	16	5
	(7 missings)	
Department		
Internal medicine	84	26
Paediatrics	82	25
Surgery	40	12
Neurology	37	11
Intensive care	36	11
Cardiology	31	10
Lung diseases	14	4
	(1 missing)	
Function		
Specialist	294	91
Chef de clinique	20	6
Other	11	3
Total work years of experience in hospital		
< 5	48	15
5-10	99	31
11-20	99	31
>20	75	23
	(3 missings)	
Total work, h/wk		
< 20	4	1
20-40	112	35
> 40	208	64
	(1 missing)	
Involved with development of guidelines		
Yes, these	48	15
Yes, other	73	23
No	202	63
	(2 missings)	

3.2. Practice guidelines on EAS

Fig. 1 shows that most of the physicians (75%) were aware of the existence of the practice guideline on EAS in their institution. It also shows that of the physicians who were aware of the practice guideline, 69% had read it. If a physician had not read the practice guideline, the most frequently mentioned reason was that (s)he had not received a request for EAS (88%). Of the physicians who had read the practice guideline on EAS, 57% had received a request for EAS since the practice guideline became available, and 88% had used the practice guideline, and felt supported by it (97%).

Physicians who had used the practice guideline and felt supported by it, mentioned the following reasons for the support: 'clear procedure/decision-making' (n = 26), 'clear about what is allowed' (n = 12), 'generally clear' (n = 8), 'in communication with others, justification of the decision-making' (n = 4), 'gives confirmation/feel more certain about the decision' (n = 4), 'no obligation to perform EAS' (n = 2), 'content of guideline is good' (n = 2). Physicians who had used the practice guideline but did not feel supported by it, mentioned the following reasons for the lack of support: 'do not agree with content of the guideline' (n = 1), 'the Euthanasia Act is clear' (n = 1). Reasons why physicians sometimes felt supported by the practice guideline on EAS, but not in all cases, were: 'not suitable for the specific situation' (n = 2) and 'guidelines are not practical' (n = 1) (not in figure).

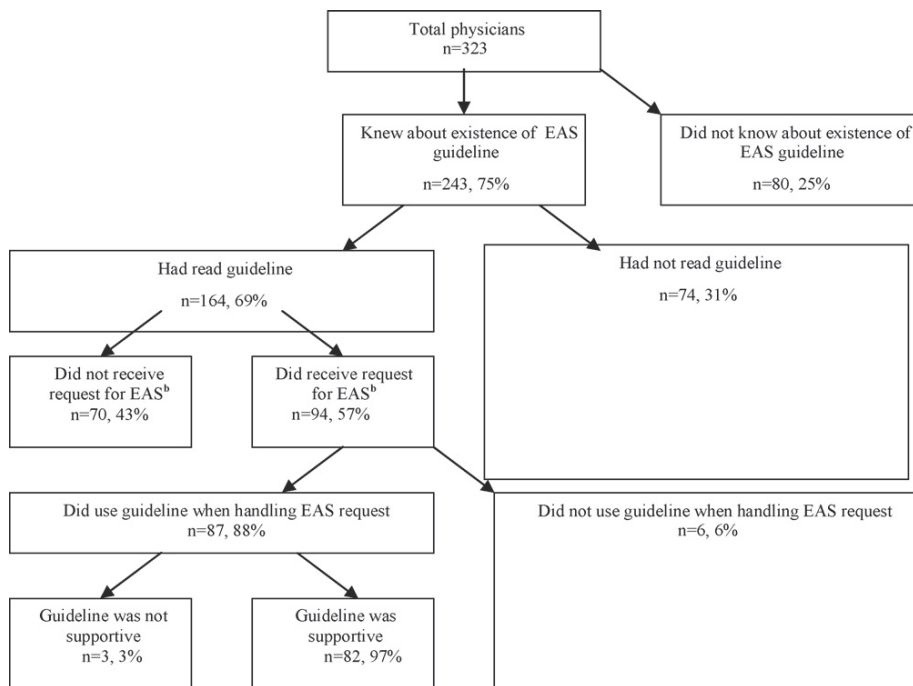


Figure 1: Awareness, use and supportiveness of practice guidelines on euthanasia and physician-assisted suicide (EAS) indicated by physicians working in institutions with EAS guideline (rounded percentages and absolute numbers)^a (a, missing observations: 0–4; b, since availability of the guideline).

3.3. Practice guidelines on DNR

Fig. 2 shows that two-thirds of all physicians were aware of the existence of the practice guideline on DNR in their institution. It also shows that of the physicians who were aware of the practice guideline, 76% had read it. If physicians had not read the practice guideline, the most frequently mentioned reason was that they already knew what to do (74%). Of the physicians who had read the practice guideline on DNR, 98% had seriously considered a DNR decision since the availability of the practice guideline, and 92% had used the practice guideline, and felt supported by it (91)%.

Physicians who had used the practice guideline and felt supported by it, mentioned the following reasons for support: 'clear procedure/phased plan' (n = 8), 'clear content' (n = 4), 'generally clear' (n = 7), 'obligation to record DNR agreements' (n = 2), 'confirmation/supports my decision' (n = 4), 'content of guideline is good' (n = 4), 'other' (n = 3), 'useful in communication with others about the decision' (n = 1). Of the physicians who did not feel supported by the practice guideline, the most frequently mentioned reason was 'do not agree with content of the guideline' (n = 3) of which 'sometimes better not to discuss DNR decision with patient' (n = 1). Other reasons that were mentioned were: 'already know how to handle/no need for a guideline' (n = 2), 'not suitable for the specific situation' (n = 2), 'guidelines are brief' (n = 1). Reasons why physicians sometimes felt supported by the practice guideline on DNR, but not in all cases, were: 'not suitable for the specific situation' (n = 5) and 'sometimes better not to discuss DNR decisions with patient' (n = 6) (not in figure).

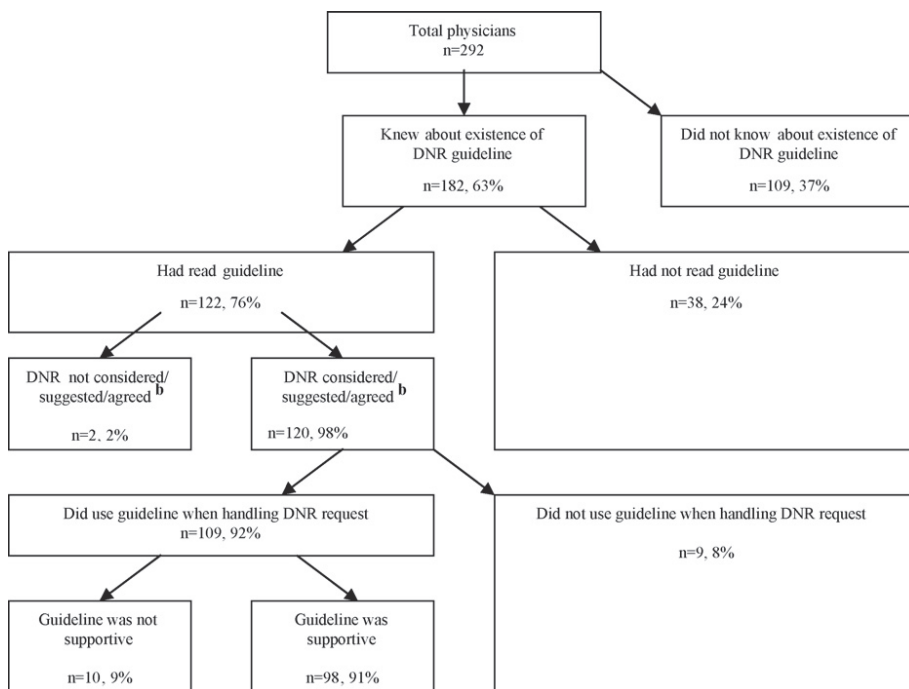


Figure 2: Awareness, use and supportiveness of practice guidelines on do-not-resuscitate (DNR) indicated by physicians working in institutions with DNR guideline (rounded percentages and absolute numbers)^a (a, missing observations: 1–20; b, since availability of the guideline).

3.4. Practice guidelines on PS

Fig. 3 shows that 35% of all physicians were aware of the existence of the practice guideline on PS in their institution. It also shows that if physicians were aware of the practice guideline, 83% had read it. If a physician had not read the practice guideline, the most frequently mentioned reason was that PS was not considered and the patient went to a palliative care unit. Of the physicians who had read the practice guideline, 77% had seriously considered a PS decision since the availability of the practice guideline, and all had used the practice guideline, and felt supported by it (94%).

Physicians who had used the practice guidelines and felt supported by them, mentioned the following reasons: 'clear procedure' (n = 6), 'content of guideline is clear' (n = 1), 'generally clear' (n = 2), 'confirmation/supports decision' (n = 3). One physician did not feel supported by the practice guideline because it was not suitable for the specific situation (not in figure).

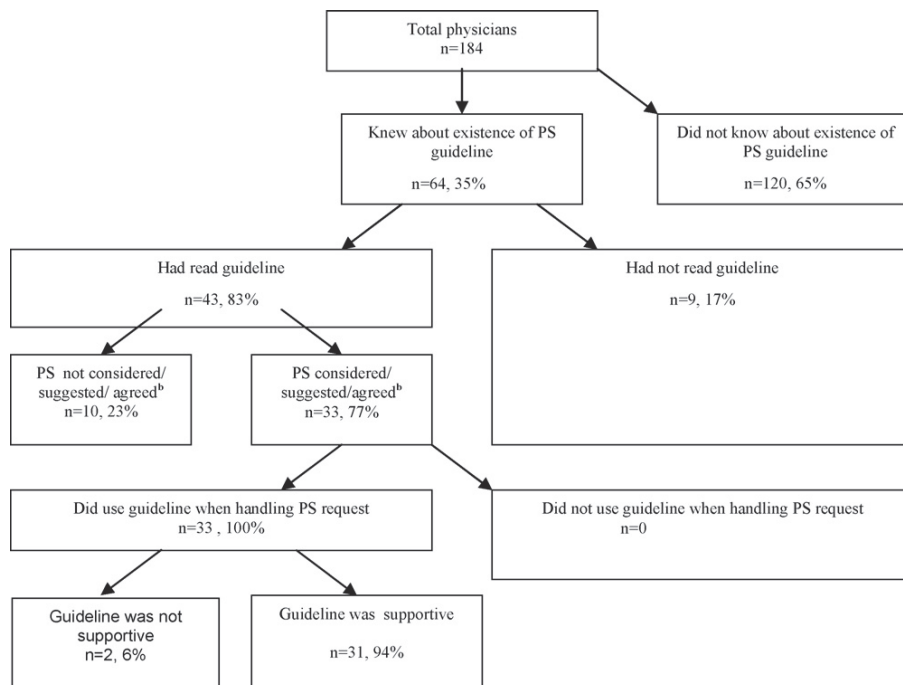


Figure 3: Awareness, use and supportiveness of practice guidelines on palliative sedation (PS) indicated by physicians working in institutions with PS guideline (rounded percentages and absolute numbers)^a (a, missing observations: 2; b, since availability of the guideline).

3.5. *Opinions with regard to statements about institutional guidelines on medical end-of-life decisions in general*

Table 2 shows that 90% of the physicians (strongly) agreed with the statement 'A hospital should have practice guidelines with regard to medical end-of-life decisions'. More than two-thirds of the physicians agreed with the statement 'Every professional has to take notice of the presence and content of institutional guidelines on medical end-of-life decisions on his/her own initiative'. Eight percent of the physicians agreed with the statement 'Practice guidelines on medical end-of-life decisions are not useful in most of the cases because they do not apply to daily practice'.

Table 2: Opinions of physicians with regard to statements about practice guidelines on medical end-of-life decisions in general (n=325)^a (rounded percentages)

	Totally disagree	Disagree	Neutral	Agree	Totally agree
– A hospital should have practice guidelines with regard to medical end-of-life decisions	2	3	6	38	52
– Every professional has to take notice of the presence and content of institutional guidelines on medical end-of-life decisions on his/her own initiative	3	14	22	38	25
– Practice guidelines on medical end-of-life decisions are not useful in most cases because they do not relate to daily practice.	10	52	31	6	2
– Hospitals do not have to develop their own practice guidelines on medical end-of-life decisions, because there are sufficient national guidelines	10	37	33	15	5
– Practice guidelines create too much bureaucracy	11	46	29	11	3

^a Each statement between 50 and 54 missing

3.6. Factors associated with awareness of practice guidelines

Table 3 shows that in the multivariate analysis 4 variables remained associated with awareness of EAS guidelines. Physicians who had been involved in the development of practice guidelines (OR 2.3) and who strongly agreed with the statement that every professional has to take the initiative to know of the presence and content of end-of-life guidelines (OR 3.0) more often were aware of the EAS guidelines, while physicians who strongly agreed on the statement that practice guidelines create too much bureaucracy (OR 0.4) and pulmonologists or paediatricians (OR's 0.2 and 0.1 compared to physicians in internal medicine) were less aware. For both DNR guidelines and palliative sedation guidelines two variables remained significant in the multivariate analyses.

Physicians were more aware of DNR guidelines when they had been involved in development of practice guidelines (OR 2.3) and less aware if they strongly agreed with the statement on hospitals not having to develop their own practice guidelines on end-of-life decision-making (OR 0.3). Physicians were more aware of palliative sedation guidelines when they agreed with the statement that every professional has to take the initiative to know of the presence and content of end-of-life guidelines (OR 2.4) and less if they were paediatricians (OR 0.2 compared to physicians in internal medicine) (Table 3).

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Table 3: Variables associated with awareness of institutional guidelines on euthanasia and physician-assisted suicide (EAS), do-not-resuscitate (DNR) and palliative sedation (PS)^a

Awareness of guidelines on:	EAS N=323			DNR N=292			PS N=184		
	N in sample	% yes	OR(95%CI)	N in sample	% yes	OR(95%CI)	N in sample	% yes	OR(95%CI)
Characteristics of Physicians									
Gender: female	81	69	0.7(0.4-1.2)	71	49	0.5(0.3-0.8)	38	29	0.7(0.3-1.6)
Age: < 45 years old	100	70	0.6(0.3-1.2)	93	51	0.4(0.2-0.8)	51	35	0.8(0.3-1.9)
45-55 years old	147	77	0.8(0.4-1.6)	128	66	0.7(0.4-1.4)	93	32	0.7(0.3-1.5)
> 55 years old	71	80	1.0	64	72	1.0	39	41	1.0
Involved in developing practice guidelines									
[in general or on end-of-life decisions]: no	202	70	1.0	182	56	1.0	118	32	1.0
yes	119	85	2.4(1.4-4.4)	107	74	2.2(1.3-3.7)	64	41	1.4(0.7-2.7)
Work experience: <5 year									
5-10 years	48	73	1.0	40	50	1.0	32	73	1.0
11-20 years	98	66	0.7(0.3-1.6)	88	59	1.4(0.7-3.1)	55	66	0.9(0.4-2.3)
>20 years	75	84	2.0(0.8-4.7)	70	70	2.3(1.0-5.2)	43	84	1.4(0.5-3.5)
Department: Internal medicine									
Lung diseases	14	69	0.2(0.04-0.7)	12	50	0.6(0.2-2.0)	9	44	0.8(0.2-3.4)
Surgery	40	78	0.3(0.09-0.8)	33	73	1.5(0.6-3.8)	27	41	0.7(0.3-1.8)
Neurology	37	73	0.2(0.07-0.6)	35	43	0.4(0.2-1.0)	20	25	0.3(0.1-1.3)
Cardiology	31	68	0.2(0.05-0.5)	27	74	1.6(0.6-4.4)	23	30	0.4(0.1-1.3)
Intensive care	36	89	0.6(0.2-2.3)	32	78	2.1(0.8-5.4)	22	45	0.8(0.3-2.4)
Paediatrics	82	55	0.09(0.04-0.2)	78	58	0.8(0.4-1.5)	43	16	0.2(0.07-0.5)
									0.2(0.06-0.7)

Strongly agreeing with the statement 'Every professional has to take notice of the presence and content of institutional guidelines on medical end-of-life decisions on his/her own initiative'. ^d	171	86	3.7(2.0-6.7)	3.0(1.5-5.7)	146	71	1.6(1.0-2.8)	b	92	43	2.7(1.3-5.5)	2.4(1.1-5.2)
Strongly agreeing with the statement 'Hospitals do not have to develop their own practice guidelines on medical end-of-life decisions, because there are sufficient national guidelines'. ^d	55	76	0.9(0.4-1.8)	b	50	42	0.3(0.1-0.5)	0.3(0.2-0.6)	31	32	0.9(0.4-2.0)	b
Strongly agree with the statement 'Practice guidelines create too much bureaucracy'. ^d	40	63	0.4(0.2-0.8)	0.4(0.2-0.9)	35	57	0.6(0.3-1.3)	b	26	31	0.8(0.3-1.9)	b

Significant values in bold print.

^a Multiple logistic regression: between 2 and 52 missing observations.

^b Not entered in multiple backwards logistic regression.

^c Removed in the backward regression analyses

^d Reference group are physicians who are neutral or (strongly) disagree with this statement.

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4. Discussion and conclusion

4.1. Discussion

In this study we investigated the awareness, use and supportiveness of practice guidelines on EAS, DNR and PS among physicians, and identified physicians predictors of awareness.

Three-quarters of the physicians were aware of the existence of practice guidelines on EAS, and 63% and 35%, respectively, were aware of practice guidelines on DNR and PS. The majority of the physicians who had been in a situation in which the practice guidelines were applicable had used the practice guidelines when handling a request for EAS (88%), DNR (92%) or PS (100%) and felt supported by them. In general, physicians had a positive attitude with regard to the necessity and usefulness of institutional guidelines on medical end-of-life decisions. More positive attitudes and involvement in the development of practice guidelines were associated with increased awareness of the presence of practice guidelines. Furthermore, especially physicians working in a paediatric department were less often aware of the presence of practice guidelines than physicians working in other departments. However, this study has some limitations. Only 12 hospitals were included in the study and although in the choice of hospitals attention was paid to variation in possibly important characteristics, this means that the results are not fully representative for all Dutch hospitals. The response percentage of 52% is reasonable, but not high. Comparison of respondents with the national data showed that the distribution of the physicians' characteristics with regard to gender and age did not differ from the national data on gender and age.¹¹ Finally, this was a retrospective study, which could be affected by recall bias, especially when recalling experiences with the use of guidelines in specific situations.

There was a difference in awareness of the existence of practice guidelines on EAS, DNR and PS. More physicians were aware of the practice guideline on EAS, than the practice guideline on DNR and even less were aware of the practice guideline on PS. It might be easier to be aware of the practice guideline on EAS, since EAS decisions differ from DNR and PS decisions, and the requirements for EAS are defined in the Euthanasia Act. In 2005, only 11% of all Dutch hospitals had formulated practice

guidelines at ward level for palliative sedation before the practice guideline on PS was introduced in the Netherlands.⁹ The present study was carried out from October 2005 to March 2006, and therefore there might have been less awareness of practice guidelines on PS because they had not yet been fully implemented in the hospitals. It is remarkable that the practice guideline on PS was read more by the physicians who were aware of their presence (83%) than the practice guidelines on DNR (76%) and EAS (69%). This is possibly because the practice guideline on PS is new, as a result of the relatively new increase attention that is being paid to palliative sedation in Dutch health care institutions.¹²

The majority of the physicians who had read the practice guidelines and had been in a situation in which the practice guidelines were applicable had also used the practice guidelines (EAS 88%, DNR 92% and PS 100%). This shows that physicians are not only aware of the existence of the practice guidelines, but that they are also using them. However, these high rates of practice guideline use are not consistent with the results of other studies on guideline compliance¹³⁻¹⁵, although in a Canadian study¹⁶ oncologists reported that they were using practice guidelines routinely or most of the time. A Dutch study showed that the characteristics of the guidelines and their users can affect the actual use of the guidelines. Guidelines that are easy to understand, and which do not require specific resources, are more likely to be used.¹⁷ It is also possible that the use of practice guidelines is so high because physicians feel the need for support from practice guidelines, especially when they are faced with complex decisions with far-reaching consequences, such as end-of-life decisions. The results of our study showed that physicians who use the practice guidelines feel supported by them, and the most frequently mentioned reason for feeling supported by the all three practice guidelines was the 'clear procedure'. This demonstrates that practice guidelines on medical end-of-life decisions can give physicians advice on how to proceed, and can also reassure them about the appropriateness of their actions. Especially in the case of medical end-of-life decisions, with which most physicians do not have very much experience with, practice guidelines can be very useful. A prerequisite is that guidelines are of good quality and, if available, based on evidence. Above that, physicians should also be aware of the existence of these guidelines.

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R1 The majority of physicians (90%) agreed with the statement 'A hospital should
R2 have practice guidelines on medical end-of-life decisions, and 63% agreed with the
R3 statement 'Every professional should be aware of the existence and content of the
R4 institutional guidelines on medical end-of-life decisions, on their own initiative'. This
R5 indicates that it is important that managements develop and introduce practice
R6 guidelines on medical end-of-life decisions in their hospitals. Most physicians seem
R7 to have a positive attitude towards practice guidelines and are active in finding out
R8 about them. Of course, this does not rule out the necessity of paying attention to the
R9 dissemination of practice guidelines among physicians, as is illustrated by the fact
R10 that the awareness is not 100%.

R11 This study confirms the assumption that it is important for physicians to be involved
R12 in the development of guidelines.⁶ Physicians in our study, who were involved in the
R13 development of practice guidelines on EAS and DNR were more often aware of these
R14 guidelines, so it seems to be advisable to involve physicians in the development or
R15 review of practice guidelines. An explanation for the fact that physicians working in
R16 internal medicine and intensive care departments were more frequently aware of
R17 the practice guidelines on EAS and PS could perhaps be that it seems evident that
R18 these departments more often provide this specific end-of-life care.

R19 *4.2. Conclusion*

R20 In conclusion it appears that practice guidelines on medical end-of-life decisions
R21 are useful for physicians: their attitudes to these practice guidelines are generally
R22 positive, and when they are aware of the presence of such practice guidelines in their
R23 institution, they gain support when using them.

R24 *4.3. Practice implications*

R25 Since there is room for improvement in the awareness of practice guidelines among
R26 physicians, and especially the practice guideline on PS, it is recommended that health
R27 care institutions pay more attention to the dissemination of practice guidelines among
R28 physicians, and also involve them in the development of the practice guidelines.

R29 All authors confirm all institution/personal identifiers have been removed or
R30 disguised so the institution/personal described are not identifiable and cannot be
R31 identified through the details of the story.
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Chapter 7

Education on end-of-life care in the medical curriculum: students' opinions and knowledge

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Abstract

Objectives: The aims of this study were to investigate: (1) opinions of medical students regarding quantity and content of education on end-of-life care in the curriculum, (2) medical students' knowledge of different aspects of the euthanasia act, and (3) factors associated with positive opinions about the quantity and content of education on end-of-life care in the curriculum.

Methods: A total of 204 medical students received a questionnaire; 176 completed it (response rate, 86%).

Results: Approximately half of the students (55%) considered the quantity of end-of-life care education in the curriculum moderate; 35% rated it as good. Half of the students rated the content of end-of-life care education as moderate (50%); 47% rated it as good. Fourteen percent of the students gave correct answers to 6 or 7 of the 8 questions about the euthanasia act. Students who took the elective course "Terminal and Palliative Care," students who had experience with a patient requesting euthanasia and physician-assisted suicide in their personal lives, and students with more knowledge of the euthanasia act were more positive about the quantity of end-of-life care education. Students who completed fewer clerkships and totally agreed with the statement, "Everyone has the right to decide about their own life and death" were more positive about the content on end-of-life care education.

Conclusions: The data of this study suggest that more attention can and should be paid to education on end-of-life care in the medical curriculum, so students are well prepared to provide adequate end-of-life care.

Introduction

The probability that physicians will see patients in their last phase of life in medical practice is high. A survey among physicians from six European countries and Australia showed that 57%–95% had experience with intensifying the alleviation of pain or other symptoms while taking into account the possible hastening of death; 37%–86% had experience with forgoing life-sustaining treatment, and 12%–46% had experience with deep sedation until death.¹ Approximately 50% of these physicians had not had any formal training in palliative care. Physicians in The Netherlands were the exception; they reported that they had received palliative care training relatively frequently (78%).²

The World Health Organization defines palliative care as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual”.³ To meet the conditions of this definition and to provide adequate end-of-life care, medical training in palliative care is important.

An international survey of medical education in palliative medicine in Canada, the United Kingdom, the United States, and Europe has shown variability in the availability of palliative care courses and faculty positions in palliative medicine. The highest percentage of mandatory rotations in palliative medicine was in medical schools in the United Kingdom (64%) compared to the United States (11%), Canada (14%), and Western Europe (19%). The number of medical schools with faculty positions ranged from 14% in the United States to 62% in Canada.⁴

A survey among European physicians showed that they felt insufficiently prepared to care for the dying⁵, and there were earlier reports that medical students in the United States felt unprepared to provide end-of-life care.^{6–8} A recent study compared the experiences of and education on palliative care among medical students in the United Kingdom and the United States, and found that medical students in the United Kingdom were more prepared for caring for patients at the end of life.⁹

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R1 In a Dutch study among 55 undergraduate students at the VU University Medical
R2 Center in Amsterdam, carried out in 2001, it was found that medical students were
R3 satisfied with the quality of education on palliative care, but they were unsatisfied
R4 about the quantity.¹⁰

R5 Paying attention to euthanasia and physician-assisted suicide (EAS) is important in
R6 the medical curriculum in The Netherlands because EAS is allowed under specific
R7 conditions, and most physicians (84%) receive requests for EAS in daily practice.¹¹ The
R8 above findings underscore the importance of including palliative care and end-of-life
R9 decision making in the medical curriculum. The aims of this study were to investigate
R10 (1) the opinions of medical students regarding quantity and content of education
R11 on end-of-life care in the curriculum, (2) medical students' knowledge of different
R12 aspects of the euthanasia act, and (3) factors associated with positive opinions about
R13 the quantity and content of education on end-of-life care in the medical curriculum.
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R15 **Methods**

R16 *Design and data collection*

R17 The duration of basic medical training in The Netherlands is 6 years. It consists of
R18 theoretical and clinical training, and the last two study years focus on clinical training
R19 (clerkships).
R20

R21 All students start with an internal medicine clerkship, followed by all other hospital
R22 clerkships, the last of which is a public health clerkship. There are several mandatory
R23 tutorials and lectures on end-of-life care and the euthanasia act in the first years of
R24 the medical curriculum of the VU University Medical Center in Amsterdam, and also
R25 an elective course in the fourth year, which involves four group meetings. The length
R26 of each group meeting is 2 hours. The first group meeting focuses on palliative care,
R27 the second on euthanasia. Hypothetical patient cases are used in these meetings.
R28 Each student also has to write an individual paper on terminal and palliative care.
R29 During the last two group meetings they have to give a presentation about their paper.
R30 In the academic year 2006/2007 final-year medical students at the VU University
R31 Medical Center in Amsterdam ($n=204$) following a mandatory tutorial in their public
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health clerkship, received a written anonymous questionnaire. At the beginning of the tutorial 30 extra minutes were allotted for answering the questionnaire. In the questionnaire students were asked about their opinion regarding quantity and content of end-of-life care education on a three-point scale (bad, moderate, good). They were also asked to score their judgment on attention for specific topics in the medical curriculum (three-point-scale, ranging from insufficient, to sufficient, to too much) and furthermore questions about their knowledge about the euthanasia act and euthanasia definition were part of the questionnaire and their opinions on specific statements on end-of-life care (five-point-scale, ranging from strongly agree to strongly disagree). Additional demographic characteristics like gender, religion, age, clerkship experience, involvement in care for terminal patients, and experience with a patient requesting EAS were also asked.

Data analysis

Descriptive statistics were used to investigate the opinions of the students with regard to education on end-of-life care in the medical curriculum, their knowledge about the euthanasia act and the definition of euthanasia (based on the Dutch euthanasia act).¹² The answers to the open-ended question about the definition of euthanasia were coded and categorized. The definition was complete if the following four aspects were mentioned: the explicit aim of the physician to end the patient's life (intention), the administration of drugs (action), an explicit request from the patient (involvement of patient), and death as a result (effect). Logistic regression was used to determine whether background variables were associated with reported positive opinions about the content and quantity of education on end of-life care in the curriculum.

The following variables were considered in this analysis: gender, age, religion, clerkship experience, participation in the elective course "terminal and palliative care", experience with a patient requesting EAS and care for terminal patients, (dis)agreement with statements about end-of-life care, and knowledge about the euthanasia act. All variables were first analyzed with univariate logistic regression.

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R1 Subsequently, all significant variables ($p < 0.05$) were included in a stepwise backward
R2 multivariate logistic regression analysis.

R3 **Results**

R4 *Student characteristics*

R5 A total of 204 medical students received a questionnaire, and 176 completed the
R6 questionnaire (response rate, 86%).

R7 Table 1 shows that 70% of the students were female, and 56% of all students
R8 were over 25 years of age. Almost half of the students (48%) had completed 7 to 9
R9 clerkships, and 46% had completed 10 to 12 clerkships. One quarter of the students
R10 (26%) indicated that they had participated in the elective course “Terminal and
R11 Palliative Care”. Table 1 also shows that 30% of the students had experience with a
R12 patient requesting EAS during their internship/study, and 62% had been involved in
R13 providing care for terminal patients during their internship/study. Almost all of the
R14 students indicated that it is important that the medical curriculum include education
R15 on palliative care and the euthanasia act (98% and 96%, respectively). Finally, 61% of
R16 the students agreed with the statement “Everyone has the right to decide about their
R17 own life and death”, and 65% of the students agreed with the statement, “Further
R18 improvements in palliative care will lead to a decrease in the number of cases in
R19 which physicians are involved in actively ending the life of a patient”.

R20 *Opinions regarding quantity and content of education on end-of-life care in the R21 medical curriculum*

R22 Approximately half of the students (55%) indicated that the quantity of education on
R23 end-of-life care in the basic curriculum was moderate, while 35% rated it as good.
R24 Moreover, half of the students rated the content of education on end-of-life care in
R25 the first 4 years of the study as moderate (50%), while 47% rated it as good.

Table 1: Demographic characteristics and the experiences and opinions of medical students concerning education on end-of-life care in 2007 (n=176)^a

	%
Gender	
male	30
female	70
Religion	
No	57
Roman Catholic	11
(Dutch) Reformed	15
Islamic	7
Other	10
Age	
≤25 years	44
>25 years	56
Clerkships completed	
4-6	3
7-9	48
10-12	46
13-15	3
Participated in the elective course "Terminal and palliative care"	26
Experience with a patient who requested euthanasia and physician-assisted suicide (more than one answer possible):	
No	61
Yes, during internship/study	30
Yes, in private situation	16
Involved with care for terminal patients (more than one answer possible):	
No	31
Yes, during internship/study	62
Yes, in private situation	19
Opinions on end-of-life care (% (totally) agree):	
- It is important that attention is paid to education on palliative care.	98
- It is important that attention is paid to education on the euthanasia act.	96
- Everyone has the right to decide about their own life and death.	61
- Further improvement in palliative care will lead to a decrease in the number of cases in which physicians are involved in the active ending of life.	65

^a 0-10 missing

R1 According to the students, insufficient attention was paid to specific topics such as
R2 how to deal with advanced directives (60%), communication skills with regard to
R3 terminal patients (58%), medico-technical aspects (51%), palliative/terminal sedation
R4 (43%), and spiritual aspects (41%). Most students were of the opinion that sufficient
R5 attention was paid to the requirements for due care (75%) and review procedure
R6 (70%) as aspects of the euthanasia act, and also that sufficient attention was paid to
R7 the ethical aspects of end-of-life care (78%; Table 2).
R8

R9 *Knowledge about different aspects of the euthanasia act*

R10 Most of the students (95%) knew that a physician who has a conscientious objection
R11 to euthanasia should refer a patient who requests euthanasia to another physician.
R12 Most students (95%) also knew that the statement “the family of the patient should
R13 agree to a request for euthanasia” was not true. Two thirds of the students (65%)
R14 knew that requests for euthanasia is not only allowed for patients in the terminal
R15 phase. One third of the students (30%) knew that a written request for euthanasia
R16 may be granted for an incompetent patient, provided that the other requirements
R17 for due care are met.

R18 The number of correct answers to the 8 questions about the euthanasia act ranged
R19 from 0 to 7. Approximately, one quarter of the students (26%) had 0–3 correct
R20 answers, 61% had 4–5 correct answers, 14% had 6–7 correct answers, and none of
R21 the students had 8 correct answers (Table 3).
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R23 *Knowledge about the definition of euthanasia*

R24 The aspect of the definition of euthanasia that was most frequently mentioned was
R25 “death as a result” (65%), while 40% mentioned “an explicit request from the patient”.
R26 The aspect “the administration of drugs” was mentioned least (2%). Another aspect
R27 that was frequently mentioned, which is not included in the definition, but is one of
R28 the requirements of due care, was “hopeless and unbearable suffering” (62%).
R29 One third of the students (35%) named 2 of the 4 aspects of the definition of
R30 euthanasia correctly, 46% named 1 of the 4 aspects correctly, 18% named 0 aspects
R31 correctly, and none of the students named all 4 aspects correctly (Table 4).
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Table 2: Opinions of medical students concerning education on end-of-life care in the medical curriculum (n=176)^a

	Bad %	Moderate %	Good %
What do students in general think about their education on end-of-life care:			
-Quantity of education on end-of-life care education in the curriculum	10	55	35
-Content of the end-of-life care in the curriculum	3	50	47
	Insufficient %	Sufficient %	Too much %
Attention paid to the following topics in the medical curriculum:			
Palliative care			
- Communication skills with regard to terminal patients	58	49	-
- Medical-technical aspects	51	77	3
- Spiritual aspects	41	55	5
- Psychosocial aspects	20	40	2
Medical end-of-life decisions			
- How to deal with advanced directives	60	61	2
- Palliative/terminal sedation	43	71	1
- Increasing pain and symptom control with possible life-shortening effect	37	56	1
- Euthanasia and physician-assisted suicide	31	65	4
- Forgoing potentially life-prolonging treatment	27	39	1
Euthanasia Act			
- Review procedure	28	75	2
- Requirements for due care	23	70	2
Ethical aspects of end-of-life care	12	78	10

^a 1-5 missing

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Table 3: Students' knowledge about different aspects of the euthanasia act (n=176)^a

	Correct answer		Wrong answer		Did not know the answer	
	%		%		%	
- A physician who has a conscientious objection to euthanasia should refer a patient to another physician (statement is true).	95		3		2	
- The family of the patient should agree to a request for euthanasia (statement is not true).	95		3		2	
- A request for euthanasia is <u>only allowed</u> for patients in the terminal phase (statement is not true).	65		30		5	
- A request for euthanasia of children between 12 and 16 years may only be granted if the parents agree (statement is true).	57		22		21	
- Euthanasia is not allowed for patients suffering only from psychiatric disorders (statement is not true).	35		42		23	
- A written request for euthanasia for an incompetent patient may be granted, provided that the requirements for due care are met (statement is true).	30		65		5	
- Consultation in cases of euthanasia has to be done in consultation with a SCEN physician. (statement is not true)	23		39		39	
- The Regional Euthanasia Review Committee always reports its findings to the Public Ministry (statement is not true).	21		56		23	
Number of correct answers	0-3		4-5		6-7	
	%		%		%	
	26		61		14	
					0	

^a 0-3 missing

Factors associated with a positive opinion of the quantity and content of education on end-of-life care in the medical curriculum

Medical students who had participated in the optional course “Terminal and Palliative Care” (odds ratio [OR] 2.9), who had experience with a patient requesting EAS in their personal lives (OR 3.0) and had more knowledge about the euthanasia act (OR 5.4), were more positive about the quantity of education on end-of-life care. The results of the multivariate analysis presented in Table 5 show that medical students who completed 10–15 clerkships (OR 0.5) were less positive about the content of education on end-of-life care in the medical curriculum while the medical students who totally agreed with the statement, “Everyone has the right to decide about their own life and death” felt more positive about it (OR 2.6).

Table 4: Elements of the definition of euthanasia named by medical students in percentages (n=176)^a

The elements of the definition:		%
-	Death is the result (effect)	65
-	Explicit request from a patient (involvement of patient)	40
-	Explicit aim of physician to end life (intention)	14
-	Administration of drugs (action)	2
Other aspects mentioned as part of the definition:		
-	Unbearable and hopeless suffering	62
-	Competence of the patient	18
-	Requirements due care	10
Number of correct elements of the definition mentioned:		
0		18
1		46
2		35
3		2
4		0

^a 21 missing

Table 5: Factors associated with a positive opinion about the content and quantity of education on end-of-life care in the medical curriculum
^a (n=176)

	Positive opinion about content of education on end-of-life care in the curriculum				Positive opinion about quantity of education on end-of-life care in the curriculum				
	% pos	Univar ^e OR(95%CI)	Multiv ^e OR(95%CI)	% pos	Univar ^e OR(95%CI)	Multiv ^e OR(95%CI)	% pos	Univar ^e OR(95%CI)	Multiv ^e OR(95%CI)
Characteristics of Students									
Gender:									
female	48	1.7(0.6-2.2)	^c	39	1.7(0.8-3.4)				
male	45	1.0		27	1.0				
Age:									
≤25 years	37	1.0	^d	27	1.0				
>25 years	53	1.9 (1.0-3.6)		41	1.9 (1.0-3.6)				
Religion:									
No	49	1.0	^c	41	1.0				
Yes	43	0.6 (0.3-1.1)		29	0.8 (0.4-1.4)				
Completed clerkships:									
4-9	56	1.0	1.0	38	1.0				
10-15	37	0.5 (0.2-0.8)	0.5 (0.2-0.9)	32	0.8 (0.4-1.4)				
Participated in the optional course 'Terminal and palliative care':									
No	42	1.0	1.0	29	1.0				
Yes	60	2.1 (1.0-4.2)	2.0 (0.9-4.2)	44	3.1(1.5-6.3)	2.9 (1.3-6.4)			

Experience with a patient requesting for euthanasia and assisted suicide to his or her physician:					
No	43	1.0	c	30	1.0
Yes, during clerkship/study	53	1.4 (0.7-3.1)		33	1.1 (0.5-2.5)
Yes, in private situation	54	1.5 (0.7-3.6)		61	3.7(1.6-8.8)
					3.0(1.1-8.1)
Involved with care for terminal patients:					
No	46	1.0	c	30	c
Yes, during clerkship/study	51	1.2 (0.6-2.4)		36	1.3 (0.6-2.7)
Yes, in private situation	38	0.7 (0.3-1.7)		45	2.0(0.8-4.9)
Totally agree with the statement 'It is important that attention is paid to education on palliative care'. ^b	47	2.6 (0.3-26.4)	c	36	1.7 (0.2-16.2)
Totally agree with the statement 'It is important that attention is paid to the euthanasia act'. ^b	48	2.3 (0.4-12.0)	c	36	1.4 (0.3-7.3)
Totally agreeing with the statement 'Everyone has the right to decide about their own life and death'. ^b	55	2.3 (1.2-4.3)	2.6 (1.3-5.1)	42	2.1 (1.1-4.2)
					2.0(0.9-4.4)
'Totally agreeing with the statement 'Further improvement in palliative care will lead to a decrease in the number of cases in which physicians are involved in active ending of life'. ^b	45	0.9 (0.5-1.6)	c	32	0.7 (0.3-1.3)
Knowledge about the Euthanasia Act					
0-3 correct answers	38	1.0		25	1.0
4-5 correct answers	47	1.5 (0.7-3.0)		33	1.5 (0.7-3.3)
6-7 correct answers	61	2.5 (0.9-7.2)		63	5.0 (1.7-14.6)
					5.4 (1.7-17.6)

^a Multiple logistic regression: missing between 3-17; opinion 'good' vs reference group of 'moderate' or 'bad'

^b Reference group consists of medical students who are neutral or (strongly) disagree with this statement

^c Not entered in multiple backwards logistic regression

^d Removed in the backward regression analyses

^e Significant values in bold print

OR, odds ratio; CI, confidence interval

Discussion

In this study we investigated opinions regarding quantity and content of education on end-of-life care in the medical curriculum among medical students at the VU University Medical Center in Amsterdam, their knowledge about the euthanasia act, and identified factors associated with a positive opinion about the quantity and content of education on end-of-life care in the medical curriculum. Almost all medical students were of the opinion that education on palliative care (98%) and the euthanasia act (96%) was important. Approximately half of the students considered that the quantity of education on end-of-life care was moderate (55%) and 35% considered it to be good. Moreover, 50% of the students rated the content of education on end-of-life care in the basis curriculum as moderate, and approximately 47% thought that the content was good.

How to deal with advance directives (60%) and communication skills with regard to terminal patients (58%) were most frequently mentioned by students as aspects to which insufficient attention was paid in the curriculum. Their knowledge about a number of aspects of the euthanasia act appeared to be insufficient. Students who completed the elective course “Terminal and Palliative Care,” those who had experience with a patient requesting EAS in their personal lives, and students with more knowledge about the euthanasia act, were more positive about the quantity of education on end-of-life care in the curriculum. Those who had completed less clerkships and totally agreed with the statement ‘Everyone has the right to decide about their own life and death’ were more positive about the content of education on end-of-life care in the curriculum.

Methodological considerations

This study has some limitations. The study focuses on only one medical school in The Netherlands, so the results might therefore not be representative of all medical schools in The Netherlands. However, we also requested information about the quantity of education on end-of-life care included in the curriculum in other medical schools in The Netherlands. In most of the medical schools, the quantity of education on end-of-life care was comparable. Our research was carried out in 2006–2007,

and since that time a new medical curriculum for “problem-oriented learning” has been implemented at the VU University Medical Center in Amsterdam. However, in the new curriculum a similar amount of attention is paid to end-of-life care, but it is no longer possible for students to participate in the elective course in which terminal and palliative care is studied in more depth. Although, the population was tilted significantly toward female participants (70%), this is in line with the general medical student population (65% female and 35% male).¹³

Furthermore, this was a retrospective study, so the results could be affected by recall bias, especially when recalling education on end-of-life care.

Opinions about education on end-of-life care in the medical curriculum

According to the students, in particular insufficient attention was paid to communication skills with regard to terminal patients and how to deal with advanced directives. Similar findings have been reported elsewhere. Ury et al.¹⁴ found that the majority of interns had little experience and low self-perceived comfort and skills with regard to important elements of end-of-life communication during medical school.

Data from a national study among physicians in The Netherlands also showed that not all physicians in medical practice are aware of how to deal with advance directives.¹¹ Medical students can therefore benefit from mandatory training in palliative and end-of-life care.

Porter-Williamson et al.¹⁵ evaluated the requirements of a new curriculum in palliative medicine for third-year medical students in the United States. Their study showed that a 4-day curriculum in palliative medicine improved third-year medical student’s knowledge of the definition of physician-assisted suicide. Other studies have also reported an effect of palliative care curricula on the knowledge, attitudes and skills of medical students.^{16,17} Therefore, we agree with Ross et al.¹⁸, who recommend the development of relevant educational programs to educate and train students in these specific topics.

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Knowledge of different aspects of the definition euthanasia and the euthanasia act

There seems to be a discrepancy between the students' knowledge and their opinions about the attention that is paid to the euthanasia act in the curriculum. Despite their lack of knowledge, the students thought that sufficient time was devoted to the requirements for due care (75%), the review procedure (70%), and various aspects of the euthanasia act.

Apparently students sometimes overestimate their own knowledge. However, it may also be the case that knowledge is inadvertently mixed with opinions about euthanasia, or perhaps the students did not mention certain aspects because they thought they were too obvious to mention.¹⁹

It was also striking that only 30% of the students knew that a written request for euthanasia may be granted for an incompetent person. This percentage is consistent with the knowledge of Dutch physicians, as we found in another study (40%).¹¹ A possible explanation could be that the students do not agree with this statement and are of the opinion that a written request for euthanasia may not be granted for an incompetent person. Another possibility is that in practice it never or hardly ever occurs that physicians follow an advance euthanasia directive in a patient that has become incompetent.

Knowledge about the euthanasia act and the definition of euthanasia becomes really relevant when the students start working in medical practice, but education on end-of-life care is a first step with which to prepare them for medical practice, because insufficient knowledge of the euthanasia act and the definition of euthanasia might result in less prudent decision-making when they receive a request for euthanasia.

Factors associated with a positive opinion about the quantity and content of education on end-of-life care in the medical curriculum

Medical students who participated in the elective course "Terminal and Palliative Care" were more positive about the quantity of education on end-of-life care in the curriculum. This suggests that it might be advisable to make such elective courses obligatory. However, it could be possible that there was a self-selection bias in those students who took the elective course having more interest in and thereby desire for more end-of-life education.

Medical students who completed 10–15 clerkships were less positive about the content of education on end-of-life care in the curriculum. Students with more experience might be better at recognizing relevant content for the medical curriculum. They are more likely to have had experience with patients in their terminal phase of life during their practical training in various clinical departments.

Medical students who totally agreed with the statement, “Everyone has the right to decide about their own life and death” were more positive about the content of education on end-of-life care in the curriculum. A probable explanation for this could be that these students recognize the importance of ethical issues related to patient autonomy.

In conclusion, the results of this study suggest that more attention can and should be paid to education on end-of-life care in the medical curriculum, so students are well prepared to provide adequate end-of-life care.

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Author Disclosure Statement

No competing financial interests exist.

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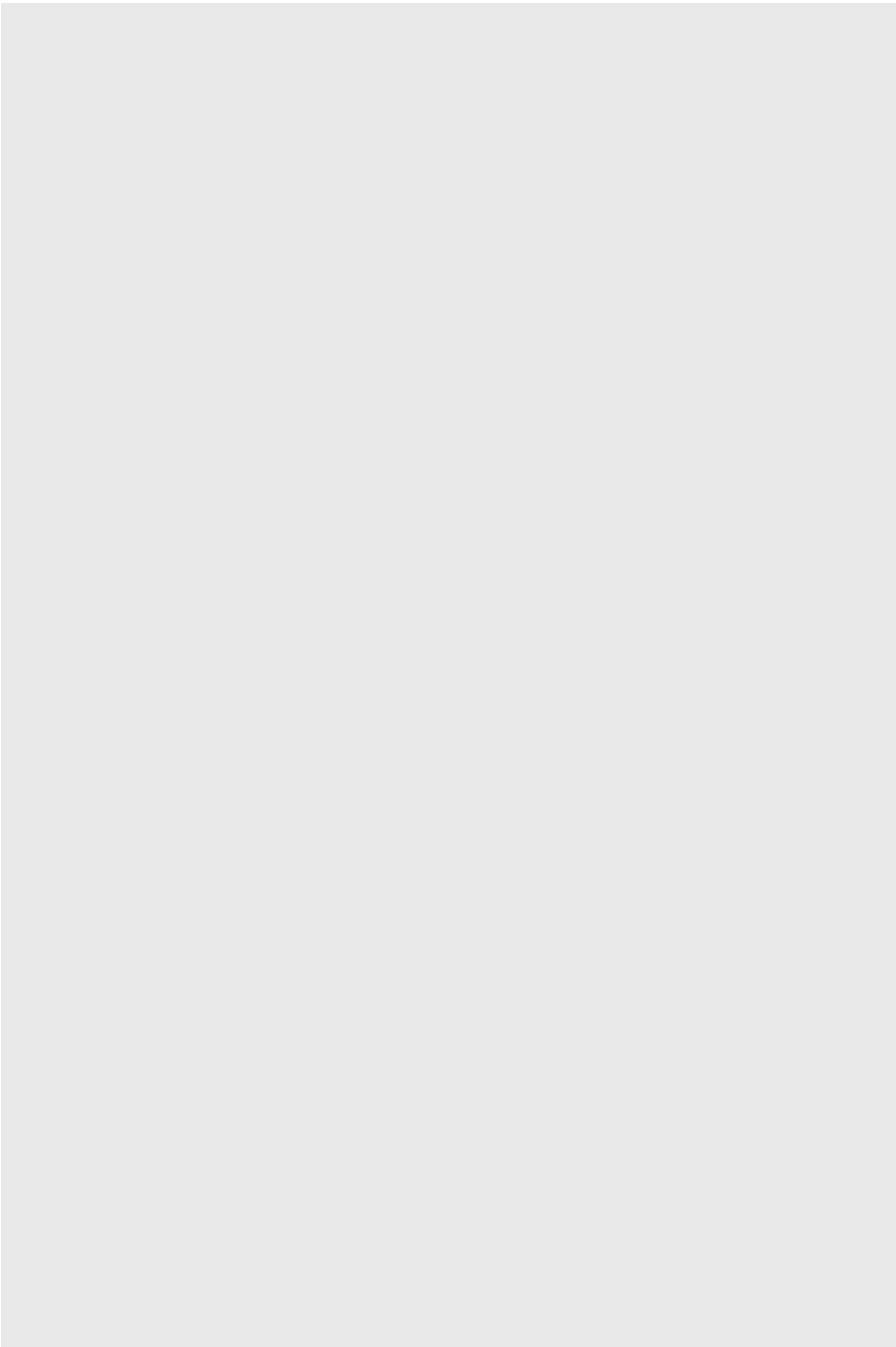
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Chapter 8

General discussion



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8.1 Introduction

This thesis focused on end-of-life policies and guidelines in Dutch health care institutions. In general, the principal benefit of guidelines is improvement of the quality of care that is provided for patients.^{1,2} Guidelines can not only improve the consistency of the care, but also offer healthcare professionals explicit recommendations on how to proceed, and include authoritative recommendations that support them in the appropriateness of their treatment policies.² These aspects are also relevant for practice guidelines concerning medical end-of-life decisions which are difficult decisions due to ethical and legal aspects, and because multiple health care providers (physicians, nurses) are involved in these decisions. All these aspects can be clearly described in practice guidelines. However, simply describing these aspects is not enough. It is also important that health care providers feel supported by the guidelines and actually apply them in practice.

The main objectives of this thesis can be sub-divided into 2 levels. Certain objectives are related to the institutional level, because this is the level at which policies and guidelines are developed. Other objectives concern the level of physicians and medical students, because they are supposed to work with, and feel supported by guidelines, now and in the future. Based on these 2 levels, the main objectives of this thesis were:

I. At institutional level:

- a) 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.
- b) To describe 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) To describe the content of institutional EAS guidelines in hospitals and nursing homes, and the content of hospital guidelines for do-not-resuscitate (DNR) decisions.
- d) To compare the existence, development, dissemination and content of EAS policies and practice guidelines for medical end-of-life decisions in 2005 and in 1994.

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II. At *physicians and medical student level*:

- a) To describe the awareness and use of institutional euthanasia and physician-assisted suicide (EAS), do-not-resuscitate (DNR) and palliative sedation (PS) practice guidelines for medical end-of-life decisions by physicians in Dutch hospitals.
- b) To describe the opinions and knowledge of medical students with regard to education on end-of-life care in the medical curriculum.

Before presenting the results, the strengths and limitations of the methods used in the studies will be discussed in Section 8.2. In Section 8.3 the main findings will be presented and discussed in relation to the objectives of this thesis, and the implications for policy-makers and future research will be discussed in Section 8.4.

8.2 Strengths and limitations of the studies

8.2.1 Questionnaire survey institutions

The management of all health care institutions in the Netherlands received a questionnaire on end-of-life policies and guidelines in the survey among institutions. Strengths of this study are that all sectors with patient groups for whom medical end-of-life care is relevant have been investigated, and that not only a sample, but all institutions were included in the study. Although the response rate was 68%, and the response rate differed per type of institution, the responding institutions did not differ significantly from the non-responding institutions, except that there was a higher rate of response from the larger nursing homes. A limitation of the survey might be that the managements of the health care institutions were requested to complete the questionnaire, and it was not always clear who was representing the management team, and how familiar he or she was with EAS policy statements and practice guidelines for medical end-of-life decisions. However, in our letter of introduction we did suggested the possibility of asking the person who knew most about the subject to fill in the questionnaire. In addition, in the reminder phone-calls we asked to talk to a quality officer, if such a function existed in the institution,

because these officers are generally most knowledgeable about the subject. Another limitation is that the findings were based on self-reports, which could cause information bias and social desirability bias. Therefore the answers might not truly reflect actual practice within the health care institutions. This applies, in particular, to information about dissemination of the results, because for most institutions information about the content of the policy and guidelines was backed up by a copy of the documents.

8.2.2 Content analysis EAS and DNR practice guidelines in nursing homes and hospitals

In the survey among institutions the managements of all Dutch hospitals and nursing homes were asked to provide a copy of their EAS guidelines and all Dutch hospitals were asked to provide a copy of their DNR guidelines. A strength of the study is that we systematically assessed the guidelines, based on checklists that were specifically developed for this purpose. A limitation of this type of study is the possible subjectivity of the assessments, so to prevent this, several measures were taken. First, the assessors were trained together in the use of the checklist, which resulted in a similar way of using the checklist. Secondly, all documents were assessed by two researchers separately, who discussed any differences in assessment. If consensus was not achieved, a third assessor was consulted. The effectiveness of this approach is reflected in the high percentage of agreement between the assessors (74% -100% per aspect for EAS guidelines and 85%-100% per aspect for DNR guidelines).

8.2.3 Questionnaire survey physicians

All physicians working in the departments of internal medicine, pulmonology, surgery, neurology, cardiology, pediatrics and intensive care in the 12 selected hospitals received a questionnaire about their awareness and use of EAS, DNR and PS guidelines. A limitation was that the 12 hospitals were not a random sample of hospitals. However, in the choice of the hospitals attention was paid to variation in possibly important characteristics, such as the presence of practice guidelines on EAS and DNR or PS, the size of the hospital, the region, and academic or general hospitals. Although the response rate was 52% and the sample was not random, the distribution of the physicians' characteristics with regard to gender and age did not

R1 differ from the national data. Another limitation of this survey was that the results
R2 were also based on self-reports from the physicians, which could be affected by
R3 recall bias, especially when recalling experiences with the use of practice guidelines
R4 in specific situations. However, a request for EAS occurs infrequently, and might have
R5 a considerable impact on a physician, so that it is fairly easy to recall.
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R7 *8.2.3 Questionnaire survey medical students*

R8 Final-year medical students at the VU University Medical Center in Amsterdam,
R9 following a mandatory tutorial in their public health clerkship, received a written
R10 questionnaire about their experience with education on end-of-life decision-making
R11 and palliative care and on their knowledge about certain aspects of the Euthanasia
R12 law. The response rate was 86%.

R13 Although there were significantly more female participants (70%), the participating
R14 students did not differ from medical students in general.³ One limitation of this
R15 survey was that the results were based on self-reports from the students, which
R16 could be affected by recall bias, especially when recalling the amount of education
R17 that focused on end-of-life care. Furthermore, it is important to realize that the study
R18 involved in only 1 of 8 medical faculties in the Netherlands. However, there are no
R19 indications that education on end-of-life care is more extensive in any of the other
R20 faculties.
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R22 A general limitation of the studies in this thesis is that we do not know anything about
R23 the effects of these practice guidelines on medical practice. We do not know whether
R24 health care institutions with practice guidelines for medical end-of-life decisions,
R25 deliver better quality of care than institutions without these practice guidelines. It is
R26 also not known which aspects of guidelines will contribute to more prudent practice.
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8.3 Main Findings

8.3.1 Institutions

Existence of EAS policy statements and practice guidelines for all medical end-of-life decisions

Main results

The results presented in Chapter 2 of this thesis show that most institutions (70%) had a written EAS policy statement, especially hospitals (80%), nursing homes (90%) and hospices (88%). Written EAS policy statements were least often present in institutions for the mentally disabled (33%) and psychiatric hospitals (50%).

With regard to practice guidelines for different end-of-life decisions, it was found that the majority of institutions had a practice guideline only for EAS and DNR decisions (62% and 63%, respectively). A minority had guidelines for PS (27%), the alleviation of symptoms with a possible life-shortening effect (27%) and withdrawing or withholding treatment (34%). Practice PS guidelines were more often present in hospices (38%) and hospitals (41%), and practice guidelines for the alleviation of symptoms with a possible life-shortening effect and withdrawing or withholding treatment were most often present in hospitals (39% and 46% respectively) and nursing homes (32% and 37%, respectively).

It is noticeable that for all types of institutions the percentage with an EAS policy statement has increased since 1994⁴ when the first Dutch study on policy and guidelines for medical end-of-life decisions took place: 69% versus 80% for hospitals, 13% versus 50% for psychiatric hospitals, 74% versus 90% for nursing homes, and 16% versus 33% for institutions for the mentally disabled in 1994 and in the present study, respectively.

Moreover, the percentage of hospitals, nursing homes and institutions for the mentally disabled with institutional practice guidelines for the alleviation of symptoms with a possible life-shortening effect, DNR decisions, and withdrawing or withholding treatment was also higher in 2005 than in 1994. The most striking increase occurred in DNR decisions, from 37% to 77% in hospitals, from 16% to 73% in nursing homes, and from 3% to 29% in institutions for the mentally disabled.

R1 The increase in EAS policy statements and end-of life practice guidelines in the
R2 Netherlands, was also found in Belgium.^{5,6} It is likely that in both countries there are
R3 similar reasons for these developments, because in both countries a euthanasia law
R4 was enacted in 2002. This has probably increased the attention that is paid especially
R5 to EAS. Another reason could be the increase in attention that is paid in health care
R6 to working according to protocols and practice guidelines in order to achieve better
R7 quality of care.⁷ The development of a quality policy, including protocols and practice
R8 guidelines for different areas of care, has taken place in many institutions. End-of-life
R9 care is one of the topics to be addressed in such developments.

R10
R11 Institutions that need extra attention

R12 It can be seen as a positive development that there is an increase in the existence of
R13 written policy statements and practice guidelines in all types of institutions. However,
R14 some institutions are lagging behind in this development. Despite the fact that the
R15 percentage of written EAS policy statements has increased in psychiatric hospitals,
R16 a quarter of these institutions still had no written or verbal EAS policy statement
R17 in 2005. More than half of the psychiatric hospitals also had no practice EAS
R18 guidelines. However, explicit and persistent requests for physician-assisted suicide
R19 are not unusual in Dutch psychiatric practice.⁸ It is also known that requests from
R20 psychiatric patients are sometimes granted and reported to the Euthanasia Review
R21 Committee.⁹ Moreover, in 1998, national practice guidelines were formulated to
R22 assist psychiatrists in handling requests for physician-assisted suicide from psychiatric
R23 patients.¹⁰ These guidelines were updated in 2004 and 2009. They could be used in
R24 psychiatric hospitals which do not have such a guidelines, or could be used as basis
R25 for the development of EAS guideline.

R26 Although our results showed an increase in the existence of practice guidelines in
R27 institutions for the mentally disabled, most of these institutions still did not have
R28 practice guidelines for medical end-of-life decisions (between 64% and 85% for the
R29 different medical end-of-life decisions). One might argue that this is not surprising,
R30 since most clients in these institutions are not in the last phase of life, or do not
R31 have a life-threatening disease. However, the results of a Dutch study showed that
R32 medical end-of-life decisions are an important aspect of medical care for mentally
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disabled people. It was found that medical end-of-life decision-making in this group predominantly involved decisions to forgo potentially life-prolonging treatment, and EAS did not occur.¹¹

The necessity of practice guidelines for EAS might therefore not be obvious in institutions for the mentally disabled, but this does not apply to guidelines for other end-of-life decisions. A Dutch study on end-of-life care for the mentally disabled in residential care facilities revealed problems in various areas, for example in the field of pain management, communication about end-of-life issues, and co-operation between care providers and organizations for terminal care.¹² A case study of the palliative care needs of people with intellectual disabilities in the UK identified difficulties and delays concerning diagnosis of the illness, consent issues, conflicts between the carers and the family, truth-telling, and the need for professional support.¹³

In 2007, the NVAVG (Netherlands Society of Physicians for People with Intellectual Disabilities) introduced a general guideline on medical end-of-life decisions concerning people with mental disabilities.¹⁴ In the same year, national guidelines for (non-) resuscitation policies in the care for the mentally disabled people were also published.¹⁵ This might result in a further increase in the existence of such guidelines in institutions for the mentally disabled.

Guidelines that need extra attention

Only one quarter of all institutions had formulated practice guidelines for PS, and these were mainly hospitals (41%) and hospices (38%). However, it should be noted that this study took place before the national guideline for PS was introduced in the Netherlands in 2005.¹⁶ Since then the debate on PS has been continued, and this resulted in a revision of this guideline in 2009 by the Royal Dutch Medical Association.¹⁷ Subsequently, there might have been an increase in the number of institutions with practice PS guidelines. This may also have been stimulated by the public debate in the Netherlands and other countries about the appropriate way of performing PS.^{18,19} PS occurs in approximately 7% of all deaths in the Netherlands²⁰, which is about 9700 deaths a year, and occurs most often in hospitals. PS is also common in other countries.²¹ This suggests that a guideline for PS can be beneficial

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R1 in supporting physicians with this difficult end-of-life decision- making, in which they
R2 do not always have very much experience.

R3 Guidelines for the alleviation of pain with a possible life-shortening effect, and
R4 guidelines for withholding or withdrawing treatment were still only present in the
R5 minority of institutions, although these end-of-life decisions occur frequently. In
R6 2005, 24.7% of all deaths in the Netherlands were the result of intensified alleviation
R7 of symptoms, and 15.6% were the result of withholding or withdrawing potentially
R8 life-prolonging treatment.²²

R9
R10 In conclusion

R11 We found improvements in the presence of EAS policy statements and practice
R12 guidelines for medical end-of-life decisions in institutions in the Netherlands in the
R13 past decade. However, there is still room for further improvement, because guidelines
R14 can contribute to an improvement in the quality and continuity of the care that is
R15 provided. Of course, it should be realized that the mere presence of guidelines will
R16 not influence the quality of end-of-life care. After developing policy statements and
R17 a guideline for EAS and practice guidelines for medical end-of-life decisions, the next
R18 important step is to disseminate them to the professionals working in the institution.

R19
R20 *Development and dissemination of institutional practice guidelines on medical end-*
R21 *of-life decisions and EAS policy statements to relevant parties*

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R23 Main results

R24 The results presented in chapter 3 of this thesis show that physicians (79%), ethics
R25 committees (79%), boards of directors (64%) and nurses (61%) were often involved
R26 in the development of institutional practice guidelines for medical end-of-life
R27 decisions. In most institutions the Euthanasia Act and national guidelines (73% and
R28 71%, respectively) were the most frequently reported source for the development
R29 of institutional guidelines for medical end-of-life decisions. Most institutions
R30 systematically disseminated their EAS policy statements to physicians and nurses/
R31 nursing staff (78% and 73%, respectively). Compared to the other institutions,
R32 nursing homes least often systematically disseminated their written EAS policy to
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nurses (66%). Systematic dissemination of the EAS policy statement to patients and/or relatives was less common in institutions: this occurred in 55% of the nursing homes, 38% of the institutions for the mentally disabled and hospices, 16% of the hospitals, and only in 1 psychiatric hospital.

Systematic dissemination of practice guidelines for medical end-of-life decisions to physicians and nurses working in the institution was common in most hospitals and nursing homes. Institutional practice PS guidelines were most often systematically disseminated in hospitals (76%) and nursing homes (85%), and institutional practice guidelines for withholding or withdrawing treatment were least often systematically disseminated in hospitals and nursing homes (69% and 62%, respectively). Institutional practice guidelines for medical end-of-life decisions were rarely available in psychiatric hospitals, institutions for the mentally disabled and hospices.

Compared to data from the 1994 study, the systematic dissemination of EAS policy statements in hospitals in particular to nurses, remained almost the same (nurses: 83% versus 80%, and physicians: 89% versus 80%). In 2005, however, less nursing homes systematically informed their physicians and nurses about the institutional EAS policy than in 1994 (82% versus 94%, and 66% versus 90%, respectively). The reason for this decrease is unknown.

The systematic dissemination of EAS policy statements to patients has increased since 1994. In hospitals the percentage has increased from 4% to 16% and in nursing homes from 31% to 55%. One possible reason for this might be the increased attention that has been paid to patient participation in medical end-of-life decisions during the past decade. However, part of this change might be due to a change in focus of the studies: in 1994 dissemination to patients was studied, and in 2005 dissemination to patients and/or relatives was studied.

The results of a Belgian study²³ also showed that in Flemish Catholic hospitals and nursing homes the 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.

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Development of institutional practice guidelines

Involving people who have to work with the guidelines in practice in the development of the guidelines is seen as a way to enhance the use of the guidelines in practice.^{1,24}

It is noticeable that, compared to physicians, fewer nurses were involved in the development of institutional practice guidelines. It is important that nurses are also involved, because they have an important role in daily end-of-life care and medical end-of-life decisions (e.g. in decisions about the alleviation of pain and symptoms with a possible life-shortening effect and EAS decisions).²⁵⁻²⁷ The Euthanasia Act and national guidelines were the most frequently used sources for the developments of the institutional practice guidelines (73% and 71%, respectively). These can be considered as good sources of information, and can be used as a basis for the development of EAS guidelines. National guidelines are usually developed by experts, have been extensively discussed, and are considered to be a good reference framework. One could even argue whether it is necessary to develop guidelines at institutional level if national guidelines already exist. However, for institutions it is desirable that they explicitly state whether or not, for example EAS, is allowed in their institution. Finally, institutional practice guidelines can provide clarity about the specific procedures in the specific institution (e.g. availability of consultants).

Dissemination of written EAS policy statements to physicians, nurses and patients

Although most institutions systematically disseminated their EAS policy statements to physicians and nurses/nursing staff working in their institution, approximately one quarter of all institutions did not do so. It is desirable that health care institutions always systematically disseminate their policy statement to physicians and nurses, and not only on request, in order to state clearly whether or not EAS is allowed in the institution. For physicians and nurses this is important, because they can be confronted with requests for EAS.

We also found that the systematic dissemination of their EAS policy statement to patients and/or relatives was relatively uncommon in institutions. For individual patients, however, it is questionable whether an EAS policy statement should always be actively communicated. Not all patients are in a life-threatening condition, and not all patients want to be confronted with this issue. In such cases the dissemination

of an EAS policy statement would not be appropriate, or could even be confusing or disturbing. This could explain why nursing homes more often systematically disseminate their EAS policy statement to patients and their relatives than hospitals, since more nursing home patients are in the last phase of their life . However, it is recommended that the EAS policy statement in a hospital or nursing home should be made available to the patient council, and also all patients who wish to know about it.

Dissemination of institutional practice guidelines to physicians and nurses

Despite the existence of institutional practice guidelines for medical end-of-life decisions, not all institutions systematically disseminate these guidelines to physicians and nurses working in their institution. There is also a variation in the dissemination of the guidelines. For example, institutional practice PS guidelines were more often systematically disseminated than all other institutional practice guidelines. It is desirable that institutions always systematically disseminate all their institutional practice guidelines to physicians and nurses working in their institution. These guidelines can only improve the quality of care if they are actually used in practice. A first step in achieving this is to make potential users (e.g. physicians and nurses) aware of their existence. Attention could be paid to this issue in an employment procedure and on intranet.

In conclusion

It is apparent that there is still room for improvement in the way institutions disseminate EAS policy statements and practice guidelines for medical end-of-life decisions. Another important factor in the usefulness of practice guidelines to improve quality of care is that the content is good, with sufficient practical details.

Content of institutional EAS guidelines in hospitals and nursing homes

Main results

In Chapter 4 the content of institutional hospital and nursing home practice guidelines for EAS before and after the enactment of the Euthanasia law in 2002 is described.

R1 Most of the guidelines stated that the attending physician is responsible for the
R2 decision to grant or refuse a request for EAS. The majority of the guidelines contained
R3 a description of the due care criteria, but the aspects that are relevant for assessing
R4 these requirements were not always described. Only half of the guidelines stated
R5 that an advance euthanasia directive can be considered as a request for euthanasia,
R6 and half of the guidelines did not describe the role of the nurse in the performance
R7 of euthanasia. Compared to hospital guidelines, nursing home guidelines were more
R8 often stricter than the law in excluding patients with dementia (30% versus 4%) and
R9 incompetent patients (25% versus 4%). As from 2002, the guidelines were less strict
R10 in categorically excluding specific patients groups (32% versus 64%), and in particular
R11 incompetent patients (10% versus 29%).
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R13 Due care criteria

R14 After receiving a request for euthanasia the decision-making process should meet
R15 the due care criteria. They are the core of the decision-making process for the
R16 physician. Although in the majority of the guidelines the due care criteria were
R17 described (in 1994 all the official requirements were described in only 65% of the
R18 guidelines), aspects that are relevant for assessing these criteria were not always
R19 described. This could cause problems for physicians when interpreting the criteria.
R20 The results of a Dutch study showed that physicians almost always adhered to the due
R21 care criteria during the decision-making process after a request for euthanasia, but
R22 25% occasionally experienced problems with the assessment of these criteria. This
R23 applied, in particular true to the due care criteria unbearably and hopelessly suffering,
R24 and a voluntary and well-considered request.²⁸ In order to be really helpful for the
R25 users, the guidelines should describe which aspects must be taken into consideration
R26 in assessing the due care criteria. For instance, knowing how to determine whether
R27 a possible alternative is reasonable or realistic, is important when assessing whether
R28 there are no more reasonable alternatives available. Elaborating on the assessment
R29 of the due care criteria in practice EAS guidelines could also increase the feeling of
R30 legal certainty for the physician. For instance, a description of the procedural aspects
R31 of the law, what can be considered to be an alternative treatment, or what to do
R32 in case of consultation. We cannot totally equate practice guidelines on end-of-
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life decisions with clinical guidelines. Clinical guidelines are mostly evidence based developed 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 are key steps in the development of these evidence-based guidelines.²⁹ Practice guidelines on medical end-of-life decisions are usually not based on scientific evidence (evidence-based), but more on consensus among professionals. However, the key steps in the development of evidence based guidelines can be used as useful tools for the development of practice guidelines on end-of-life decisions.

EAS in relation to the law

The hospitals and nursing homes described restrictions in their institutional practice EAS guidelines. The guidelines were actually stricter than the law with regard to their content, in particular with regard to the exclusion of specific patient groups (e.g. dementia patients and incompetent patients). Compared to the hospital guidelines, the nursing home guidelines were more often stricter than the law in excluding patients with dementia (30% versus 4%) and incompetent patients (25% versus 4%). One could wonder whether it is justified for the professionals working in the institution and the patients that institutions in which EAS is allowed, can exclude patient groups. However, institutions have the possibility to limit the possibilities for EAS in their institution as a recent European resolution (2010) states: "No person, hospital or institution shall be coerced, held liable or discriminated against in any manner because of a refusal to perform, accommodate, assist or submit to [among other things] euthanasia, for any reason".³⁰ If they do have a policy that is stricter than law, health care institutions should at least explicitly make this stricter policy known to the professionals working with the guideline, and members of the patient council. Furthermore guidelines do not always correctly or clearly explain important aspects of the law or elaborate on difficult but important aspects. For example, only about half of the guidelines stated that an advance euthanasia directive can be considered as a request for euthanasia. Research among physicians, medical students and euthanasia consultants revealed that the majority of physicians and

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R1 medical students in the Netherlands were not aware of the fact that euthanasia
R2 on the basis of an advance directive can be legal (under certain conditions).^{28,31,32}
R3 Providing accurate information about all aspects of the law in guidelines could help
R4 to improve this lack of knowledge.
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R6 Role of the nurse

R7 Our results show that limited attention is paid to the role of the nurse in the
R8 performance of euthanasia. Only half of the guidelines described this role, which is
R9 similar to the findings in 1994. However, other studies have reported that nurses are
R10 often involved in the performance of euthanasia, and perform tasks that are illegal
R11 and beyond their professional responsibilities.^{33,34} Physicians should always take the
R12 responsibility in administering the drugs for euthanasia, and they should not leave
R13 these actions to nurses. In order to improve the collaboration between physicians and
R14 nurses, and to prevent procedural, ethical and legal misunderstandings, guidelines
R15 can play an important role.³³ Above that, institutional practice guidelines can describe
R16 responsibilities of health care professionals and prevent illegal practices.³⁵ Guidelines
R17 should therefore also include information which accurately states the boundaries.²⁸
R18 Compared to the 1994 results, more attention was paid to mentioning the nurse as
R19 a possible participant in the EAS decision-making process (30% in 1994 versus 90%
R20 in 2005).
R21

R22 It is a positive development that the guidelines that were developed or revised after
R23 the enactment of the law more frequently adhered to the law. For instance, there
R24 was a substantial decrease in the percentage of guidelines that categorically excluded
R25 specific patient groups (approximately 6 out of 10 before 2002 and 3 out of 10 after
R26 2002). This could either be because the law clarified the regulations, or because the
R27 regulations became more readily accepted by the developers of the guidelines. In
R28 line with our findings, in Belgium it was found that the due care criteria as stated
R29 in their Euthanasia law had a positive impact on attention paid to these criteria in
R30 guidelines.^{36,37}

R31 However, it is not clear whether it is a deliberate choice of institutions to have EAS
R32 guidelines that are stricter than law or whether they are not aware of the boundaries
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of the law. If the latter is the case, improved knowledge of the law should lead to adjustment of the guidelines.

If it is a deliberate decision, it is important that patients are aware of this policy, so that they can take this into account in their choice of a health care institution. To keep guidelines up-to-date it is recommended that they are reviewed regularly, for instance no later than three years after their 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.³⁸

In conclusion

The results of our study show that information that was described in the practice EAS guidelines was not always comprehensive, for instance with regard to advance euthanasia directives, the way in which the due care criteria should be applied, and the role of the nurse. Moreover, it was found that guidelines were sometimes stricter than the law.

Content of institutional hospital guidelines on for DNR

Main results

In Chapter 5 the content of institutional hospital practice guidelines for DNR is described.

Most hospitals described in their DNR guidelines a default position for patients who have a cardiac arrest (i.e. resuscitate, unless). More than half of the hospital guidelines (56%) provided information on when to initiate a discussion about a DNR decision; 32% of the guidelines stated that this should take place on admission, 20% at the onset of clinical deterioration, and 20% for patients with high risk of cardiac arrest. In almost all hospital guidelines in 2005 it was stated that the individual DNR decision should be recorded in the medical and/or nursing file. Approximately three quarters of the hospital guidelines described the need for evaluation of an individual DNR decision. In general, compared to 1994, the guidelines in 2005 paid more attention to the fact that DNR discussions should start on admission to the institution and that individual DNR decisions should be evaluated.

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R1 Default position

R2 Although most hospitals have a default position for use of DNR decisions, one in five
R3 hospitals still have no default position. It can be debated whether this is necessary
R4 in hospitals, since the default position of all hospitals (resuscitate, unless...) is in
R5 line with 'normal practice', i.e. that patients will be resuscitated, unless otherwise
R6 is decided. On the other hand, it could be used as a starting point for a discussion
R7 about whether (or not) to resuscitate individual patients.
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R9 Discussing individual DNR decisions

R10 Another important aspect is the moment at which discussions about individual DNR
R11 decisions should be started. One third of the hospital guidelines stated that this
R12 should start on admission. One in five hospital guidelines stated that a discussion
R13 should start at the onset of clinical deterioration, and one in five stated that it should
R14 start in patients with a higher risk of cardiac arrest. However in practice, how much
R15 clinical deterioration and what kind of deterioration is required? Above that, at the
R16 onset of clinical decline, it is hard to determine the exact moment when to start, and
R17 there is also a chance that physicians forget to do so at that moment. The percentage
R18 of hospitals recommending discussions on admission increased from 14% in 1994 to
R19 32% in 2005, but remains low.

R20 For individual patients it is questionable whether an individual DNR decision
R21 should always be actively discussed. Not all patients are in a life-threatening
R22 condition, and not all patients want to be confronted with this issue. For seriously
R23 ill patients admitted to a hospital this may be different. A study of patient-physician
R24 communication about resuscitation showed that these patients wish to be involved
R25 in this important end-of-life decision, but communication about resuscitation
R26 preferences occurred infrequently after hospital admission.³⁹ The initiation of this
R27 discussion certainly requires a careful approach, and it should be explained to
R28 patients why it is important, even for those for whom resuscitation does not seem
R29 to be relevant. A literature review of DNR orders in America showed that there is
R30 substantial variability and inconsistency as to which patients are asked about their
R31 wishes involving resuscitation.⁴⁰
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Autonomy

It is important that patients are fully informed about the consequences of whether or not they are resuscitated. Any discussion about the appropriate use of DNR discussions should clear the wishes of the patient and also the risks and benefits for the patient.⁴¹ Only then patients can make a decision about their own situation, and can decide whether or not they wish to be resuscitated. It is also important to know whether patients have an advance directive stating that they do not want to be resuscitated, because if a patient does not want to be resuscitated, this wish has to be respected by the physician.^{42,43} The majority of hospital guidelines state that a discussion with the patient is mandatory or desirable, and the results of other research have indicated that the majority of patients do wish to be involved in end-of-life decisions such as resuscitation, and would also wish their relatives to be involved in case of incompetency.^{44,45} However, the physician has the final responsibility concerning individual DNR decisions if a patient wants to be resuscitated (the physician can also decide that resuscitation would be futile).

Evaluating individual DNR decisions

Approximately three quarters of the hospital guidelines describe the need for evaluation of an individual DNR decision. The attention that is paid to the evaluation of an individual DNR decision in hospital guidelines in the Netherlands has increased since 1994 (from 61% to 76%). However, these percentages are lower than those found in other studies carried out in Australian and Canadian hospitals.^{46,47} The clinical condition of a patient can change over time, and this may have consequences for the futility of the resuscitation and the patient's preference with regard to this specific decision.⁴⁶ Therefore it is important to pay attention to the evaluation of the individual DNR order. It is recommended that DNR orders are evaluated with a fixed frequency in order to ensure that the patient's rights and wishes are respected. The evaluation of DNR orders is only recommended in 41% of the DNR guidelines.

In conclusion

The results of our study show that, although several aspects of hospital DNR guidelines have improved since 1994, there is still room for improvement with respect

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R1 to describing the specific relevant aspects of the DNR decision-making process. It is
R2 recommended that hospitals pay more attention to the content of their institutional
R3 DNR guidelines, in particular with respect to initiating the discussion on whether or
R4 not to resuscitate in case of a cardiac arrest, and the recording and evaluation of the
R5 DNR decisions.
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R7 8.3.2 *Physicians and medical students*

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R9 Awareness and use of institutional practice guidelines for medical end-of-life
R10 decisions by medical specialists
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R12 Main results

R13 Chapter 6 describes the awareness and use of institutional practice guidelines for
R14 EAS, DNR and PS, by medical specialists. Most of the physicians were aware of the
R15 existence of the practice guidelines for EAS (75%) and DNR decisions (63%), and 35%
R16 were aware of the existence of the PS guidelines in their institution. Of the physicians
R17 who had read the guidelines and had been in a situation in which they had to consider
R18 a request for euthanasia, 88% had used the guidelines for euthanasia; corresponding
R19 percentages are 92% for DNR decisions and 100% for PS guidelines. When used,
R20 almost all physicians felt that the guidelines had been supportive. Especially
R21 physicians with a more positive attitude towards guidelines, and involvement in the
R22 development of guidelines were more aware of the presence of the guidelines. The
R23 most frequently mentioned reason for feeling supported by all three institutional
R24 practice guidelines was ‘the clear procedure’ described in the guidelines.

R25 Our results show a difference in awareness of the existence of practice EAS, DNR
R26 and PS guidelines. More physicians were aware of the practice EAS guidelines (75%),
R27 than the practice DNR guidelines (63%), and even less were aware of PS practice
R28 guidelines (35%). These differences in awareness might be due to the fact that EAS
R29 decisions differ from DNR and PS decisions, since the due care criteria for EAS are
R30 enacted in the Euthanasia law in 2002. However, 25% of the physicians were still not
R31 aware of the existence of the practice EAS guidelines in their institution. As already
R32 mentioned in Section 8.3.1., this study was carried out before the national practice
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PS guideline was introduced in the Netherlands, so this might have influenced the implementation of these guidelines in the hospitals. The results of a Dutch study showed that after the introduction of the national guideline for PS, physicians reported changes in palliative sedation practice. These changes were in line with recommendations in the guideline. It was reported that benzodiazepines were used more frequently for sedation, and the involvement of the patient in the decision-making process had improved.⁴⁸

It can be seen as a positive development that the majority of physicians who had read the practice guidelines, and had been in a situation in which the guidelines were applicable, had also actually used these guidelines. This indicates that the physicians are not only aware of the existence of the guidelines, but also actually using them in medical practice. A possible explanation for the high use of guidelines could be that physicians feel the need for the support they provide. In particular when they are confronted with these complex decisions with which most physicians have very little experience. The results of our study support this hypothesis. The physicians who had used the practice guidelines felt supported by them, and the most frequently mentioned reason was the 'clear procedure'. This is important because one of the main goals of practice guidelines is that they are supportive. A study on the impact and meaning of euthanasia guidelines in clinical practice in Flemish hospitals also showed that physicians and nurses felt positively supported by the euthanasia policy in the euthanasia care process on practical and professional level.⁴⁹

The results of this study confirm the assumption that it is desirable to involve physicians in the development of guidelines.¹ Physicians who had been involved in the development of practice EAS and DNR guidelines were more often aware of these guidelines. Therefore, one way to improve the acceptance by physicians of institutional practice guidelines for medical end-of-life decisions might be to involve them in the development of these guidelines. The results presented in Chapter 3 showed that in the majority of health care institutions (79%) this is already the case. Of course, it is not possible to involve all physicians working in the institution in the development of the guidelines. The participation of representatives of the physicians would therefore be advisable. Another way to improve acceptance could be by

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inviting physicians in the institution to comment on the guidelines. It gives them the opportunity to critically review the institutional practice guidelines, and also to focus on the content of the guidelines. In the past decades several studies were published about the implementation of clinical practice guideline.^{24,50,51,52} Cabana et al. conducted a systematic review and identified a diversity of barriers to physicians guideline adherence (e.g. lack of awareness, lack of familiarity, lack of agreement and external barriers). Nevertheless, not all barriers apply to all settings.⁵¹ Therefore, it is important, to make an analysis of the target group and target setting before starting the implementation process.²⁴ A study on implementing a resuscitation policy for patients at the end of life in acute hospital setting showed that there was a need for ongoing staff support and training in applying the resuscitation policy to decisions for patients with end stage illness in acute hospital.⁵³

A possible reason for physicians not using practice guidelines on medical end-of-life decisions might be that these physicians fear curtailment of their professional autonomy. Following a guideline might be perceived as a prescribed receipt without taking into consideration the specific situation of a patient.⁵⁴ Of course, it is important to realize that feeling supported by guidelines is not the same as following guidelines implicitly without taking into consideration the specific situation of the patient.

In conclusion

There is room for improvement in the awareness of practice guidelines among physicians, and especially the practice guideline for PS. Paying more attention to practice guidelines for medical end-of-life decisions in the medical curriculum, and in particular the content of the guidelines, could stimulate physicians' awareness and use of these guidelines in the future.

Opinions and knowledge of medical students with regard to education on end-of-life care in the medical curriculum

Main results

The results presented in chapter 7 of this thesis show that almost all medical students were of the opinion that education on palliative care (98%) and the euthanasia act

(96%) was important. Approximately half of the students (55%) rated the quantity of end-of-life care education in the curriculum as moderate, and 35% rated it as good, 50% of the students rated the content of end-of-life care education as moderate, and 47% rated it as good. The students were of the opinion that in the curriculum insufficient attention was paid to the subjects of “how to deal with advance directives” (60%) and “communication skills with regard to terminal patients” (58%).

Their knowledge about various aspects of the euthanasia act and the definition of euthanasia also appeared to be insufficient. One third of the students (35%) named 2 of the 4 aspects of the definition of euthanasia correctly, 46% named only 1 of the 4 aspects correctly, 18% named no aspects correctly, and none of the students named all 4 aspects correctly. Students who took the elective course on “Terminal and Palliative Care”, students who had personal experience with a patient requesting EAS, and students with more knowledge of the euthanasia act were more positive about the quantity of end-of-life care education. Students who completed fewer clerkships, and totally agreed with the statement, “Everyone has the right to decide about their own life and death”, were also more positive about the content of end-of-life care education.

Opinions about education on end-of-life care in the curriculum

It can be seen as a positive result that almost all medical students had a positive attitude toward education on palliative care and the euthanasia act. However, not all students were satisfied with the quantity and content of the education on end-of-life care in the curriculum. In particular they were of the opinion that insufficient attention was paid to communication skills with regard to terminal patients and how to deal with advanced directives. Similar findings have been reported elsewhere.⁵⁵

Aspects of the euthanasia act and knowledge about the euthanasia definition that need extra attention

In this study the students knowledge about the euthanasia act was studied, and their knowledge about certain aspects was certainly not optimal. For example, 7 out of 10 students did not know that a written advance euthanasia directive may be granted for an incompetent patient, provided that the other due care criteria are met. One

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R1 reason for this might be that students do not agree with this statement, and their
R2 knowledge is inadvertently mixed with their opinions about euthanasia. Another
R3 reason could be a lack of knowledge about certain aspects of the euthanasia act.
R4 The results of a Dutch study among physicians also showed that not all physicians
R5 in medical practice were aware of how to deal with advance directives, and 6 out
R6 of 10 physicians did not know that a written request for euthanasia can be granted
R7 for an incompetent patient.²⁸ The student's knowledge about the definition of
R8 euthanasia also appeared to be sub-optimal. It may be the case that the students did
R9 not mention certain aspects of the euthanasia definition because they thought they
R10 were too obvious to mention. However, they did frequently mention the due care
R11 criteria 'hopeless and unbearable suffering'. One could argue that it is important for
R12 medical students to know about all aspects of the euthanasia act and the definition
R13 of euthanasia, because this becomes extremely relevant in medical practice.
R14 Education on end-of-life care, paying specific attention to this issue can be a first step
R15 in the preparation of students for medical practice. It is important to address these
R16 issues early in the medical training and not only for those students who choose a
R17 specialty in which they will frequently be confronted with decisions concerning EAS.
R18 A mandatory course on the end-of-life care for all students in the medical curriculum
R19 would therefore be preferable.⁵⁶

R20
R21 In conclusion

R22 There is still room for improvement in education on end-of-life care in the medical
R23 curriculum. In particular, more attention should be paid to communication skills
R24 with regard to terminal patients and how to deal with advanced directives. More
R25 attention should also be paid to the content of the euthanasia act and the definition
R26 of euthanasia definition in order to improve medical students' knowledge about
R27 these concepts.
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Implications for policymakers

Compared to 1994, there is a modest but significant increase in the percentage of institutions with EAS policy statements and practice guidelines for medical end-of-life decisions. However, many institutions still do not have practice guidelines for medical end-of-life decisions. It is remarkable that 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 for medical end-of-life decisions to physicians and nurses. The content analysis of the hospital and nursing homes EAS guidelines indicates that approximately one third of the guidelines are stricter than law, especially with regard to the exclusion of specific patient groups (e.g. dementia patient and incompetent patients). However, guidelines that were developed or revised after the enactment of the law more frequently adhered to the law. Moreover, the information contained in the guidelines with regard to advance euthanasia directives, the way in which the due care criteria should be applied, and the position of the nurse, also needs to be improved. The content analysis of the hospital DNR guidelines showed that several aspects have improved since 1994. However, there is still room for more improvement with respect to describing the specific relevant aspects of the DNR decision-making process, such as when to initiate discussions about whether or not to resuscitate in case of a cardiac arrest, and the recording and evaluation of the decision.

More attention can and should be paid to education on end-of-life care in the medical curriculum, to ensure that students are well prepared to provide adequate end-of-life care. The results of our study have led to a number of recommendations, which can be divided into the following topics: recommendations with regard to the development and content of practice medical end-of-life guidelines, recommendations concerning the dissemination of the practice guidelines, and recommendations concerning medical education on end-of-life care. The recommendations are made, assuming that formulating, disseminating and implementing good quality guidelines is desirable. This assumption is based on the logic that providing information can help professionals in careful decision-making, certainly in the light of the interest in

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R1 guidelines that physicians have expressed in this study. However, from the results of
R2 this study we do not know whether health care institutions with practice guidelines
R3 for medical end-of-life decisions deliver better quality of care than institutions
R4 without these practice guidelines.
R5

R6 Development and content

R7 -Although we have no data on the effects of guidelines, we recommend that all health
R8 care institutions formulate a policy statement and guidelines for EAS and for other
R9 medical end-of-life decisions. Our results showed that physicians who had used the
R10 practice guideline on EAS, DNR and PS felt supported by it.
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R12 -It is recommended that when health care institutions start to develop institutional
R13 practice guidelines for medical end-of-life decisions, they make use of the existing
R14 national guidelines. They could adapt or amend these guidelines to suit their
R15 own institution. National guidelines have been developed by experts, have been
R16 extensively discussed, and can be considered as a good reference framework.
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R18 -Health care institutions should have high quality up-to date guidelines that
R19 accurately state the boundaries of the law. If they have a policy that is stricter than
R20 law, health care institutions should at least explicitly make this stricter policy known
R21 to the professionals working with the guidelines, and also to members of the patient
R22 council. To keep guidelines up-to-date it is recommended that they are reviewed
R23 regularly, and as a general rule they should be reviewed no later than three years
R24 after they were formulated. This 3-year limit should be extended or reduced if there
R25 is any evidence that focus on a specific guideline is evolving quickly or slowly.³⁸
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R27 -It is recommended that physicians are involved in the development of institutional
R28 practice guidelines. Involving the professionals who have to work with the guidelines
R29 in practice in the development of the guidelines is one way in which to enhance use
R30 of the guidelines in practice.
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R32 -More attention should be paid to the role of the nurses in practice EAS and DNR
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guidelines, because they are often important participants in these decision-making processes.

-EAS practice guidelines should always describe the official due care criteria and aspects that are relevant for assessing these criteria. Only EAS guidelines that provide adequate information and sufficient practical details about the specific process can support physicians and nurses in the decision-making process.

-DNR practice guidelines should always describe the basic DNR assumptions and the responsibilities of all caregivers involved in order to avoid misunderstandings.

Dissemination

-Health care institutions should systematically disseminate practice guidelines to all relevant persons. Guidelines can only make a contribution to improve the quality of care if they are actually used in practice. A first step in achieving this is to make potential users (e.g. physicians and nurses) aware of their existence. This subject could be included in an employment procedure, but should also be included in training/education.

-It is recommended that a written EAS policy statement is available in a hospital or nursing home for all patients who wish to know about it. If patients are aware of whether or not EAS is allowed in a specific institution, it gives them the opportunity to choose an institution in which the policy statement corresponds with their own point of view. This could be made clear in an information leaflet containing the hospital or nursing home policy statement. Of course it is important to pay explicit attention to the way in which, and the moment at which patients are informed about the EAS policy statement.

Medical education on end-of-life care

-It is recommended that more attention is paid to education on end-of-life care in the medical curriculum, in order to prepare medical students to provide adequate end-of-life care. A mandatory course on care of end-of-life for all students with more

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R1 attention for the subjects ‘how to deal with advance directives’ and communication
R2 skills with regard to terminal patients’ in the medical curriculum would be preferable.
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R4 **Recommendations for future research**

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R7 The objective of this thesis was to gain more insight into institutional policies and
R8 guidelines on medical end-of-life decisions at two levels: the institutional level and
R9 at the level of physicians and medical students. On the basis of the information has
R10 been gathered, some recommendations for future research can be made.
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R12 -With regard to the quality of care that is provided, more insight is needed to
R13 determine to what extent practice guidelines for medical end-of-life decisions
R14 influence the quality of end-of-life care. Does the use of practice guidelines improve
R15 the quality of the care?
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R17 -To gain more insight into the compliance of physicians with practice guidelines,
R18 prospective research focusing on all guidelines for medical end-of-life decisions
R19 would be preferable. It is also important to know whether physicians can work with
R20 the guidelines. Do the guidelines meet the standards of medical practice? Focus
R21 group interviews, or in-depth interviews with physicians could be helpful to gain
R22 more insight into these aspects.
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R24 -The perspective of the nurse has not been taken into account in this thesis. Although
R25 nurses do not have the final responsibility for medical end-of-life decision-making (it
R26 is the responsibility of the physician), they are often confronted with medical end-of-
R27 life decisions in medical practice.

R28 Therefore, it would be important to evaluate the experiences, wishes and opinions
R29 of nurses with regard to the content of practice guidelines for medical end-of-life
R30 decisions.
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-In this thesis we analyzed the content of EAS and DNR guidelines in more detail (Chapter 4 and 5). The content of the other medical end-of-life decisions should also be evaluated in more detail to gain more insight into the quality of these guidelines.

-The perception of patients with regard to the content of the EAS policies and the wishes they have with regard to being informed about the EAS institutional policies were not evaluated in this thesis. We do not know whether patients have the need to be informed about an institutions EAS policy, or in which form they would prefer to receive this information (systematically or non-systematically). Focus group interviews or in-depth interviews with patients could be helpful to gain more insight into these aspects.

-Finally, it is recommended that an evaluation study of institutional policies and guidelines for medical end-of-life decisions takes place in all health care institutions every five years. This would make it possible to monitor the availability, dissemination, adherence to and content of the guidelines.

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