

Chapter 4

Do guidelines on euthanasia and physician assisted suicide in Dutch hospitals and nursing homes reflect the law? a content analysis

Submitted as:

Hesselink BAM, Onwuteaka-Philipsen BD, Janssen AJGM, Buiting HM, Kollau M, Rietjens JAC, Pasmaan HRW. Do guidelines on euthanasia and physician assisted suicide in Dutch hospitals and nursing homes reflect the law? a content analysis.

Abstract

To describe the content of practice guidelines on euthanasia and assisted suicide (EAS) and to compare differences between settings and guidelines developed before or after enactment of the Euthanasia law in 2002 by means of a content analysis. Most guidelines stated that the attending physician is responsible for the decision to grant or refuse an EAS request. Due care criteria were described in the majority of guidelines, but aspects relevant for assessing these criteria were not always described. Half of the guidelines described the role of the nurse in the performance of euthanasia. Compared to hospital guidelines, nursing home guidelines were more often stricter than the law in excluding patients with dementia (30% vs. 4%) and incompetent patients (25% vs. 4%). As from 2002, the guidelines were less strict in categorically excluding patients groups (32% vs. 64%), and in particular incompetent patients (10% vs. 29%).

Health care institutions should accurately state the boundaries of the law, also when they prefer to set stricter boundaries for their own institution. Only then guidelines can provide adequate support for physicians and nurses in the difficult EAS decision-making process.

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Introduction

In 2002, the Dutch Euthanasia law was enacted.¹ This law states that euthanasia and physician-assisted suicide (EAS) is not punishable if the attending physician acts in accordance with due care criteria stated in the law. Of all deaths in the Netherlands in 2005, 1.7% were the result of euthanasia and 0.1% were the result of physician-assisted suicide.² To promote careful decision-making and performance of EAS, institutional practice guidelines can be useful. EAS requires careful decision-making, since it is a difficult process that includes clinical, legal, ethical and personal emotional aspects.³ Physicians do not always have very much experience in this respect, practice guidelines can support them in this complex decision-making process. Above that, institutional practice guidelines can describe responsibilities of health care professionals and prevent illegal practices.⁴ Guidelines should therefore also include information which accurately states the boundaries of the law.⁵ The results of a Dutch study among clinical physicians and nursing home physicians who indicated that there were no practice guidelines on EAS in their institution, showed that half of them felt a need for such guidelines.⁶

The usefulness of practice guidelines depends, among other things, on their content. For guidelines on EAS it is relevant that the specific phases of the euthanasia decision-making process, the participants in the decision-making process, and that at least the six due care criteria as laid down in the Dutch law are described. In 1994, the content of euthanasia guidelines was investigated at institutional level in Dutch nursing homes, before the enactment of the Euthanasia law. The results showed that only 65% of the guidelines described all due care criteria.⁷ Euthanasia has also been legalized in Belgium in 2002.⁸ The content of the euthanasia guidelines in nursing homes and hospitals was studied in Belgium in 2005 and 2006, respectively. These guidelines described several phases of the euthanasia care process, including the involvement of caregivers, patients and relatives; and also addressed ethical issues.^{9,10} In 2005, the existence of practice guidelines on EAS at institutional level was investigated in Dutch hospitals, nursing homes, psychiatric hospitals, hospices, and institutions for the mentally disabled. The results showed that 62% of the institutions had practice guidelines for EAS. In this paper we focus on the content of

R1 EAS guidelines of Dutch hospitals and nursing homes, since EAS guidelines do most
R2 exist in these institutions (hospitals 89% and nursing homes 79%).¹¹ Furthermore, we
R3 know that about half of all Dutch hospital physicians and 74% of all Dutch nursing
R4 home physicians have received explicit requests for EAS.⁵ In addition, hospitals and
R5 nursing homes do differ in their patient population. There is a high percentage of
R6 incompetent patients in nursing homes, and hospitals more often have younger
R7 patient with incurable diseases. It would be interesting to see if guidelines differ in
R8 their attention for specific patient groups.

R9 As mentioned above, in 2002 the Euthanasia law was enacted in the Netherlands.
R10 Besides differences between hospitals and nursing homes, we also focus in this
R11 paper on differences between guidelines that were written/revised before the
R12 enactment of the law (until 2001) and guidelines that were written/revised after the
R13 enactment of the law (as from 2002), to see if and in what way the law affects the
R14 content of institutional EAS guidelines and in what way is the law implemented in
R15 these guidelines?

R16 Therefore the aims of this study were: (1) to analyse the content of practice guidelines
R17 for EAS in hospitals and nursing homes, and (2) to compare differences between
R18 these settings and guidelines developed before or after enactment of the Euthanasia
R19 law.

R22 **Methods**

R24 *Study population and Design*

R25 The present study was part of the Evaluation study of the Euthanasia Act.² Data were
R26 collected from October 2005 through March 2006. Questionnaires were sent to all
R27 Dutch hospitals and nursing homes. The management of these institutions (119
R28 hospitals and 218 nursing homes) were asked whether they had a guideline on EAS,
R29 and if so to provide a copy of this guideline. Of these institutions, 56 (19 hospitals
R30 and 37 nursing homes) had to be excluded because they did not meet the inclusion
R31 criteria (7 × 24-hours in-patient nursing care), or they had merged with another
R32 institution. Of the 281 remaining institutions, 192 returned the questionnaire (68%).
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A total of 154 of these institutions indicated that they had an EAS guideline, 150 of them provided a copy of the guideline. Of the 150 received guidelines, 99 guidelines (46 hospitals-and 53 nursing home guidelines) were analyzed. We made a distinction between guidelines that were written/ revised before the Dutch Euthanasia law was enacted (before 2002) and still in use without changes at the time and guidelines that were written/ revised after this law was enacted (after 2002). The other 51 guidelines were excluded, because they did not meet the definition of an EAS guideline used in this study: a written protocol to guide caregivers in approaching a problem that includes a decision-making process and/or a phased care plan and at least describe the due care criteria to some extent. Of the institutions in this study (ie. Hospitals and nursing homes with a EAS guideline), 91% of the hospitals and 34% of the nursing homes had an ethics committee, 41% of the hospitals and 34% of the nursing homes had a religious affiliation. Whether or not an institution had a religious affiliation did not seem to be related to the existence of practice guidelines on EAS.¹¹

Checklist

The guidelines were analysed using a checklist of items, based on the study carried out in 1994⁷, the Dutch Euthanasia law¹ and literature.¹²⁻¹⁴ We piloted this initial checklist in 5 guidelines to see if the checklist was complete and no important issues forgotten, and at the same time to see if the different reviewers interpreted the items of the checklists in the same way. The final checklist included the following main topics: A) general characteristics of practice guidelines: format document, formulation and categorically excluding specific patient groups, i.e. dementia patients, coma patients, incompetent patients. (categorically excluding patient groups is more strict than the law); B) request: involved parties and their roles, objections of conscience and advance euthanasia directives; C) decision making: due care criteria, involved parties and their roles, refusal of euthanasia requests; D) performance: involved parties and their roles; report and aftercare. The following six Dutch due care criteria for EAS are laid down in the law: 1) the patient's request should be voluntary and well considered, 2) the patient's suffering should be unbearable and without prospect of improvement, 3) patient should be informed about their situation and prospects, 4) there are no reasonable alternatives, 5) another independent physician should be

R1 consulted and 6) the termination of life should be performed with due medical care
R2 and attention.¹

R3 We assigned the aspects of handling a patient's request for EAS, advance directives,
R4 conscientious objections, decision-making, due care criteria, categorical exclusion of
R5 specific patient groups and the role of the physician and nurse in the performance
R6 of EAS, to one of 3 main categories: (A) required by law, (B) more strict than law, and
R7 (C) not stated in the law. In this case the term 'law' encompasses a broad definition,
R8 namely the Euthanasia law itself, the intention of the legislator as stipulated down
R9 in documents of the House of Representatives and the Senate, the judgments
R10 of Regional Euthanasia Review Committees (Annual Reports) and professional
R11 guidelines formulated by (national) professional organisations.

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R13 *Analysis*

R14 All guidelines were analysed by couples of two reviewers (BAMH, BDOP, HMB, MK,
R15 JACR, HRWP), according to the checklist. Differences of opinion were resolved in
R16 consensus meetings. If no consensus could be reached, a third reviewer made the
R17 final decision. The percentages of agreement between the pairs of two reviewers
R18 ranged between 74% and 100% (90% on average) per aspect.

R19 Data were analysed with descriptive statistics. The statistical significance of
R20 differences between hospitals and nursing homes and guidelines until 2001 and
R21 guidelines as from 2002 were calculated using Chi-Square tests. Fisher's exact test
R22 was used if cells had an expected frequency of less than five.

Results

Receiving a patient's request for EAS

Table 1 shows that the majority of the practice guidelines (94%) contained a description of how to react to requests for EAS. In 28% of the guidelines it was stated that the physician only informs the nurse/nursing aid after a request for EAS, when the patient has given informed consent. Four percent of the practice guidelines stated that the family should always be informed after a patient has made a request for EAS, and 39% stated that this should happen only after the patient had given informed consent. Almost half of the guidelines (48%) stated that in the case of incompetent patients, advance euthanasia directives can be considered as a euthanasia request. Whether or not an institution had a religious affiliation was not related to more reluctance to perform euthanasia on the basis of an advance directive (not in table). In the majority of guidelines (95%) the subject of conscientious objections was discussed.

There were several differences between hospital guidelines and nursing home guidelines. Nursing home guidelines more frequently described in detail the role of the nurse after receiving a request for EAS. Hospitals guidelines provided more details with regard to advance euthanasia directives.

There were some significant differences between guidelines developed or revised before and after the euthanasia law. As from 2002 it was more frequently stated that an advance euthanasia directive is to be seen as a request for euthanasia if it applies to the patient's present situation (23% vs. 0%). Furthermore, to adhere to the request, all other due care criteria must be met (37% vs. 7%).

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Table 1: Handling a patient's request for EAS and procedures for advance directives and conscientious objections described in hospital and nursing homes guidelines until 2001 and as from 2002

	Total	Hospitals	Nursing homes	P-value ^d	Until 2001	As from 2002	P-value ^e
	N=99 %	N=46 %	N=53 %		N=28 %	N=71 %	
How to react to a request is discussed	94	93	94	0.591	96	93	0.453
Role of physician:							
The physician always informs the nurse after a request ^b	14	20	9	0.149	14	14	0.603
The physician only informs nurses/nursing aid after a request, when the patient has given informed consent ^a	28	24	32	0.368	36	25	0.303
Role of nurse:							
The nurse must encourage the patient to contact the physician after receiving a request ^a	14	7	21	0.043	14	14	0.603
The nurse must always inform a physician after receiving a request ^b	25	35	17	0.042	14	30	0.115
The nurse must consult a physician after receiving a request, when a patient has given informed consent ^a	45	35	55	0.047	50	44	0.568
Role of family:							
Family must always be informed after a request ^b	4	2	6	0.364	4	4	0.683
Family is only informed when a patient has given informed consent ^a	39	37	42	0.644	46	37	0.368
Family is involved in discussion of the request ^b	19	20	19	0.930	21	18	0.723
Role of others:							
Request is discussed in the treatment team ^c	20	11	28	0.031	25	18	0.455
Special team is informed ^c	18	9	26	0.023	14	20	0.528
Patient is referred to another institution ^a	1	2	0	0.465	0	1	0.717

Advance euthanasia directives can be considered as a euthanasia request in an incompetent patient	48	63	36	0.007	36	54	0.110
Details:							
Formulated when patient was competent ^a	33	43	25	0.046	25	37	0.269
Advance directive is applicable to present situation ^a	16	26	8	0.012	0	23	0.003
All other due care criteria are fulfilled ^a	28	39	19	0.026	7	37	0.003
Conscientious objections are discussed							
Details:							
Physician can refuse to be involved in decision-making or performance of euthanasia ^a	88	91	85	0.331	89	87	0.544
Physician must give patient the opportunity to contact a physician with no conscience objection ^a	78	85	72	0.118	75	79	0.676
Physician must clarify conscientious objections in an early stage ^a	27	26	28	0.805	39	23	0.092
Nurse can refuse to participate in decision-making concerning euthanasia ^a	53	46	49	0.735	36	52	0.141
Nurse can refuse to participate in further care for the patient ^b	16	15	17	0.812	21	14	0.371

a required by law

b more strict than the law

c not stated in the law

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Table 2: Aspects of decision-making requests for EAS described in the hospital and nursing home guidelines until 2001 and as from 2002

	Total	Hospitals N=46 %	Nursing homes N=53 %	P-value ^d	Until 2001 N=28 %	As from 2002 N=71 %	P-value ^d
Stated that the attending physician is responsible for decision^a	81	80	81	0.930	89	77	0.179
People, other than the attending physician, are mentioned as possible participants in decision-making:							
nurse/nursing aid ^a	86	89	83	0.384	86	86	0.603
general practitioner ^a	49	65	36	0.004	46	51	0.702
spiritual caregiver ^c	54	50	57	0.511	57	52	0.651
family ^a	56	43	66	0.024	57	55	0.842
psychiatrist/psychologist ^a	35	33	38	0.595	32	37	0.675
management ^c	38	28	47	0.054	39	38	0.908
The role of the management is described	88	87	89	0.793	96	85	0.091
Details:							
Must be informed about the planned administration of euthanasia ^c	67	50	81	0.001	89	58	0.003
Must be informed after the administration of euthanasia ^c	29	37	23	0.119	25	31	0.556
Must be involved in any conflict ^c	22	24	21	0.706	25	21	0.676
Must supervise the procedure ^c	14	15	13	0.775	21	11	0.161
Must give permission for the performance of euthanasia ^c	4	9	0	0.043	0	6	0.258
Must act in case of publicity ^c	9	0	17	0.003	14	7	0.223

Aspects of how to handle in case of refusal of a euthanasia request are mentioned	60	52	66	0.161	61	59	0.887
Details:							
Reasons why request can be refused ^c	16	17	15	0.757	18	15	0.494
How to inform the patient about the refusal ^c	20	17	23	0.516	14	23	0.357
Offering the patient alternative treatment ^c	10	7	13	0.223	11	10	0.578
Informing the patient about the opportunity of referral to another physician ^a	27	22	32	0.249	32	25	0.494

a required by law

b more strict than the law

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The decision-making process

Table 2 shows that the majority of the guidelines (81%) stated that the attending physician is responsible for the decision-making regarding EAS. The most frequently mentioned group of people, other than the attending physician, as possible participants in the EAS decision-making process were the nurse/nursing aid (86%), followed by the family (56%). In 88% of the guidelines, the role of the management was described, it was most frequently stated that ‘the management must be informed about the planned administration of euthanasia’ (67%). In 60% of the guidelines there was a description of how to handle in case of refusal of a request for euthanasia, mainly stating that the patient should be informed about the opportunity of referral to another physician.

There were several differences between hospital guidelines and nursing home guidelines. Nursing home guidelines more frequently described the patient’s family as possible participants (66% vs. 43%), and less frequently described the general practitioner as a possible participant in the decision-making process (36% vs. 65%). Only the hospital guidelines (9%) stated that the management must give permission for the actual performance of euthanasia.

There was one difference between guidelines developed or revised before and after the Euthanasia law. As from 2002 it was less frequently stated that the management of the institution must be informed before the administration of euthanasia is planned (58% vs. 89%).

Mentioned due care criteria

Table 3 shows that all five due care criteria (the 6th due care criterion, i.e. the termination of life should be performed with due medical care and attention, is described in Table 5) were mentioned in most of the practice guidelines. The most frequently described due care criterion was consultation (99%), followed by voluntary and well-considered request (98%), hopeless and unbearable suffering (95%), informing the patient (84%), and no reasonable alternatives available (82%). With regard to “voluntary and well-considered request”, 79% of the guidelines stated that a written advance directive is always necessary (stricter than the law). With regard to “hopeless and unbearable suffering”, 19% of the guidelines included the aspect ‘life-expectancy’ (which is not mentioned in the law).

There were several differences between hospital guidelines and nursing home guidelines. Hospital guidelines more frequently described the due care criteria “no reasonable alternatives available” (93% vs. 72%), and more frequently provided details with regard to the due care criterion “consultation”, such as the consultant should not be a co-attending physician of the patient (85% vs. 55%), or a trainee (43% vs. 13%).

There were differences between guidelines developed or revised before and after the Euthanasia law. As from 2002, the due care criteria that were more frequently described were: “no reasonable alternatives available” (89% vs. 64%) and aspects of the due care criterion “consultation”, such as discuss the request with the patient (73% vs. 50%), a written report should be made (85% vs. 64%) and the possibility of SCEN (Support and Consultation on Euthanasia in The Netherlands) (42% vs. 4%).

Categorically excluding patient groups

Table 4 shows that 41% of the guidelines were stricter than the Euthanasia law in categorically excluding patient groups. Whether or not an institution had a religious affiliation was not related to more objections of conscience in case of specific patient groups (not in table). There were several differences between hospital guidelines and nursing home guidelines. Nursing home guidelines were more frequently stricter than the law in excluding patients with dementia (30% vs. 4%) and incompetent patients (25% vs. 4%).

There were differences between guidelines developed or revised before and after the Euthanasia law. As from 2002, guidelines less often categorically excluded patient groups (32% vs. 64%) and in particular incompetent patients (10% vs. 29%).

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Table 3: Extent to which EAS due care criteria 1 to 5 are mentioned and practical aspects concerning the requirements are given in hospital and nursing home guidelines until 2001 and as from 2002^a

	Total	Hospitals	Nursing homes	P-value ^b	Until 2001	As from 2002	P-value ^b
		N=46 %	N=53 %		N=28 %	N=71 %	
Voluntary and well-considered request is mentioned	98	100	96	0.284	100	97	0.512
Details:							
A written advance directive is necessary ^b	79	80	77	0.709	75	80	0.563
Verify that the patient has not made the request under pressure from family or friends ^a	63	63	62	0.936	64	62	0.830
Are there circumstances that can influence competence ^a	64	59	68	0.341	61	65	0.704
How often has the request been made by the patient ^a	63	57	68	0.242	79	56	0.039
At least having one conversation must be held with the patient alone ^a	30	37	25	0.180	32	30	0.802
Hopeless and unbearable suffering is mentioned	95	98	92	0.228	93	96	0.438
Details:							
The physician must agree with the patient that the suffering is unbearable ^a	56	63	57	0.515	43	66	0.033
Verify that the patient experiences the suffering as unbearable ^a	60	52	58	0.528	61	54	0.517
Life-expectancy ^c	19	24	15	0.266	25	17	0.357
Informing the patient is mentioned	84	87	81	0.432	75	87	0.117
Details:							
Inform the patient about the disease and prognosis ^a	78	87	70	0.041	71	80	0.340
Verify that the patient has a full understanding of the information ^a	18	13	23	0.217	29	14	0.092
No reasonable alternatives available is mentioned	82	93	72	0.005	64	89	0.005
Details:							
It must be clear if there is realistic palliative care available for the patient ^a	61	67	55	0.198	61	61	0.989
Discussion with patient about treatment options ^a	54	57	51	0.579	50	55	0.658
A realistic alternative is explained ^a	19	30	9	0.008	11	23	0.179
Consultation of experts ^a	17	13	21	0.310	21	15	0.481

Consultation is mentioned	99	100	98	0.535	96	100	0.283
Details:							
Not a co-attending physician ^a	69	85	55	0.001	64	70	0.553
Discussion with patient ^a	67	85	51	0.000	50	73	0.027
A written report ^a	79	83	75	0.386	64	85	0.027
Not a member of the same group practice ^a	59	67	51	0.098	54	61	0.525
Not a trainee ^a	27	43	13	0.001	18	31	0.187
SCEN (Support and consultation on Euthanasia in The Netherlands) was named ^c	31	28	34	0.542	4	42	0.000
Physician does not know patient ^a	17	17	17	0.957	25	14	0.195

a required by law

b more strict than the law

c not stated in the law

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Table 4: Categorical exclusion of specific patient groups in EAS in hospital and nursing home guidelines, until 2001 and as from 2002

	Total	Hospitals	Nursing homes	P-value ^d	until 2001	As from 2002	P-value ^d
	%	N=46 %	N=53 %		N=28 %	N=71 %	
Categorically excluding patient groups	41	26	55	0.004	64	32	0.004
Patient groups:							
-Never in dementia patients ^b	18	4	30	0.001	25	16	0.269
-only in competent patients ^b	15	4	25	0.005	29	10	0.029
-only in case of physical suffering ^b	11	15	8	0.226	18	8	0.284
-never in coma patients ^b	4	0	8	0.121	4	4	1.000
-only in the terminal phase ^b	4	2	6	0.621	7	3	0.317
-other	4	7	2	0.335	7	3	0.317

a required by law

b more strict than the law

c not stated in the law

d χ^2 -test

Role of the physician and nurse

Table 5 shows that the majority of guidelines (91%) described the role of the physician in the performance of euthanasia and, 33% of the guidelines described the role of the physician in assisted suicide. Fifty-one percent of the guidelines contained a description of the role of the nurse in the performance of euthanasia. Little attention was paid to adherence to 'the method, substance and dosage according to the recommendations of the Royal Dutch Pharmaceutical Society (25% for euthanasia vs. 9% assisted suicide).

There were several differences between hospital guidelines and nursing homes guidelines. Hospital guidelines more frequently stated that only the physician is allowed to administer the drugs for euthanasia (83% vs. 62%) and more frequently described the physician's role in physician-assisted suicide (46% vs. 23%).

There was one difference between guidelines developed or revised before and after the Euthanasia law. As from 2002 it was less frequently stated that the physician should be present when the drugs are administered (31% vs. 57%) and also in the period between the administration of the drugs and the patient's death (31% vs. 54%).

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Table 5: Role of the physician and the nurse in the performance of EAS described in hospital and nursing home guidelines until 2001 and as from 2002

	Total	Hospitals	Nursing homes	P-value ^d	Until 2001	As from 2002	P-value ^d
		N=46 %	N=53 %		N=28 %	N=71 %	
Role physician in euthanasia mentioned	91	93	89	0.320	93	90	0.506
Details:							
Only physician can administer the drugs for euthanasia ^a	72	83	62	0.025	75	70	0.649
Order and obtain drugs from a pharmacist ^a	56	61	60	0.322	54	56	0.803
Perform entire administration personally ^a	35	30	40	0.340	39	34	0.607
Present when drugs are administered ^a	38	43	34	0.332	57	31	0.016
Present in period between administration of drugs and death ^a	37	43	32	0.242	54	31	0.036
Talk to the patient shortly before administration of drug ^a	27	22	32	0.249	21	30	0.412
Adhere to method, substance and dosage recommended in Royal Dutch Pharmaceutical Society advisory report ^a	25	20	30	0.225	21	27	0.582
Role of physician in assisted suicide mentioned	33	46	23	0.015	21	38	0.115
Details:							
Be present ^a	24	33	17	0.070	14	28	0.147
Present in period between administration of drugs and death ^a	21	28	15	0.110	14	24	0.290
Adhere to method, substance and dosage recommended in Royal Dutch Pharmaceutical Society advisory report ^a	9	4	13	0.118	4	11	0.215
On call between administration of drugs and death ^a	5	11	0	0.014	4	6	0.562
On call during the administration of drugs ^a	5	7	4	0.433	4	6	0.562

Role of nurse in EAS mentioned	51	52	49	0.757	54	49	0.702
Details:							
Can assist in multiple a ^t sa	22	26	19	0.389	21	23	0.905
Can be called in for the preparation of EAS ^a	17	22	13	0.262	21	15	0.333
Consultation at moment of performance ^c	24	22	26	0.588	25	24	0.912
Is allowed to perform EAS ^b	0	0	0	0	0	0	0

a required by law

b more strict than the law

c not stated in the law

d χ^2 -test

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Discussion

We found that most guidelines stated that the attending physician is responsible for the decision to grant or refuse a request for EAS. The due care criteria were mentioned in the majority of guidelines, but aspects relevant for assessing these criteria were not always described. Half of the guidelines described the role of the nurse in the performance of euthanasia. Compared to the hospital guidelines, the nursing home guidelines were more frequently stricter than the law in excluding patients with dementia (30% vs. 4%) and incompetent patients (25% vs. 4%). As from 2002 the guidelines were less strict than before 2002 in categorically excluding patient groups (32% vs. 64%), in particular incompetent patients (10% vs. 29%).

A strength of this study is that all Dutch hospitals and nursing homes were invited to participate, and approximately two third did so. The possible subjectivity of content analysis can be considered a limitation of the study. However, all the guidelines were assessed according to a checklist by two trained researchers, and the agreement between the assessors was high. Another limitation could be that we know now which topics and relevant aspects of these topic are mentioned in the guidelines, but not how exactly these are stated in the guidelines, and more importantly if these descriptions are helpful for users. Mentioning a topic in a guideline does not necessarily mean that it is a good guideline that supports users. However that was not the scope of this part of the study, but of another part of our study about awareness and use of practice guidelines on medical end-of-life decisions. We found that hospital physicians (of hospitals of which the guidelines are evaluated in this study) do feel supported by the EAS guideline of their institution.¹⁵ Physicians who had used the practice guideline and felt supported by it, most mentioned the 'clear procedure/decision-making' as a reason for the support.¹⁵

New, compared to the earlier study on the content of the guidelines⁷, is that we could sub-divide the information we analysed into aspects that were required by law, aspects that were stricter than the law, and aspects that were not stated in the law but can be of practical value in guidelines.

The due care criteria

The majority of the guidelines described the due care criteria, ranging from 82% for 'no reasonable alternative available' to 99% for 'consultation of another physician'. Describing the due care criteria, laid down in the Euthanasia law, can be seen as a minimum requirement for high-quality EAS guidelines, but are not of much value if not operationalized in enough detail to be useful in practice. Therefore, they should describe which aspects must be taken into consideration in assessing a due care criterium in order to be really helpful for the users. However, this is especially difficult for the two more subjective due care criteria 'hopeless and unbearable suffering' and 'voluntary and well considered request'. It is known from other research that one quarter of Dutch physicians who had received a request for EAS, had experienced problems in the decision-making, mainly with regard to these due care criteria (hopeless and unbearable suffering (79%) and whether the request was voluntary or well considered (58%)).¹⁶ With respect to the more procedural due care criteria, there is still room for improvement in many guidelines. For instance, knowing how to determine whether a possible alternative is reasonable or realistic, is important when assessing whether there are no more reasonable alternatives available. However, this was only included in 19% of the guidelines.

EAS guidelines and the Euthanasia law

There are two ways in which the EAS guidelines not always reflect the Euthanasia law. First, the guidelines are not always complete in providing information about the law. For example, only about two thirds of the hospital guidelines and one thirds of the nursing home guidelines stated that an advance euthanasia directive can be considered as a request for euthanasia. A content analysis of euthanasia policies of nursing homes in Flanders (Belgium) also showed that only 31% of the guidelines described a procedure for handling advance directives. In that study, it was found that the religious affiliation of the institution influenced describing such a procedure in the guidelines. Nursing homes with no religious affiliation more often described this procedure in their guidelines compared to Catholic nursing homes.¹⁰ In our study it was found that religious affiliation did not influenced describing such a procedure in the EAS guidelines.

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R1 However, it is also possible that it is not left out on purpose, but because of lack
R2 of knowledge. Research among Dutch physicians, medical students and euthanasia
R3 consultants revealed that the majority of physicians and medical students in the
R4 Netherlands were not aware of the fact that euthanasia on the basis of an advance
R5 directive is legal (under certain conditions).^{5,17,18}

R6 Secondly, some guidelines provide information that can be considered stricter
R7 than law. An example is that about two thirds of the guidelines state that a written
R8 advance directive is always necessary, while according to the law it is not necessary
R9 that a patient has written down the request, although it is considered desirable. An
R10 important way in which about 6 out of 10 institutions were stricter than the law, was
R11 in categorically excluding specific patient groups, such as dementia patients, stating
R12 that it was illegal to grant a euthanasia request in these groups. Although it is clear
R13 that it is probably more difficult to meet the due care criteria in these patient groups,
R14 they are not excluded by law. However, institutions have the possibility to limit the
R15 possibilities for EAS in their institution as a recent European resolution (2010) states:
R16 “No person, hospital or institution shall be coerced, held liable or discriminated
R17 against in any manner because of a refusal to perform, accommodate, assist or
R18 submit to [among other things] euthanasia, for any reason”.¹⁹

R19 However, it is not clear whether it is a deliberate choice of institutions to have EAS
R20 guidelines that are stricter than law or whether they are not aware of the boundaries
R21 of the law. If the latter is the case, improved knowledge of the law should lead to
R22 adjustment of the guidelines. If it is a deliberate decision, it is important that patients
R23 and professionals are aware of this stricter policy, so they can take this into account
R24 in their choice of a health care institution.

R25 Finally, it should be acknowledged that practice EAS guidelines should also address
R26 aspects that are not described in the law, but are necessary to ensure practical
R27 feasibility. For instance, it is very useful to address how to act if a request for
R28 euthanasia is refused, because it is known that approximately 8 out of 10 requests
R29 made in hospitals and in 9 out of 10 requests made in nursing homes do not result in
R30 euthanasia.²⁰ There was little [60%] attention for the aspect how to act if a request
R31 is refused in the guidelines. A study on content analysis of euthanasia policies of
R32 nursing homes in Belgium also showed that there was little attention for this
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aspect.¹⁰ However, as mentioned before, from another part of the study we know that physicians felt supported by the EAS guideline of their institution, especially with regard to the 'clear procedure/decision-making'.¹⁵

Roles of nurse

In recent years increasing attention has been paid to the role of the nurse in euthanasia, among other things in the development of Dutch EAS guidelines for nurses and physicians.¹⁴ In line with this, almost 9 out of 10 guidelines mention the nurse as a possible participant in the decision-making. This is a substantial increase, compared to 1994 when it was found that 3 out of 10 EAS guidelines mentioned involvement of the nurse in decision-making.⁷ However, we also found that only half of the guidelines described the role of the nurse in the performance of euthanasia. The aspects that were described in some guidelines were accurate, indicating that nurses are not allowed to perform euthanasia, but can be involved in the preparation, and can assist a physician in multiple ways. Other studies have reported that nurses are often involved in the performance of euthanasia, and perform tasks that are illegal and beyond their professional responsibilities.^{21,22} More attention should be paid to nurses in institutional practice guidelines, in order to clarify their role in the euthanasia process.

Hospitals versus nursing homes

Several differences were found between hospitals and nursing homes. Some are possibly related to the way work is organised in the different institutions, i.e. a description of the role of a team in dealing with a request, and the possible participation of family in the decision-making. The latter was more frequently found in nursing homes guidelines than in guidelines from hospitals. Family might play a more important role in nursing homes, since many patients are of become incompetent and mostly stay in a nursing home for a long period (until death) compared to patients in hospitals.

It is noticeable that, while especially in nursing homes many patients are incompetent, mainly due to dementia, hospitals more frequently state that an advance euthanasia directive can be considered as a euthanasia request in an incompetent patient, which

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R1 is in line with the law. Above that, nursing homes guidelines were more frequently
R2 stricter than the law in excluding patients with dementia and incompetent patients,
R3 compared to hospital guidelines. This is probably related to reluctance to perform
R4 euthanasia on the basis of an advance euthanasia directive. This is noticeable as
R5 patients with dementia are a substantial part of the nursing home patient population.
R6 It is known that nursing home physicians more frequently consider euthanasia
R7 in an incompetent patient unacceptable than clinical specialists (55% vs. 16%).⁵
R8 Furthermore, data for the Netherlands showed that in practice it never or hardly
R9 ever occurs that physicians follow an advance euthanasia directive in a patient that
R10 has become incompetent.²³

R11 Also in Belgium it seems that nursing homes do have somewhat restrictive policies
R12 towards euthanasia. This may be explained by the fact that the majority of Belgian
R13 nursing homes had a restrictive stance on euthanasia.¹⁰
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R15 *Before and after the enactment of the law*

R16 In the Netherlands, with the enactment of the Euthanasia law the already existing
R17 EAS regulations were formalised in the law. Yet, our study shows that guidelines that
R18 were developed or revised after the enactment of the law more frequently adhered
R19 to the law. For instance, there was a substantial decrease in the percentage of
R20 guidelines that categorically excluded specific patient groups, approximately 6 out
R21 of 10 before 2002 and 3 out of 10 after 2002. This could either be because the law
R22 clarified the regulations, or because the regulations became more readily accepted
R23 by the developers of the guidelines. In line with our findings, in Belgium it was found
R24 that the due care criteria as stated in their Euthanasia law had a positive impact on
R25 attention paid to these criteria in guidelines.^{9,10}

R26 Especially in Flemish Catholic nursing home guidelines attention was given to
R27 palliative care and interdisciplinary cooperation, both important elements of the
R28 palliative filter. However, the absence of a palliative filter in the Netherlands does
R29 not mean that there is no attention for palliative care in Dutch nursing homes.
R30 More than half of the Dutch nursing homes guidelines mentioned that it must be
R31 clear if there is realistic palliative care available for the patient.
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In conclusion

The results of our study show that the content of institutional practice guidelines on EAS are not always an optimal source of information for physicians. Information with regard to advance euthanasia directives and due care criteria is not always complete. The role of the nurse also deserves more attention in many guidelines. Finally we recommend that health care institutions accurately state the boundaries of the law, also if they prefer to set stricter boundaries for their own institution. Only guidelines which provide adequate information and sufficient practical details with regard to the procedure that must be followed after a request for EAS, can provide adequate support for physicians and nurses in the difficult EAS decision-making process. However, guidelines can only be supportive in the process, but have to be interpreted for each individual patient and request. It does not solve the ethical decision-making.

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Chapter 5

A content analysis of Dutch hospital guidelines for do-not-resuscitate decisions

Submitted as:

Hesselink BAM, Pasman HRW, van Delden JJM, van der Heide A, Kollau M, van der Wal G,
Onwuteaka-Philipsen BD. A content analysis of Dutch hospital guidelines for
do-not-resuscitate decisions.

Abstract

Background: To analyse the content of hospital guidelines regarding do-not resuscitate (DNR) decisions and to compare guidelines in 2005 and 1994.

Methods: Content analysis of hospital guidelines (n=41) based on checklists.

Results: Most hospitals described in their guideline for DNR decisions a default-procedure for handling when in-patients have a cardiac arrest. More than half of the hospital guidelines (56%) provided information on when to initiate discussion about a DNR decision; 32% of the guidelines suggested that this should be done when a patient is admitted, 20% at onset of clinical deterioration, and 20% for patients with a 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 guidelines described the need to evaluate each individual DNR decision. Between 1994 and 2005, more guidelines recommended that discussions about DNR should start on admission (14% vs. 32%), and that individual decisions should be evaluated (64% vs. 76%).

Conclusions: Although hospital DNR guidelines have become more specific since 1994, there is still room for improvement. It is recommended that hospitals pay more attention to the content of their DNR guidelines, in particular with respect to the initiation of the discussion about whether or not to resuscitate in case of a cardiac arrest, and the recording and evaluation of the decision.

Introduction

If a patient who is admitted to a hospital has a cardiac arrest, it should be clear to the caregivers whether or not they should start resuscitation. This depends on institutional and individual policies. Hospitals can determine a general policy on what to do if a patient has a cardiac arrest (whether or not resuscitate), a so called default position. In addition to this general policy, an individual policy can be determined for each patient by a physician (possibly together with the patient and/or the family) at the time of admission. Moreover, individuals (patients) can take the initiative themselves, and can complete an advance directive, in which they state whether or not they want to be resuscitated in case of a cardiac arrest.

In a study on the incidence of DNR decisions in six European countries (Belgium, Denmark, Italy, the Netherlands, Sweden, and Switzerland) carried out in 2001/2002, the percentage of patients who died non-suddenly and for whom an individual DNR decision was available, ranged from 16% (Italy) to 73% (Switzerland). The percentage of deceased patients for whom an institutional DNR order was available ranged from 5% (Belgium) to 22% (Sweden). In the Netherlands the percentage of individual DNR decisions for non-suddenly deceased patients increased from 48% in 1990 to approximately 60% in 2001.¹

For professionals in institutions, guidelines can provide a framework for the process and documentation of DNR decisions in order to prevent incorrect interpretations at patient level.² In 2005, approximately three quarters of Dutch hospitals had institutional DNR guidelines.³ This was a significant increase compared to 1994, since at that time 37% of the hospitals had institutional DNR guidelines.⁴ In 2004, only four European countries (20%) had a formal DNR policy in some hospitals.⁵

To be supportive for professionals, the content of institutional DNR guidelines must be clear, complete and explained in sufficient detail. In 1994, the content of DNR guidelines in Dutch hospitals was evaluated, and it appeared that these guidelines could be improved in several ways, such as describing when to start discussions about individual DNR decisions, describing who has the final responsibility, and including an evaluation of the individual DNR decision.⁶ In other countries there was also a wide variation in the content (i.e. documentation of the DNR decision, advance care

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R1 directives) of these guidelines.^{7,8} It would be interesting to see if there are changes in
R2 DNR policy through time. If so, it may demonstrates that the medical community in
R3 the Netherlands is more open and willing to address the issue of code status.

R4 Therefore, in this paper we describe the content of institutional DNR guidelines in
R5 Dutch hospitals in 2005 with regard to: [1] aspects of the DNR policy, [2] aspects
R6 of the DNR decision-making process, [3] aspects of the registration and evaluation
R7 of individual DNR decisions, and [4] differences between hospital DNR guidelines
R8 in 2005 and 1994, to determine if whether the guidelines have been changed and
R9 improved in during the course of a decade.

R10 **Methods**

R11 *Definitions*

R12 In this study a do-not-resuscitate (DNR) decision is defined as an explicit anticipatory
R13 decision not to attempt cardiopulmonary resuscitation when a patient has a heart or
R14 respiratory arrest.

R15 An *institutional* DNR order is a document in which it is stated that at institutional
R16 level it has been decided, as a rule (not) to resuscitate any patients.

R17 An *individual* DNR decision refers to a decision not to resuscitate an individual patient
R18 in case of a cardiac arrest.

R19 A practice guideline is defined as a written protocol to guide caregivers in their
R20 approach to a problem that includes a decision-making process and/or a phased care
R21 plan.

R22 *Study population and design*

R23 The present study was part of the Evaluation Study of the Euthanasia Act.⁹ Data were
R24 collected from October 2005 through March 2006. The management of a total of 119
R25 hospitals were asked whether they had guidelines for DNR decisions, and if so they
R26 were asked to provide a copy of the guideline. Of these 119 hospitals, 19 had to be
R27 excluded because they had merged with another institution. Of the remaining 100
R28 hospitals, 73 returned the questionnaire. A total of 56 hospitals indicated that they
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had institutional guidelines concerning DNR decisions, and provided a copy of the guidelines. A total of 41 hospital guidelines were analyzed. The other 15 guidelines were excluded because they were very brief, or provided no practical guidance for caregivers on how to react in case of a cardiac arrest, and therefore were not considered to meet the definition of guidelines in our study. This study is a replica of the study carried out by Haverkate et al.⁶

Checklist

For the analysis of the guidelines we developed a checklist of items, based on the study carried out in 1994.⁶ The checklist included the following main topics: a) general characteristics of the practice guidelines: definition of DNR and default position, b) decision-making concerning DNR: involved parties and their roles, and c) registration and evaluation of the decision.

Analysis

Each guideline was checked by two trained reviewers (BAMH, HRWP, HVD, MK, BDOP), using the checklist. Differences were solved in consensus meetings. If no consensus could be reached, a third reviewer was consulted. The initial percentages of agreement between the reviewers ranged between 85% and 100% (average 98%). The data were analysed with descriptive statistics.

Results

General aspects of DNR policy

Table 1 shows that 46% of the hospital guidelines stated that a DNR decision is an anticipatory decision. In 81% of all guidelines a default position for patients with a cardiac arrest was described, and it implied in all guidelines that resuscitation should always be initiated, unless stated otherwise (for example unless an individual DNR decision is made or resuscitation attempts are futile).

More than half of the guidelines (56%) described in detail the initiation of discussions with the patient concerning DNR decisions. The recommendation in 32% of the

guidelines was that the discussion about (non-)resuscitation should start on admission to the hospital, 20% recommended that it should be initiated at the onset of clinical deterioration, 20% when there is a higher risk of cardiac arrest, and 17% when there is little chance of successful resuscitation. In 66% of the guidelines there was a description of the information that was needed for an individual DNR decision; the patient's wish was most often mentioned (in 63%). None of the guidelines mentioned the subject of 'slow codes ('run slowly' to the patient) or partial codes (resuscitation efforts are explicitly limited).

The percentage of guidelines that described a default position had increased from 66% in 1994 to 81% in 2005, but the content of the default positions had not changed. The percentage of guidelines that described in detail how to initiate discussions with the patient concerning DNR decreased from 67% to 56%, and in 2005 it was more often described that discussions should start on admission to the hospital (from 14% in 1994 to 32% in 2005).

Table 1: General aspects described in hospital Do-not-resuscitate (DNR) guidelines

	1994 N=80 %	2005 N=41 %
Stated that DNR decision is an anticipatory decision	n.a.	46
Description of default:	66	81
Always resuscitate	0	0
Resuscitate, unless	66	81
Do not resuscitate, unless	0	0
Never resuscitate	0	0
Description of when to initiate the discussion on resuscitation/DNR:	67	56
On admission to hospital	14	32
On admission to a special unit (IC)	9	2
Onset of clinical deterioration	41	20
Higher risk of resuscitation	34	20
Little chance of success	24	17
Description of information needed for individual DNR decision:	n.a.	66
Patient's wish		63
Chance of success		37
Expected quality of life		24
Other		17

The role of participants in the DNR decision-making process

Table 2 shows that the majority of the guidelines (78%) stated that the physician is responsible for the final DNR decision concerning individual patients, and 56% stated that it is not desirable to inform the patient about a DNR decision in case of 'therapeutic exception' (i.e. informing would seriously harm the patient). A total of 71% of the guidelines stated that a discussion with the patient about DNR is mandatory. Furthermore, 88% of the guidelines described the role of nurses in the DNR decision-making process, and implied in general (71%) that nurses should be involved in these discussions. The role of the family of incompetent patients was also described in the majority of the hospital guidelines (78%), and implied mainly (56%) that the decision should be discussed with the family, although the family should not have any responsibility for the decision.

Furthermore, compared to 1994, there were more hospital guidelines in 2005 in which it was recommended that it is not desirable to inform patients about DNR decisions in case of 'therapeutic exception'. The guidelines also more often stated that proxies/family of incompetent patients should be informed compared to the 1994 guidelines.

Procedures after an individual DNR decision

All guidelines, stated that the content of individual DNR decisions should be registered (Table 3), and 98% stated that the content should be recorded in the medical and/or nursing file, for instance on a separate page and/or by marking the cover of the file with a coloured sticker. None of the guidelines stated that the content of the decision should be made directly visible, e.g. at the side of the patient's bed. Of the 76% of guidelines that stated that a DNR decision should be evaluated, 41% stated in more detail that individual DNR decisions should be evaluated with a fixed frequency.

The percentage of guidelines stating that individual DNR decisions should be evaluated increased from 64% in 1994 to 76% in 2005.

Table 2: Description of role of participants in decision-making in hospital Do-not-resuscitate (DNR) guidelines

	1994 N=80 %	2005 N=41 %
Description of who is responsible for final individual DNR decision^a :	75	80
-physician	75	78
-patient	0	7
-family/proxies	0	0
Description of the circumstances in which it is not desirable to inform the patient about the individual DNR decision:	n.a	59
-yes, with 'therapeutic exception' ^b	25	56
-yes, futile resuscitation		5
Discussion with patient on individual DNR decision is described:	89	88
-discussion is necessary/mandatory	n.a	71
-discussion is desirable/important	n.a	17
Role of nurse explicitly described; namely^a:	80	88
-to be informed	18	20
-to provide information	34	27
-to be involved in discussion	62	71
Role of proxies/family of incompetent patient explicitly described; namely^a:	65	78
-to be informed ^b	4	24
-to provide information	18	10
-in discussions, but no responsibility for decision	58	56
-in discussion and also responsible for decision	5	15

^a one or more answers possible

^b significant difference

Table 3: Procedural aspects described in hospital Do-not-resuscitate (DNR) guidelines

	1994 N=80 %	2005 N=41 %
Explicitly described that the decision for resuscitation/DNR should be recorded	94	100
- in the medical and/or nursing file		98
- visible on patient		0
- visible near patient's bed		0
Evaluation of the individual DNR order is described:	64	76
yes, but with no fixed frequency		34
yes, with fixed frequency		41
Other		2

Discussion

Although the percentage of hospitals that describe their default position in written guidelines has increased between 1994 and 2005 (from 66% to 81%), one in five guidelines still include no default position. One could debate whether making a default position explicit is necessary in hospitals, since the default position (resuscitate, unless...) is usually in line with 'regular practice', i.e. that patients will be resuscitated, unless otherwise decided. On the other hand, when institutions do not have an explicit default position on DNR, and no individual DNR decision has been made, the individual health care professionals must decide what to do if a patient has a cardiac arrest, since immediate action is required in such a situation. This underlines the importance of individual DNR decision-making. But what is the most appropriate moment at which to start the DNR discussion? One third of the guidelines in our study stated that discussions about individual DNR decisions should start on admission. It may be debated if it is appropriate to discuss about resuscitation with every patient that is admitted to a hospital.¹⁰ Research suggests that discussions about resuscitation should occur early in a patient's admission, also before clinical deterioration occurs.¹¹ However, a literature review of DNR orders in America showed that there is substantial variability and inconsistency as to which patients are asked about their wishes involving resuscitation.¹² Our study showed that one in five hospital guidelines recommended that discussions should be initiated at the onset of clinical deterioration, and one in five also state that it should be initiated in patients with a higher risk of cardiac arrest. However in practice, how much clinical deterioration and what kind of deterioration is required? Above that, at the onset of clinical decline, it is hard to determine the exact moment which to start, and there is also a chance that physicians forget to do so at that moment. A study on the perceptions of do-not-resuscitate policies of dying patients with cancer showed that some patients preferred an early DNR discussion, although the majority of patients preferred a later discussion if possible.¹³

DNR guidelines should indicate the exact moment at which to initiate discussions with the patient concerning DNR. This is only included in 56% of the guidelines. The percentage of hospitals recommending discussions on admission increased from 14% in 1994 to 32% in 2005.

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Although the physician has the final responsibility for individual DNR decisions if a patient wishes to be resuscitated (the physician can also decide that resuscitation would be futile), it is important that a patient receives full information about the consequences of whether or not to resuscitate. This implies that patients can make a decision about their own situation, and can decide whether or not they want 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 wish to be resuscitated, this decision has to be respected by the physician.^{14,15} The majority of hospital guidelines state that discussions with the patient are mandatory or desirable, but other studies have found 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 if they became incompetent.^{16,17} However, it has been reported that approximately 50% of patients who were admitted via the emergency department of a hospital could not participate in the decision about resuscitation orders within 24 hours of admission, and that another 30% refused to discuss resuscitation.¹⁸

In order to ensure that nurses and other professionals are fully informed about an individual DNR decision, it is important that the decision is correctly registered. One way of doing this is to record the decision in the medical and nursing files. In almost all guidelines in 2005 it was stated that the individual DNR order should be recorded in the medical and/or nursing file. The decision could also be made clearly visible on the patient by means of a medallion or bracelet. However, this could endanger the privacy of the patient. On the other hand, research on wristband identification has shown that patients appreciate having their wishes visible, and want to be reassured that their wishes will be honored.¹⁹ None of the guidelines stated that the decision should be made visible near the patient's bed. However, putting a discrete DNR code near the patient's bed could be an easy way of immediately making it clear to all professionals what they should do if a patient has a cardiac arrest, since immediate action is required if a patient wants to be resuscitated.

Approximately 75% of the hospital guidelines describe the need for evaluation of an individual DNR decision. Although increasing attention has been paid to the

evaluation of this decision in guidelines in the Netherlands since 1994 (from 64% to 76%), this percentage is still lower than in DNR guidelines in Australian and Canadian hospitals (86%).^{7,20} The evaluation of individual DNR decisions is important, because the clinical condition of a patient can change over time, and this may have consequences for the success of the resuscitation and the patient's preference with regard to this specific decision.⁷ It is therefore important that a fixed frequency for evaluation is determined, but this is only included in 41% of the DNR guidelines.

There were fewer hospitals included in this study than in the 1994 study, partly because the number of hospitals has decreased in the past ten years, due to mergers. Furthermore, the response rate was higher in 1994, possibly because the questionnaire was sent by the Health Care Inspectorate.

The possible subjectivity of content analysis can be considered as a limitation of the study. However, all the guidelines were assessed according to a checklist by two trained researchers, and the agreement between the assessors was high. It is also important to remember that if a hospital has no DNR policy this does not mean that there are no agreements with regard to DNR. Nevertheless, it is recommended that these agreements are written down in DNR guidelines.

Conclusions

Although several aspects of hospital DNR guidelines are improved since 1994, there is still room for improvement in describing the specific relevant aspects of the DNR decision-making process. It is recommended that in the guidelines more attention is paid to the content of the decision, and in particular with respect to initiating the discussion about whether or not to resuscitate in case of a cardiac arrest, and the recording and evaluation of the decision. Making clear in guidelines what professionals should do in daily practice is one way of contributing to the quality of care and promoting more careful decision-making on whether or not to resuscitate, taking the situation and wishes of patients into account.

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